Understanding

Melanoma

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

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

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<th>Name</th>
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<td>Specialist nurse</td>
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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. We would particularly like to acknowledge the contribution of the many consultants, nurses and other healthcare professionals who so kindly gave up their time and expertise to contribute to previous editions of this booklet.

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<td><strong>Surgery:</strong> Used to remove the melanoma and the area close to it. <strong>Biological (targeted) therapies:</strong> Drugs that find ways to stop melanoma cells from dividing and growing. <strong>Chemotherapy:</strong> Drugs to slow down and control the growth of cancer. <strong>Radiotherapy:</strong> A course of X-ray treatments to control the disease and relieve pain. Sometimes you will have a choice of treatment. See page 30 for advice about making a decision.</td>
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### Are there side-effects from treatment? [Page 34]

Your doctor and the team caring for you will talk to you about possible side-effects. Read about each of the treatments to learn more about their side-effects.

**There are treatments to help with most side-effects, so tell your doctor. Don’t suffer in silence!**

### Clinical trials [Page 41]

Clinical trials are when cancer patients get a new type of treatment to see if it works better than existing treatments. Ask your consultant if there are any trials suitable for you.

### We’re here for you [Page 73]

If you or your family have any questions of worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

**Ways to get in touch**
- Call our Cancer Nurseline on 1800 200 700
- Drop into a Daffodil Centre
- Email us: cancernurseline@irishcancer.ie
Introduction

This booklet has been written to help you to learn more about melanoma skin cancer. The booklet is divided into 8 parts:

- About melanoma gives an introduction to melanoma.
- Diagnosis and tests goes through what you can expect when you are diagnosed and going through further tests.
- Treating melanoma lays out the different treatments you may have and how they are done.
- Managing side-effects and symptoms gives advice on how to deal with the physical effects of melanoma and its treatment.
- After treatment looks at what you can do to stay healthy after melanoma treatment.
- Coping and emotions discusses how you can cope with your feelings and the emotional effects of having cancer.
- Advice for carers contains practical advice and support for those caring for people with cancer.
- Support resources gives information on where to get help and support. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

Reading this booklet

Remember you do not need to know everything about melanoma straight away. Read a section that you are interested in. Then read another section when you want to know more.

If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700 or email the nurses at cancernurseline@irishcancer.ie. You can also visit a Daffodil Centre. See page 73 for more about Daffodil Centres. You can email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.

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Understanding 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 starts in cells in the prostate gland, breast cancer starts in cells in the breast.

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 are not cancerous and do not spread to other parts of your body. Malignant tumours are cancerous and can spread to other parts of your body. This happens when a cell or group of cells breaks away and is carried by your bloodstream or lymphatic system to other tissues and organs in your body, where they can form a secondary tumour. This is also called metastasis.

What is the lymphatic system?
The lymphatic system protects us from infection and disease. The lymph vessels are separate to blood vessels. They are tiny tubes, which usually lie just under the skin. They transport lymph fluid, which carries extra fluid and waste from body tissues.

Lymph nodes, pouches where the fluid collects, are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.

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.

Melanocytes 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.
Understanding melanoma

What is a mole?

A mole is a group of melanocytes that form a mark on your skin. The most common moles are birthmarks and childhood moles.

If a birthmark or mole gets darker, larger, lumpy or starts to bleed, visit your family doctor (GP). See page 53 to learn more about checking your skin for changes to birthmarks or moles.

What is melanoma?

Melanoma is a cancer in the cells that make melanin, called melanocytes. Melanoma is also known as malignant melanoma. Melanoma begins when healthy melanocytes change and grow out of control. It usually starts on the surface of the skin, either in normal-looking skin or a mole. If not caught early, melanoma will spread along the surface of the skin before penetrating deeper. Eventually it can reach the lymph and blood vessels. In rare cases, melanoma may develop in other parts of your body.

If melanoma is diagnosed and treated early, there is a very good chance of a cure.

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 new or long-standing 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 starts 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.

- **Amelanotic melanoma**: This is a rare melanoma, and unlike the others, it may have no color or be slightly red.

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 be found under your fingernails or toenails. It can also be found in the tissues that line areas inside your body. For example, in your eyes, nose, mouth, lungs, bowel, rectum or anus. These types of melanoma are not discussed in detail in this booklet. For more information, contact our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Email: cancernurseline@irishcancer.ie

Cancer Nurseline Freephone 1800 200 700
**What increases my risk of melanoma?**

The exact cause of melanoma is unknown. But there are certain risk factors that can affect your chances of getting the disease.

Having a risk factor doesn’t mean you will definitely get cancer. Sometimes people without any known risk factors develop cancer.

Some things that can increase your risk of melanoma are:

- **UV rays**: Exposure to ultraviolet (UV) rays from sunlight, tanning lamps or sun beds greatly increases your risk of developing melanoma. Being outside can expose your skin to the sun’s harmful UV rays, even on cool or cloudy days. About 90% of melanomas are thought to be caused by too much exposure to UV rays. Regular sun holidays, working outdoors, outdoor sports or severe sunburn or blistering as a child or teenager may increase your risk of developing melanoma later in life.

- **Sunbeds**: People who have used a sunbed, even just once, have a 20% increased risk of melanoma. Using sunbeds or sun lamps from a young age increases your risk even more.

- **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.

- **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 the risk of developing it also increases with age.

- **History of melanoma or non-melanoma skin cancer**: Your risk is increased if you or a close 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 certain illnesses including HIV/AIDS, or if you are taking certain medications that suppress your immune system.

- **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.

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**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.

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**How common is melanoma?**

Melanoma is one of the most common cancers among people aged 15–29.

The number of people in Ireland being diagnosed with melanoma has tripled in the last 20 years.

Each year around 1,000 cases of melanoma are diagnosed in Ireland. At present more men than women are affected.

**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.
To sum up

- Melanoma is a cancer in the cells that make melanin.
- The risk of developing melanoma 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 new mole that looks different from existing moles, or changes in existing moles including size, shape or colour.
- Melanoma can happen in other parts of the body, but this is rare.

Diagnosis and tests

- Being diagnosed with melanoma
- What tests will I have?
- Staging melanoma
- Asking about your prognosis
Understanding melanoma

Being diagnosed with melanoma

Hearing that you have melanoma can be a huge shock. You may be feeling:
- Upset and overwhelmed by your emotions
- Confused by all the information being given to you
- Worried about what will happen next
- Scared about the future

Everyone reacts differently to a cancer diagnosis. However you feel, you are not alone. There are many people who can help and support you at this time.

If you need to talk to someone, or if you want more information or advice:
- Ask to speak to the medical social worker or cancer liaison nurse at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence — call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre
- Email our cancer nurses at cancernurseline@irishcancer.ie
- Talk to other people going through the same thing. Join our online community at www.cancer.ie/community

We hope this booklet will help you too. It has information on what to expect when you have been diagnosed with cancer. It also has tips on how to cope – practically, emotionally and financially. More helpful information is available on our website www.cancer.ie

Email: cancernurseline@irishcancer.ie

Telling people about your diagnosis

It can be hard to tell other people the news that you have been diagnosed with cancer.

You may want to talk about your diagnosis, or you may prefer not to tell people straight away. Talking can help you to get support from friends and family. On the other hand, you may find it hard to cope with other people’s reactions when they hear the news. For example, they may fuss over you or be upset. Remember, melanoma is not infectious and cannot be passed on to other people.

Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre if you would like to talk things over with a cancer nurse. You can also ask for a copy of our booklet Who Can Ever Understand? This booklet can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests will I have?

Excision biopsy

A biopsy means taking a sample of cells and looking at them under a microscope. But with a mole a sample is usually not taken. Instead, the entire mole is removed by your dermatologist or plastic surgeon. This is called an excision biopsy and it can both diagnose and treat melanoma.

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 the melanoma is thicker than 1 mm, there is a chance it could have spread or might come back in the future.

The pathologist will check whether the melanoma has been fully removed. 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. Pathologists will also be looking for breaks in the surface of the melanoma (ulcerations) that can only be seen under the microscope.

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.

Often an excision biopsy is the only treatment you need and the biopsy results show that all the 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 22 for more about staging melanoma.

After being diagnosed with melanoma, you may have more tests to find out about your cancer and your general health.

Most people do not need further tests.

Further tests you may have include:

- **Blood tests**: Most patients with melanoma do not require blood tests, but blood tests may be done to check your general health.

- **PET scan**: 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 of your cells. This sugar is first injected into your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found. An hour after the injection, the scan is taken and can show if the cancer has spread to other tissues and organs. During the scan, you will lie on a table which moves through a scanning ring. Before the scan, you may have to fast (not eat) for a few hours. Newer devices combine PET and CT scans.

- **CT scan (CAT scan)**: This is a special type of X-ray that gives a detailed picture of the tissues inside your body. A CT scan of the chest, head, abdomen, or pelvis, may be recommended if it is suspected that the melanoma has spread. During the scan you will lie on a table which passes through a large doughnut-shaped machine. A rotating X-ray beam takes pictures of the body from many angles. A computer then combines the pictures and makes a detailed image of the body. The scan is painless and takes between 10 and 30 minutes. You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. Before you take the drink, let the radiographer know if you are allergic to iodine or have asthma. The injection may make you feel hot all over for a few minutes. Preparations for a CT scan can vary. The doctor or nurse in your hospital will tell you what to do. This test is usually done as an outpatient, so you should not need to stay in hospital.

- **Ultrasound scan**: This is a scan that uses sound waves to look at collections of lymph nodes (called basins) and soft tissue. It is done in the X-ray department of the hospital. The scan is painless and only takes a few minutes. Some gel is first put on the skin, which is then scanned to give more information about the cancer.
- **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 lymph 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, your doctor will look at your lymph nodes with an ultrasound machine, or may remove the lymph nodes in surgery. For more details, see page 34. If there are no melanoma cells present in the sentinel lymph node, it is unlikely that other lymph nodes will have melanoma cells. Further treatment is usually not needed.

A sentinel lymph 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.

- **MRI scan:** This is a scan that uses magnetic energy to build up a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people are afraid they may feel claustrophobic during the MRI scan. If you are anxious, contact the radiographer the day before. They may be able to give you medication to relax you on the day. An MRI can also be 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 in your body, like a pacemaker or pin, you may not be suitable for the test. Usually you can go home soon after the scan. You shouldn’t need to stay in hospital.

- **Bone scan:** Bone scans are very sensitive and can sometimes be used to 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 test results

It usually takes two weeks or more for all the test results to come back and for your multidisciplinary team to review them. 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

> This may not be a straight road. With melanoma, often you don’t have a final diagnosis or “stage” for weeks. The waiting for results can be very hard. Reach out at these times as much as you can.
Understand melanoma

Stage 1A: The melanoma is less than 0.8 mm thick. The covering layer of skin over the tumour is not broken — it is not ulcerated.

Stage 1B: The melanoma is less than 0.8 mm thick and the skin is broken (ulcerated). Or it is between 0.8 and 1 mm thick, and may be either ulcerated or not ulcerated.

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

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

Stage 2C: The melanoma is thicker than 4 mm 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 have melanoma cells.

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.

Staging melanoma

The tests you have help the doctor to stage your cancer. Staging means finding out the size of the cancer, how deeply it has grown into the skin and if it has spread to other parts of your body. Knowing the stage of your cancer is very important, as it helps your doctor to decide the best treatment for you.

With melanoma, staging looks at:
- The thickness (depth) of the tumour.
- 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.

What are the stages of melanoma?

Stage 0: Melanoma in situ. 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.

Stage 1–2: Early stage melanoma. The melanoma cells are found in the top layer of your skin only. The melanoma has not spread to lymph nodes or other organs.

Stage 3: Medium stage or locally advanced melanoma. 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.

Stage 4: Advanced melanoma. The cancer has spread to distant parts of your body like your lung, liver or brain. This is also called metastatic melanoma.

Staging 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.
Genetic mutation testing
In certain cases, a pathologist will test the tumour to look for any gene changes (mutations). Each gene mutation makes the cancer act in a different way.

Knowing which gene mutations affects your tumour helps the doctors to plan the best treatment for your cancer. See page 38 for more information.

To sum up
- Staging means finding out the size of the tumour and if the cancer 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 cancer do not need further tests.
- Further tests like scans and genetic mutation testing may be used to stage the cancer.

If you decide you want information on your prognosis:
- Think carefully about how you will cope with the information before asking for your prognosis.
- Get information on prognosis from your doctor. He or she knows your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Avoid looking online. It can be hard to understand the information you find online without an expert like a doctor to help. The information may not really apply to your situation or to your particular cancer type.
- Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor again after you have thought about everything.
- Get emotional support if you need it. If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email kannurseline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Asking about your prognosis
Your prognosis is information about how your disease is likely to progress, including average survival times for your type of cancer (life expectancy). Many people with cancer have questions about their prognosis.

Should I ask about my prognosis?
If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

It’s not always easy for doctors to answer a question about life expectancy, as the answer is based on a ‘typical’ experience. In reality, experiences can vary a lot from person to person. What happens to you might be quite different from what the doctor expects.
Treating melanoma

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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. See page 34 for more on wide local excision.

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.

Even if your early stage melanoma was successfully treated with excision surgery, it is very important to protect your skin from UV rays. See the SunSmart code on page 55 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 reduce the risk that the melanoma will come back in the same area. If melanoma is found in your lymph nodes, these will be removed under general anaesthetic. See page 34 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 36 for more details.

**Chemotherapy:** Chemotherapy uses drugs to control cancer. It is used less than surgery and biological therapies in treating melanoma. See page 40 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 41 for more details.

**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 you can talk to cancer nurses by calling our Cancer Nurseline on 1800 700 200, emailing the nurses at cancernurseline@irishcancer.ie or visiting a Daffodil Centre.

**Specialist cancer centres**
Melanoma is treated in specialist cancer centres in Ireland. The staff at these centres have great expertise in managing patients with melanoma. As a result, you may be transferred to another hospital from the one where you received your diagnosis.
Understanding melanoma

Deciding on treatment

**Multidisciplinary team:** A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, a dermatologist, specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

**Treatment options:** Your doctor and nurse will discuss your treatment options with you. Do ask as many questions as you like, no matter how small or trivial you think they are. All questions are important. You could use the fill-in page at the back of this booklet for your questions and answers. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and talk to one of our cancer nurses.

**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 the treatment if you are unsure when it’s 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. It may help to talk to your GP as well. The important thing is that you are fully aware 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 may be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- 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. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

**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. Don’t be afraid to ask your doctor about your treatment.

**Waiting for treatment to start**

Planning cancer treatment takes time. Most people want to start treatment right away. You may worry that the cancer will spread during this time.

Cancer treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. This also gives you time to talk about all your treatment options with your doctors, family, and friends.

Cancer Nurseline Freephone 1800 200 700
If you are worried, talk to your doctor. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

### Who will be involved in my care?

Usually a team of health professionals – your multidisciplinary team – will be involved in your treatment and care.

**Surgeon**
A doctor who specialises in surgery.

**Medical oncologist**
A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

**Radiation oncologist**
A doctor who specialises in treating cancer patients using radiotherapy.

**Radiation therapist**
A specially trained person who delivers the radiotherapy and gives advice to cancer patients about their radiation treatment.

**Oncology liaison nurse / clinical nurse specialist**
A specially trained nurse who works in a special cancer care unit. She or he gives information and reassurance to you and your family from diagnosis and throughout treatment unit.

**Medical social worker**
A person trained to help you and your family with your social issues and practical needs. They can give counselling and emotional support. They can give advice on benefits and financial matters and on practical supports and services available to you when you go home.

**GP (family doctor)**
Your GP can be a great support to you. You can talk to your GP about your medication and any side-effects you have. You can also contact your GP about any worries you have or if you are finding it hard to cope.

**Palliative care team**
This team is specially trained in managing pain and other symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the ‘homecare team’ or the ‘hospice homecare team’. A specialist palliative care service is available in most general hospitals.

**Physiotherapist**
A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

**Dietitian**
An expert on food and nutrition. They are trained to give advice on diet during your illness and use diet to help symptoms.

**Psycho-oncology team**
These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

**Psychologist**
A specialist who can talk to you and your family about emotional and personal matters and can help you to make decisions.

**Counsellor**
A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

**Community health services**
These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.
Understanding melanoma

**Surgery**

The aim of surgery is to remove the melanoma and the area close to it.

**Wide local excision surgery**

‘Wide local excision’ is a kind of surgery to remove the melanoma and an area around it and underneath it to reduce the risk of the melanoma coming back in the same area. 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 (the donor site) 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.

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 by 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. It may occur some time after the surgery. This is called lymphoedema.

Contact your doctor or specialist nurse if you notice swelling or a feeling of heaviness, tightness, soreness or stiffness in the affected area. For more information or a free factsheet on preventing and treating lymphoedema, call our Cancer Nurseline on 1800 200 700, drop into a Daffodil Centre or visit our website: [www.cancer.ie](http://www.cancer.ie)

**Going home**

If you live alone or have problems getting around the house, talk to the medical social worker or specialist 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.

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**To sum up**

- The aim of surgery is to remove the melanoma and the area close to it.
- Surgery is often the only form of treatment needed.
- Excision surgery is the main treatment for melanoma.
- 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.

Email: cancernurseline@irishcancer.ie
Biological (targeted) therapies

Biological therapies work with your body. They can help fight cancer or stop it spreading.

There are different types of biological therapies that may be used to treat advanced melanoma.

Different types of biological therapies work in different ways. For example:
- BRAF and MEK inhibitors block the chemical signals that trigger cancer cells to divide and grow.
- Immunotherapy boosts your body’s immune system to fight cancer.

Examples of biological therapies used for people with melanoma include:

**BRAF inhibitors**
One type of biological therapy used in the treatment of later-stage melanoma is BRAF inhibitors. BRAF is a protein which helps to control how cells grow, but sometimes it doesn’t work properly. This means that cell growth does not switch off when it should and the abnormal cells continue to grow and spread.

Your melanoma will be tested for the BRAF gene mutation. Less than half of Irish melanoma patients have a mutated BRAF gene. If the test is positive, which means you have a BRAF mutation, you may be treated with a BRAF inhibitor. They are given in tablet form. BRAF inhibitors target the change in the BRAF gene, and cause the cancer to stop growing.

**Side-effects**
BRAF inhibitors tend to affect the skin. They can cause extreme sensitivity to the sun, causing sunburn, rash and increase your risk of developing non-melanoma skin cancer. Other side-effects include diarrhoea, joint pain, feeling sick (nausea), liver problems and thinning hair.

**MEK inhibitors**
MEK inhibitors are drugs used to treat melanoma with the BRAF mutation. They are given in tablet form. MEK inhibitors work by blocking certain enzymes to stop them helping the cancer cells to grow. You may be given a MEK inhibitor together with a BRAF inhibitor.

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

**New biological therapies**
New biological therapies are being developed all the time and existing therapies are being used in new ways. You may also be given a biological therapy as part of a clinical trial (see page 41). Ask your doctor if there are any biological therapies available to treat your cancer or if there are any trials that are suitable for you.

Biological therapies only target the cancer cells and leave normal cells alone. This means you usually get fewer side-effects than with chemotherapy. Your doctor and nurse will discuss your treatment with you in more detail and tell you about any likely side-effects.
**Immunotherapy**

Immunotherapy is a type of biological therapy (sometimes called monocolonal antibodies or targeted therapy) that boosts your body’s own immune system to fight cancer. Immunotherapy gets to work on special white blood cells called T cells, whose job it is to help your immune system fight disease and infection.

Our immune system can often be the most effective weapon to clear cancer cells from our body, but sometimes cancer cells find a way of hiding from the immune system. This allows a tumour to develop or to spread.

Immunotherapy exposes tumours again by signalling the immune system to switch on and by stopping it from switching off. The cancer is then constantly exposed to the immune system, which fights it.

There are two forms of immunotherapy currently used:

1. Anti PD-1 drugs
2. CTLA 4 inhibitors

These drugs target proteins found on the surface of T cells. PD1 and CTLA 4 are proteins that help to switch off or slow down the immune system. Normally, they do this to stop the T cells once a disease, infection or bacteria is cleared from the body. Giving anti-PD1 and CTLA4 inhibitors as a treatment helps the T cells to keep working and allow your own immune system to fight off cancer.

Immunotherapy drugs are given to patients in a specialist cancer unit via a drip.

**Side-effects**

Patients typically have few or mild side-effects from immunotherapy.

It is important to understand that any side-effects that you may feel are the result of your immune system working hard to fight cancer. Side-effects can include extreme tiredness (fatigue), skin rashes, diarrhoea or hormonal imbalances. Immunotherapy can also cause flu-like symptoms, like chills, fever, body aches, tiredness and headaches. You may feel depressed, and if you do, you may need medication. Usually the side-effects disappear once the treatment is over.

Side-effects from immunotherapy are managed differently to similar side-effects from chemotherapy that may be more familiar to your GP or emergency department. Ask your specialist cancer nurse for advice.

**Interferon**

Interferons are made of molecules called cytokines, which are naturally found in our body. They work with the immune system to fight against infection and disease. The cytokines used in interferons have been made in a lab. They are given in high doses to make your immune system fight melanoma.

Interferon is given through a drip into your vein. At first, you may have to stay in hospital to get your interferon treatment, and then go back to the hospital every day for a number of weeks. It can also be given as a small injection into the skin for a number of months.

Interferon Alpha and IL-2 are two older forms of immunotherapy. Although interferons are not as commonly used now, they still have a role to play too.

**Side-effects**

The most common side-effects of interferon are flu-like symptoms, like chills, fever, body aches, tiredness and headaches. Interferon may affect your liver function, so you could get abnormal blood test results. It can also cause nausea, vomiting and depression. If you do feel depressed, you may need medication, so ask your doctor for advice. Usually the side-effects disappear once the treatment is over.

For more information on biological therapies and their side-effects, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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To sum up

- Immunotherapy boosts your body’s immune system to fight melanoma.
- 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.
Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. The aim of radiotherapy is to destroy the cancer cells with as little damage 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.

If you do have radiotherapy for melanoma, a type called external beam radiotherapy is used. This is where the radiation comes from machines that aim radiation directly at your tumour or the tumour site.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing cancer.

Patients with cancer are sometimes asked to take part in a clinical trial. This means that instead of or in addition to the standard treatment you get a new trial drug. Or you may be given existing treatments used in different ways. For example, giving a different dose of a drug or using two treatments together.

Drugs that are used in a clinical trial have been carefully tested to make sure they are safe to use in a clinical trial.

More information

If you are interested in taking part in a clinical trial or want more information, you can read our factsheet Cancer and Clinical Trials. It’s available to read or download on our website, www.cancer.ie.

You can also get a free copy by calling our Cancer Nurseline on 1800 200 700 or by dropping into a Daffodil Centre.

You can also visit Cancer Trials Ireland at www.cancertrials.ie for a list of current trials in Ireland.
How is advanced cancer treated?

Advanced cancer is when cancer has spread to another part of your body. Cancer that has spread to another part of your body can also be called metastatic or secondary cancer. Your cancer may be advanced when it is first diagnosed. Or it may have come back some time after you were first treated. This is called recurrence.

If your cancer is advanced it can still be treated. The aim of treatment is usually to try to control the cancer rather than to cure it. Your doctor may advise different chemotherapy drugs or biological therapies that may help. There may also be treatments that you can have as part of a clinical trial (see page 41). Your doctor will tell you if there are any clinical trials that might be helpful for you.

In many cases, treatment for advanced cancer can help you to live longer with better control of your symptoms. See page 46 for more on controlling symptoms. Your doctor will discuss the best treatment option for you with the healthcare team.

Palliative care

The palliative care team are experts in managing the symptoms of advanced cancer, such as breathlessness, pain and nausea. Palliative care also offers emotional support and comfort to patients and their families. Palliative care includes end-of-life care, but your doctor may also recommend palliative care earlier in your illness, to help to manage your symptoms and improve your quality of life.

The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, chaplains and counsellors. Palliative care can be arranged by your family doctor (GP), public health nurse or by the hospital. Palliative care is a free service for all patients with advanced cancer. You do not need medical insurance.
Managing side-effects and symptoms

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Will treatment affect my sex life? 47
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How can I cope with fatigue?

Fatigue means feeling extremely tired. Fatigue is a very common symptom of cancer.

Fatigue when you have cancer can be caused by many things, including:
- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Usually fatigue improves once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count a transfusion can make you feel better. If you are not eating well a dietitian may be able to give you some advice to help you.

Tips & Hints – fatigue

- Try to do some exercise – ask your doctor for advice about the best exercise for you.
- Build rest periods into your day and save your energy for doing the things that are most important to you.
- Ask for help at work or at home, especially with cooking, housework or childcare.
- Try to eat well and drink plenty of fluids.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself.
- If you are not sleeping well, try relaxation techniques and avoid stimulants like caffeine and alcohol before bedtime.
- Try complementary therapies like meditation, acupuncture or massage.

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist relationships counselling or sex therapy. This can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. Your doctor will advise if you can have sex while on radiotherapy. But you may find it will be some weeks before you will feel well enough to have sex again after surgery. Once you return to your usual routine your interest in sex should return too. You can also enjoy other forms of closeness, such as touching, caressing and holding each other.

Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

A helpful booklet called Coping with Fatigue is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy.
**Contraception**

If you are having sex, you should use a reliable method of contraception during and for some time after treatment. For example, there is a risk of miscarriage or birth defects in children conceived during or just after chemotherapy.

Many specialists recommend that you wait for up 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor’s advice about contraception or if you are thinking about having children after treatment.

**Asking for advice**

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to taking about these matters, so there’s no need to feel embarrassed. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a cancer nurse in confidence. Or email the nurses at cancernurseline@irishcancer.ie

**Will treatment affect my fertility?**

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. For example, it may be possible to freeze your eggs or sperm before treatment begins. Rotunda IVF at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use.

Dealing with infertility may not be easy, depending on your age and if you have already had children. 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 or with a professional counsellor. You can also call our Cancer Nurseline on 1800 200 700, email the nurses at cancernurseline@irishcancer.ie or visit a Daffodil Centre for information and support from a cancer nurse.

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**Cancer and complementary therapies**

Some people with cancer find it helpful to try complementary therapies as well as their standard treatment.

**Complementary therapies:** Complementary therapies are treatments that can be given in addition to standard medical treatment. Examples of complementary therapies are yoga, meditation, acupuncture, aromatherapy and massage.

**Standard treatment:** Standard or conventional cancer treatments include chemotherapy, radiotherapy and surgery. The effects and the side-effects of standard treatments have been scientifically tested.

**Alternative therapies:** Alternative therapies are generally treatments that are used instead of standard treatments. For example, diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health, and can make your standard cancer treatment less effective.

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**More information**

To find out more about the different complementary and alternative therapies, read our booklet *Understanding Cancer and Complementary Therapies: A Guide for Cancer Patients*. To get a copy call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also read or download the booklet on our website [www.cancer.ie](http://www.cancer.ie)

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**Cancer Nurseline Freephone 1800 200 700**
After treatment

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What follow-up will I need?

After your cancer treatment has ended you will still need to go back to the hospital for regular check-ups. This is called follow-up. At first you will see your consultant every 3–6 months, for at 1 to 5 years, but these check-ups will become less frequent over time. The follow-up will involve a full skin check, examination of the site of your surgery, lymph glands and may involve blood tests, X-rays or other scans.

Tell your doctor or nurse how you have been since your last appointment. Remember to tell them about any new symptoms, aches or pains you have, or if you are finding it hard to cope. Sometimes it helps to write down what you want to say before you see the doctor. That way you won’t forget what you wanted to say.

If you are between check-ups and have a symptom or problem that is worrying you, tell your doctor or nurse. Make an appointment to see him or her as soon as possible.

Staying healthy after treatment

Many people want to make positive changes to their lives after their treatment has ended. Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Cope better with the side-effects of treatment
- Keep up your energy and strength

Research suggests that a healthy lifestyle may also lower your risk of the cancer coming back. A healthy lifestyle includes:

- Exercising
- Eating healthy foods
- Staying at a healthy weight
- Not smoking
- Checking your skin regularly
- Protecting yourself from the sun

If you want more information or advice, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also go to our website [www.cancer.ie](http://www.cancer.ie) for tips and publications on healthy living.

Checking your skin

It’s very important to inspect your skin regularly for any changes once your treatment has ended. 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. See page 54 on how to check your skin.

Your family

If you have had treatment for any kind of melanoma or non-melanoma skin cancer, other members of your family may be at risk of developing melanoma. 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 members, including teenagers and young adults, should check their skin too, and visit a dermatologist if they are concerned about their skin.

Protecting your skin

Anyone who has been diagnosed with melanoma has a higher risk of developing another melanoma. It is very important to protect your skin from UV rays. Learn how to protect your skin using the SunSmart code on page 55 or on [www.cancer.ie](http://www.cancer.ie). If you’re not sure, ask your doctor or nurse for advice.

You can also visit a Daffodil Centre or call our Cancer Nurseline on 1800 200 700.

Email: cancernurseline@irishcancer.ie
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
- **B** = Irregular Border
- **C** = Changes in Colour
- **D** = Diameter (size)
- **E** = Evolving (growing or changing over time)

Reduce your risk of melanoma by following the SunSmart code:

- Sunscreen isn’t enough!

**Seek shade**
- Especially 11am–3pm, April–September
- For babies under 6 months

**Cover up**
- Choose a collared shirt with long sleeves
- Wear long trousers/skirts
- Pick a hat that shades your face, neck and ears

**Wear sunglasses**
- Wraparounds are best
- Make sure they give UV protection
- Children too!

**Slap on sunscreen**
- At least 30 SPF for adults
- Over 30 SPF for children
- Look for the UVA logo on the bottle
- Choose water resistant sunscreen for swimming, sports and when it’s hot
- Put it on 20 mins before going outside
- Reapply every 2 hours while you’re out

Visit the SunSmart website at [www.cancer.ie/sunsmart](http://www.cancer.ie/sunsmart)
Life after cancer

Being told your treatment has been successful is wonderful news. But it can take some time to adjust to life after cancer treatment. It isn’t unusual to feel quite low and lost after your treatment has ended, especially during the first few months.

Feelings you may have include:
- **Fear of cancer coming back** and worrying about every small symptom
- **Loneliness** without the company and support of your medical team and fellow patients
- **Stress** at having to deal with things that may have been on hold during your treatment, such as your finances, going back to work and family issues.
- **Isolation or guilt** if your family and friends expect you to get back to normal before you are ready
- **Anxiety and self-doubt** about sexual and romantic relationships
- **Anger** at what has happened and the effect on you and your loved ones
- **Depression or sadness**

There is more about how to cope with these feelings and adjusting to life after cancer on our website [www.cancer.ie/coping/life-after-cancer-treatment](http://www.cancer.ie/coping/life-after-cancer-treatment)

You can also call our Cancer Nurseline or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 59 for other ways to get support.

Email: cancernurseline@irishcancer.ie
How can I cope with my feelings?

There are many reactions when you hear you have cancer. Reactions differ from person to person. There is no right or wrong way to feel and there is no set time to have one particular emotion or not.

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

A helpful booklet that discusses in detail how you may be feeling is called Understanding the Emotional Effects of Cancer. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

Sometimes a cancer diagnosis can cause anxiety and depression. If you feel that your low moods are getting the better of you or you are finding it hard to cope, it’s important to get help. It’s not a sign of failure to ask for help or to feel unable to cope on your own. Try to talk with someone you know who is a good listener or tell your GP. Medical social workers can also offer support to you and your family.

If you are finding it difficult to get over a period of depression, your doctor may suggest treatment. Often a short course of antidepressants can work well. Professional counselling can also be very helpful.

Counselling

Sometimes it can be hard to talk to the people closest to you if you are feeling very distressed or finding it hard to cope. You may worry about upsetting or worrying your friends or family. A trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

Counselling is available free of charge at some local cancer support centres. To find out more about counselling call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at cancernurseline@irishcancer.ie.

A list of counsellors funded by the Irish Cancer Society is available at www.cancer.ie.

Ways to get emotional support

Find out about cancer support services in your area: There are lots of local cancer support services that provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 75 for more about cancer support services.

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your doctor, specialist nurse or medical social worker can refer you to psycho-oncology support services.

Join a support or educational group: Many people find it very reassuring to talk to other people who are in a similar situation and facing the same challenges. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Get one-to-one support: The Irish Cancer Society can put you in touch with a trained Survivor Support volunteer who has been through a cancer diagnosis and who can give you emotional and practical support.

Get online support: There are special websites called online communities where people with cancer can write questions, share stories, and give and receive advice and support. Visit www.cancer.ie/community to join the Irish Cancer Society online community.
Talk things through: It can be a great weight off your mind to share your feelings and concerns. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre.

How can I help myself?

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.

Use your support network: Doing things for yourself can help to make you feel more in control, but be realistic about what you can manage by yourself. Don’t be afraid to ask for help from those who want to support you or to use the support services available. Telling people what you need and how they can help means you will get the right amount of support to suit you.

Involves your family and close friends: Don’t keep your worries or any physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. If you’re feeling alone, you can also talk in confidence to one of our cancer nurses by calling our Cancer Nurseline or visiting a Daffodil Centre.

Gather information about your cancer and treatment: Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress for some people.

Try relaxation and stress management techniques: Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Try complementary therapies: Complementary therapies are treatments like acupuncture, yoga and aromatherapy that are given in addition to your standard treatment. They may help to relieve the side-effects of cancer and its treatment. They can also help you to feel better emotionally. See page 49 for more information on complementary therapies.

Accept change in your life: Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Know that there will be ups and downs: Sometimes people feel they have to be brave or positive all the time, but it’s normal to have bad days. Get help if you are finding it hard to cope.

Keep busy: Try to keep busy and make plans for the things you would like to do. This can mean taking trips, visiting loved ones or doing certain activities.

Try to cope day by day: Don’t think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Express yourself: Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of what you are going through. Other forms of creative expression, such as music and art, may help too.

Practical planning: It’s very understandable that you might feel anxious or reluctant to talk to your family or friends about how you might like to be looked after if your cancer progresses, for fear of upsetting yourself or them. However, it can give you the chance to plan and deal with any practical concerns or worries you may have in your personal life. If your cancer is advanced, you can look at our advanced cancer web pages on our website www.cancer.ie for more help with planning ahead. You can also call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for advice, information and support.
Further information and support
If you want more advice and support, you can ask your nurse or medical social worker. Or call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

How can my family and friends help?
Don’t feel you have to manage alone. Your 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 cancer 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 friend best.

So many kind and generous people asked me what I needed. I mostly had no idea! Specific questions helped, like: “I’m at the supermarket, can I bring you dinner?” or “I’m off tomorrow, can I call in at 3?”

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’s important in life for you. You may also get the chance to do and enjoy different things that you would never have done otherwise.

You and your family
Every family deals with cancer in its own way. You may feel that you don’t want your illness to upset family life, feel guilty that you can’t join in as much as before, or that you’re letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet, Who Can Ever Understand? can help to you find ways to talk about your cancer and to ask for the help and support you need.

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren’t sure what to say to them.

A useful booklet called Talking to Children about Cancer. A Guide for Parents gives practical advice for talking to children about cancer, with specific advice for different age groups. It also has information on supporting children and teenagers and helping them to deal with their emotions.

The booklet is available free of charge from Daffodil Centres or by calling the Cancer Nurseline. It’s also available on our website www.cancer.ie.
Advice for carers

Caring for someone with cancer  66
Looking after yourself  67
Caring for someone who has had treatment for melanoma can be difficult at times. Some patients manage well and need little practical support from family and friends. Others may need more support and care.

Coping with both the practical and emotional issues of treatment can be hard. Here are some things that can help to make life a little easier.

Caring for someone with cancer

Learn more about melanoma, any possible side-effects and the emotional effects it can cause. This will help you to understand how you can support your partner, relative or friend. Visit our website www.cancer.ie or call our Cancer Nurseline for a free copy of our publications.

Plan as much as you can ahead of the discharge date: Ask to speak to a medical social worker about the community services that are available. Tell your GP and local public health nurse that your loved one will be coming home. If dressings or other medical supplies are needed, make sure you have some at home before the discharge date. Ask for a contact name and telephone number at the hospital so that you can talk to somebody if you have a problem.

Encourage your relative or friend: At first your relative or friend may feel very tired after treatment. As soon as they are feeling stronger, encourage them to do things for themselves. The more involved they are in their own care, the quicker they will adapt to a new way of life.

How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Cancer Nurseline to talk to a nurse in confidence on 1800 200 700. Ask for a copy of our booklet Lost for Words – How to talk to someone with cancer. The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative.

You can also pick up a copy of the booklet at any Daffodil Centre, or download it at www.cancer.ie

Looking after yourself

Share worries: You may feel tired with all the worry and extra work. It can also be very difficult as you try to adapt to a new way of life. Make sure you share your worries with someone else. Call our Cancer Nurseline on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence. Stay in touch with your own friends and get out when you can, even if you don’t always feel like it.

Take regular breaks: If your partner or friend is anxious or depressed, try to take a break each day, even if it’s just a walk to the shops. Ideally, try to organise a longer break as well, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.

Have little treats: If you don’t want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.
If you find it difficult to cope, get help: Talk through your feelings and frustrations with a friend or your GP. Your GP can suggest other services and sources of help.

Look after your own health: See your GP sooner rather than later if you have any health concerns of your own.

Find carers support organisations or local cancer support centres: Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

Support for you
Our cancer nurses are there to support you as a carer. Call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or email cancernurseline@irishcancer.ie for confidential support, advice and information. You could also ask for a copy of our booklet, Caring for someone with cancer, or download it from our website www.cancer.ie

Support resources

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Local cancer support services 75
Helpful books 76
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Questions to ask your doctor 79
Coping with the financial impact of cancer

A diagnosis of cancer often means that you will have extra expenses, like car parking during hospital visits, medication, travel, heating and childcare costs. If you can’t work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Overnight stays in hospital
- Medicines
- Equipment like medical devices, disability aids, dressings, wigs, etc.
- Sometimes called ‘appliances’.

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you do not have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It’s important to contact your insurance company before starting treatment.

Benefits and allowances

There are benefits available from the Department of Social Protection that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer’s Allowance, Carer’s Benefit and Carer’s Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0761 074 000
- Department of Social Protection (DSP) – Tel: 1890 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It’s also a good idea to photocopy completed forms before posting them.

If you have financial difficulties

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential. Call the MABS Helpline 0761 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 73 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.
More information
For more information go to www.cancer.ie/publications and check out our booklet, Managing the Financial Impact of Cancer – A Guide for Patients and their Families. This explains:
- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

The booklet also has lots of other information to help you manage the cost of cancer. For example, disability and mobility supports, help for people in financial difficulty, help for carers and living at home and nursing home supports.

Irish Cancer Society services
Our Cancer Support Department provides a range of cancer support services for people with cancer, at home and in hospital, including:

- Cancer Nurseline
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support services
- Night nursing
- Publications and website information

- **Our Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie

For the deaf community, our Cancer Nurseline is using the Sign Language Interpreting Service (SLIS) using IRIS. Contact IRIS by text 087 980 6996 or email: remote@slis.ie

- **Our Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.

- **Our Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area**. We work with cancer support groups and centres across the country to ensure that cancer patients have access to confidential support including counselling. See page 75 for more information.

- **Patient travel and financial support services**. We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
  - **Travel2Care** is a limited fund, made available by the National Cancer Control Programme, for patients who are having
difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.

- **Irish Cancer Society Volunteer Driver Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

To access either of these services please contact your hospital healthcare professional for more information.

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.

- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer, and financial concerns. Visit our website [www.cancer.ie](http://www.cancer.ie) or call our Cancer Nurseline for a free copy of our publications.

> The Irish Cancer Society Nurseline is an amazing resource that has not only offered me practical advice as a melanoma patient, but also reassurance and guidance.

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### Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients and their families, during and after treatment, many of which are free. For example:

- **Professional counselling:** the Irish Cancer Society funds up to 8 sessions of free, one-to-one counselling in many affiliated support services

- **Support groups,** often led by professionals like social workers, counsellors, psychologists, or cancer nurses

- **Special exercise programmes,** like the Irish Cancer Society’s *Strides for Life* walking group programme

- **Stress management and relaxation techniques,** such as mindfulness and meditation

- **Complementary therapies** like massage, reflexology and acupuncture

- **Specialist services** such as prosthesis- or wig-fitting and manual lymph drainage

- **Mind and body sessions,** for example, yoga and tai chi

- **Expressive therapies** such as creative writing and art

- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what’s available.

You can call our Cancer Nurseline on Freephone 1800 200 700 to find your nearest cancer support centre. Or see our online directory at [http://www.cancer.ie/support/support-in-your-area/directory](http://www.cancer.ie/support/support-in-your-area/directory)
Helpful books

The Irish Cancer Society has a wide range of information on reducing your risk of cancer, different types of cancer, treatments, and coping. For free copies call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download or order the booklets on our website: www.cancer.ie.

You may find the following helpful:

**Treatment and side-effects**
Understanding Chemotherapy
Understanding Radiotherapy
Understanding Cancer and Complementary Therapies
Diet and Cancer
Coping with Fatigue

**Coping and emotions**
Understanding the Emotional Effects of Cancer
Lost for Words: How to Talk to Someone with Cancer
Who Can Ever Understand? Talking About Your Cancer
Talking to Children about Cancer: A Guide for Parents
A Time to Care: Caring for Someone Seriously Ill at Home
Caring for Someone with Cancer

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.

**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.

**Excision**
Removing cancer by cutting out an area of skin.

**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.
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?
- Does 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
6. Answer
7. Answer
8. Answer

### Notes

You have to be seriously organised to be seriously ill! Write everything down. If you prefer not to write during appointments, spend time afterwards jotting down the main things you discussed so you can refer back to it. Keep everything in one place. If you are not naturally organised, ask someone to help you.
Join the Irish Cancer Society team
If you want to make a difference to people affected by cancer, join our team!

Support people affected by cancer
Reaching out directly to people with cancer is one of the most rewarding ways to help:
- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Survivor Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences
Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:
- Share your cancer story
- Tell people about our services
- Describe what it’s like to organise or take part in a fundraising event

Raise money
All our services are funded by the public’s generosity:
- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Contact our Cancer Nurseline on Freephone 1800 200 700 if you want to get involved!

Did you like this booklet?
We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

More information and support
If you would like more information or someone to talk to, now or at any time in the future, please call our Cancer Nurseline on 1800 200 700.