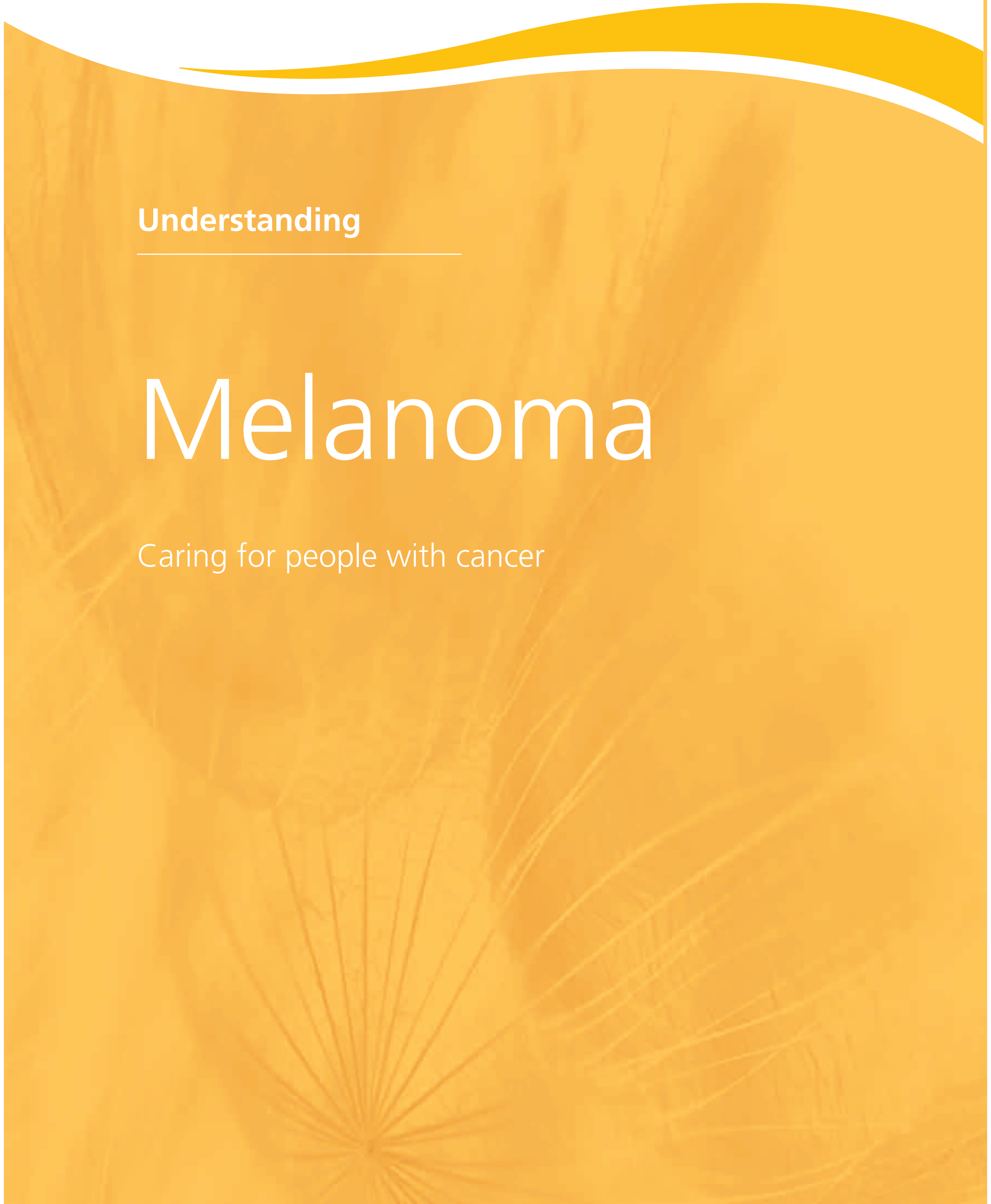
Irish
Cancer
Society



Understanding

Melanoma

Caring for people with cancer

Understanding

Melanoma

This booklet has information on:

- Treatment for melanoma skin cancer
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Family doctor (GP)

Dermatologist

Surgeon

Medical oncologist

Radiation oncologist

Radiation therapist

Medical social worker

Emergency

Daffodil Centre

Hospital records number (MRN)

Contents

Fast facts

Can my cancer be treated?

Page 31

Yes. Surgery is the main treatment for melanoma skin cancer, and can usually cure it. Other treatments such as chemotherapy, immunotherapy, targeted therapies or radiotherapy may be used also, depending on the stage of the melanoma.

Will I be OK?

Page 28

What is likely to happen to you (your prognosis) is hard to predict. It depends on a lot of things, and everyone's prognosis is different. The prognosis for melanoma is very good for most people, but your doctor will advise you on what is likely to happen in your situation.

What treatment might I have?

Page 45

Surgery: Removes the skin cancer and the area close to it.

Targeted therapies: Drugs that find ways to stop melanoma cells from dividing and growing.

Chemotherapy: Drug therapy used to destroy cancer cells or to control cancer growth.

Radiotherapy: Uses high-energy rays to destroy cancer cells. It is generally not used to treat melanoma of the skin.

Are there side-effects from treatment?

Page 45

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 or nurse. Don't suffer in silence!

Clinical trials

Page 55

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

We're here for you

Page 94

If you or your family have any questions or 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 Support Line on 1800 200 700
- Drop in to a Daffodil Centre – visit **www.cancer.ie** to find your local centre
- Email us: supportline@irishcancer.ie

See page 94 for more about our services.

Reading this booklet

This booklet is to help you throughout your cancer treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at **supportline@irishcancer.ie**

About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to your own team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About melanoma

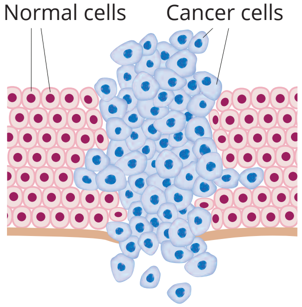
What is cancer?

Cancer is a disease of the body's cells

Cancer cells are abnormal cells that grow without control. They can form a lump (tumour).

Cancers are named after the organ or cell where the cancer starts

Melanoma is a type of skin cancer that starts in the melanocyte cells in the skin.



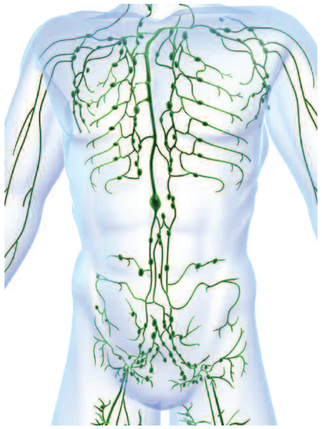
Cancers sometimes spread

If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new (secondary) tumour. This is called metastasis. Sometimes cancer cells spread into nearby lymph nodes.

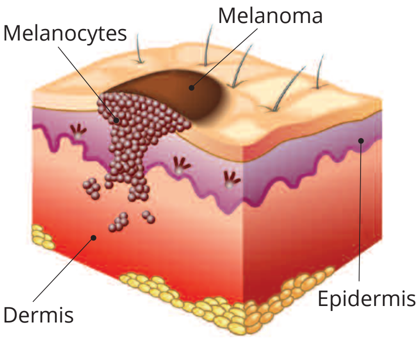
What is the lymphatic system ?

The lymphatic system is part of our immune system, which protects us from infection and disease and removes extra fluid and waste from the body's tissues.

- It is made up of lymph nodes connected by tiny tubes called lymph vessels.
- Lymph nodes are found mainly in the neck, armpit, groin and tummy.
- If cancer cells spread into lymph nodes or cancer starts in the lymph nodes they can become swollen.



Your skin



Your skin is the largest organ in your body. It protects us from heat by controlling body temperature, and protects us from sunlight, injury and infection. It also stores fat, water and vitamin D.

It has two main layers. 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.

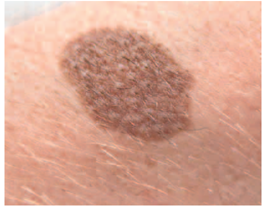
The inner or deeper layer of your skin is the dermis. It contains blood and lymph vessels, hair follicles and glands.

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

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

What is a mole?

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


Birthmark


Mole

If a birthmark or mole gets darker, larger, lumpy or starts to bleed, visit your family doctor (GP). See page 71 to learn more about checking your skin for changes to birthmarks or moles.

What is melanoma?

Melanoma is a type of skin cancer. It occurs 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 as a new mole in normal looking skin or within an existing mole. Most melanomas are new moles. Only a third arise from pre-existing moles. 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.

> Most melanomas are new moles that appear on normal skin. Only a third arise from pre-existing moles.

Melanoma is a cancer in the cells that make melanin (melanoyctes), which gives your skin its colour.

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, chest or 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 begins as a small, brown freckle or stain and gradually spreads to form a bumpy surface. It can grow slowly over many years.

Acral melanoma

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

Amelanotic melanoma

This is a rare melanoma, and unlike the others, it may have no colour 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 Support Line on 1800 200 700 or visit a Daffodil Centre.

Melanoma of the eye

Melanoma can sometimes develop in your eye, but it is rare. It develops in the lining of the eyeball called the uvea. Your doctor might call it uveal melanoma or ocular melanoma.

Signs and symptoms

Symptoms include blurred vision, seeing flashing lights and shadows. 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.

How common is melanoma?

Melanoma is one of the most common cancers among young adults. The number of people in Ireland being diagnosed with melanoma has tripled in the last 20 years. Each year about 1,200 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 very large birthmark (naevus), there is a slight risk it may change and become a melanoma.

What increases my risk of melanoma?

The exact cause of melanoma is unknown. Everyone is at some risk, but increased risk depends on several factors including your exposure to the sun, the number of moles on your skin, your skin type and family history (genetics). Having a risk factor doesn't mean you will get skin cancer. For more information on the causes of melanoma skin cancer, see our website **www.cancer.ie**

Diagnosis and tests

Being diagnosed with melanoma

Hearing that you have melanoma skin cancer 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
- **Angry** that this is happening to you

However you feel, you are not alone.

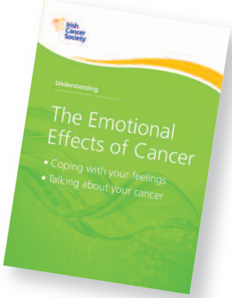
If you need to talk to someone, or if you want support or advice:

- Ask to speak to the cancer (oncology) liaison nurse/clinical nurse specialist (CNS) or the medical social worker 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 – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie.
- Speak to an Irish Cancer Society Survivor Support volunteer who has had a cancer diagnosis and really knows what you are going through. Our cancer nurses will do their best to put you in touch with a volunteer.
- Talk to other people affected by cancer. Join our online community at **www.cancer.ie/community**
- Go to your local cancer support centre. For more information, see page 100.

Telling people about your diagnosis

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don’t want to tell people straight away. You may be unsure how to break the news. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer***. It can help you find ways to talk about your cancer and to ask for the help and support you need.



Irish Cancer Society

Understanding

The Emotional Effects of Cancer

- Coping with your feelings
- Talking about your cancer

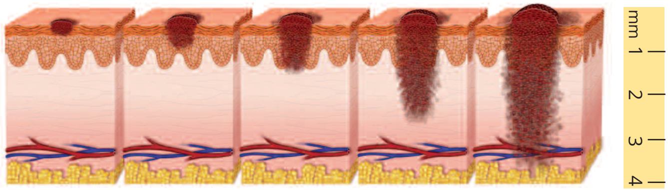
What tests will I have?

- You may need to have tests such as a skin biopsy or an excision biopsy.
- Further tests such as scans may sometimes be used to stage your cancer.

Excision biopsy (removing the mole)

A biopsy means taking a sample of cells and looking at them under a microscope. With an excision biopsy, the entire mole or affected tissue is removed and examined in the laboratory. The doctor who does the surgery is a dermatologist or plastic surgeon; the doctor examining the mole is a pathologist.

After melanoma is diagnosed, the pathologist will measure the depth, or thickness, of the cancer to see if it has 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. See page 25 for more on staging your cancer.



Most people have melanomas that are 1mm thick or less. If the melanoma is thicker than 1mm, 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. They 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 may take 2-4 weeks to come back to you. Your doctor will explain them to you in detail.

If the biopsy shows that the cancer has or might spread deeper than your skin surface, your doctor may need to do other tests to find out more about the extent or stage of the cancer and your general health. This can help them decide on the right treatment for you. See page 25 for more about staging melanoma.

In most cases, you will need further surgery to reduce the risk of the cancer coming back.

Further tests

If you are having further tests, these might include:

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 1mm into your skin, your doctor may do a test 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 may be done in the X-ray department. The 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 removed and sent to the laboratory to be examined. This is usually done during wide local excision (see page 47).

If the sentinel node has melanoma cells, your doctor may then decide to remove the remaining lymph nodes at a later date. For more details, see page 48. If there are no melanoma cells 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.

Blood tests

Some blood tests may be done to check your general health.

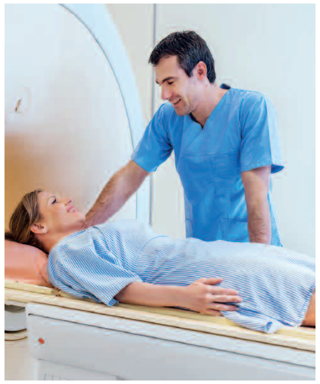
PET scan

This scan can give your doctor more information about the melanoma and if it is anywhere else in your body. A low dose of radioactive sugar is injected into your arm. The radioactivity can highlight cancer cells in your body. You will have a scan an hour or so after the injection. During the scan, you will lie on a table which moves through a scanning ring. The scan can last up to an hour. Before the scan, you may have to fast (not eat) for a few hours.

You may have to travel to a specialist centre to have a PET scan, as not every hospital has these scanners.

You will be slightly radioactive after the PET scan, so you will be advised not to have close contact with pregnant women, babies or young children for a few hours. This is normal and is nothing to worry about. The hospital staff will give you more detailed information about this.

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 your body from many angles.

A computer then combines the pictures and makes a detailed image of your 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.

MRI scan

This is a scan that uses magnetic energy to create a picture of the tissues inside your body. During the test you will lie inside a tunnel-like machine. Some people may feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious at the time of the examination.

An MRI can also be noisy, but you will be given earplugs/headphones to help block out the sound. 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.

For most scans you will be alone in the treatment room, but the medical staff can still see you and hear you. If you need anything, just speak or raise your hand.

Bone scan

Bone scans are very sensitive and can sometimes be used to find cancer cells before they show up on an 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. You will be slightly radioactive for a few hours after the scan. This is normal following a bone scan. The staff in the hospital will give you more detailed information on how to protect yourself and others following your bone scan.

Waiting for test results

It usually takes 2-4 weeks for test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend.

You can also call our Support Line 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.'

Staging melanoma

- Staging means finding out the size of the melanoma and if the cancer has spread.
- The results of your excision biopsy will help your doctors to decide if you need further staging tests done.
- Most people with early-stage melanoma do not need further tests.

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

Stages of melanoma

Stage 0: Melanoma in situ. This is the earliest stage of melanoma. The melanoma cells are only in the 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 only in the skin. It has not spread to lymph nodes or other organs.

Stage 3: Medium-stage or locally advanced melanoma.
The melanoma is in the deeper layers of your skin and may have spread to nearby lymph nodes and other tissues.

Stage 4: Metastatic (advanced) melanoma. The cancer has spread to distant parts of your body such as the lung, liver or brain.

Staging can be confusing, so ask your doctor or specialist nurse if you don't fully understand.

Additional staging details

Using the general stages 1-4, your doctor may also do a more detailed staging, adding letters (A-C) to the numbers. This will describe the thickness (see Breslow thickness on page 19), the spread (if any) and if the skin is ulcerated (broken).

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

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

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

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

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

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

Stage 3B: The melanoma can be of any thickness and is ulcerated. It has spread to 1 to 3 lymph nodes near the original tumour. The nodes can be enlarged or not enlarged.
OR: The melanoma can be of any thickness, but it is not ulcerated. The melanoma has spread to skin or lymph vessels around the original tumour. Nearby lymph nodes do not 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.

Genetic mutation testing

In certain cases, a pathologist will test the tumour for gene changes (mutations). Each gene mutation makes the cancer act in a different way. Almost half of people diagnosed with melanoma have a mutation in the BRAF gene. Knowing which gene mutation affects your tumour helps the doctors to plan the best treatment for you. See page 49 for more information. You may be offered a place in a clinical trial, based on the genetic mutation of your melanoma. See page 55 for more on clinical trials.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

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.

If you decide you want information on your prognosis:

- **Get the information on your prognosis from your doctor.** They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- **Write down your questions for the doctor or nurse before you meet them,** as it is easy to forget something when you go to the clinic. It may be good to get a family member to help you with these questions.
- **Ask a friend or family member to go with you**, if you would like some support.
- **Be careful with online information.** It may be hard to understand or even incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- **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 Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@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.

Treatment overview

How is early-stage melanoma treated?

- Surgery is the main treatment for early-stage melanoma.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

Surgery

Surgery is the main treatment for early-stage melanoma. After having the mole removed, you are likely to have further surgery to remove normal skin around the affected area. This is called wide local excision and is done to reduce the risk of the cancer coming back. See page 47 for more on wide local excision.

A team of doctors and nurses, called the multidisciplinary team (MDT), will meet to discuss your case and see if you need more treatment. (See page 38 for more about the team).

How is locally advanced melanoma treated?

You may have surgery to remove melanoma that has spread to nearby tissues (locally advanced). You may also have your lymph nodes removed (see page 48). After surgery, you may also need drug treatment, such as targeted therapies or immunotherapy. See pages 49-54 for more on these.

How is metastatic (advanced) melanoma treated?

Metastatic (advanced) melanoma means the cancer has spread to another part of your body. Treatment will depend on the type and size of the melanoma, where it is found and if any organs are affected.

You may have surgery to remove the melanoma. If melanoma is found in your lymph nodes, these may be removed under general anaesthetic. Or, if the cancer is small and only detected on sentinel lymph node biopsy, your doctor may recommend ultrasound surveillance.

Other treatments for metastatic melanoma include:

- **Targeted therapies** (see page 49)
- **Immunotherapy** (see page 50)
- **Chemotherapy** (see page 52)
- **Radiotherapy** (see page 54)

You may also be offered new drugs or a combination of drugs as part of a clinical trial (see page 55).

For more on treating cancer that has spread (metastatic cancer), see page 56.

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). This is where chemotherapy is given directly into an affected limb.

For more information on treatments for recurrent melanoma you can talk to a cancer nurse by calling our Support Line on 1800 700 200, emailing supportline@irishcancer.ie or dropping in to a Daffodil Centre.

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, histopathologist, plastic surgeon, medical oncologist, radiation oncologist, specialist nurse and radiologist. The team will meet to discuss your test results and your treatment plan.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could use the notes page at the back of this booklet for your questions and answers. If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.

Time to think

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 treating doctor or GP can 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 a particular 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, you should 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
- Possible side-effects from 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.

Specialist cancer centres

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

Who will be involved in my care?

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

Consultant An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Dermatologist A doctor with expertise in managing skin conditions. Dermatologists have undergone training to manage skin cancer by surgical excision. Most skin cancers are referred to dermatologists initially.

Plastic surgeon A doctor who performs operations to remove skin cancers and to repair or replace skin which has been damaged.

Surgeon A doctor who specialises in surgery and who can remove a tumour from your body.

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 radiotherapy and gives advice to cancer patients about their radiation treatment.

Radiologist A doctor who specialises in interpreting X-rays and scans such as ultrasound, CT, MRI and PET.

Histopathologist A doctor who examines tissues and cells, usually under a microscope, to help give a diagnosis

Oncology liaison nurse / clinical nurse specialist A specially trained nurse who works in a cancer care unit. They give information and reassurance to you and your family from diagnosis and throughout treatment.

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

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 also give advice on social welfare benefits, financial matters and practical supports and services available to you.

GP (family doctor) Your GP is still very much a part of your care and 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.

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.

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.

Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

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 'community palliative care team' or the 'hospice homecare team'. A specialist palliative care service is available in most general hospitals.

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

Individual treatment

Your experience of treatment may be quite different to what you expect or have heard. Cancer and its treatment affect people in different ways. It depends on the type and stage of your cancer, the best treatment for your individual cancer and your general health. If you have any questions or worries, ask your doctor or nurse.

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.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or contact a Daffodil Centre to speak to a cancer nurse.

You might like to focus on your health and wellbeing while you're waiting for treatment to start. For example, eating well and staying active.

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and feel better.

Eat well

Eating well when you have cancer can help you feel better. It can help you to:

- Feel stronger and maintain a healthy weight
- Cope better with the side-effects of treatment
- Reduce the risk of infection
- Recover more quickly

Ask the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Diet and Cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Keep active

Keeping active has many benefits. It can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues

Talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you. Your medical team can also refer you with a physiotherapist who will advise you on the best type of exercise for you.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking. However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment.
- Smoking can reduce how well chemotherapy or radiotherapy work.
- Smoking increases risk of complications following surgery, such as delayed wound healing and chest infections.

To get advice or support on quitting, go to www.quit.ie, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. Some hospitals have smoking cessation officers who can help and support you. You can ask your doctor or nurse for a referral to this service.

Other ways to help yourself

Get 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. If it makes you anxious, you could ask a friend to do the research for you, and tell you anything important.

Involve your family and close friends

Don't keep any worries or 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. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don't be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.

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.

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.

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.

Types of treatment

Surgery

- 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 may have surgery to remove them.

After the mole or affected area of skin is removed and melanoma is diagnosed – your doctors will most likely recommend further surgery, which is called wide local excision.

Wide local excision

Wide local excision is surgery to remove normal-looking skin around and under the melanoma site. This is to reduce the risk of the melanoma coming back. The amount of skin that needs to be removed depends on the size of the melanoma examined under the microscope (Breslow thickness, see page 19).

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

Skin grafts

Sometimes when a wider area of skin is removed the surgeon may need to do a skin graft. A graft means that layers of skin are taken from another part of your body and placed onto the wound. The skin can be taken from your thigh or upper arm. This is called the donor site. The thickness of the skin taken depends on the depth of the area to be covered.

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 go back to the hospital for dressings. Don't be put off by how the graft area looks at first. The raw look will heal and fade in time.

Small skin grafts can often be done as day surgery, so you can go home the same day.

Skin flap

Sometimes a skin flap is used. This is where the surgeon takes a thick layer of skin – with its own blood supply – from an area near the melanoma site and places it over the site to repair the wound.

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 Support Line on 1800 200 700, drop into a Daffodil Centre or visit our website: **www.cancer.ie**

Going home

Before you go home, you will be given a date to go back for a check-up, usually about 6 weeks after surgery. 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. Your nurse can organise community services – such as public health nurse visits – for you, if necessary.

Further treatment after surgery

Sometimes your doctors will recommend that you have further treatment if they feel there is a risk of the melanoma coming back, or if the cancer is found in nearby lymph nodes. This is called adjuvant treatment. It may involve drug therapies such as targeted therapies, immunotherapy and chemotherapy.

These treatments are also used to control cancer that has spread – metastatic (advanced) melanoma. See page 56.

Targeted therapies

Targeted therapies can help fight cancer or stop it spreading. Different types of targeted therapies work in different ways. For example, cancer growth inhibitors block the chemical signals that trigger cancer cells to divide and grow. This type of targeted therapy may be recommended if you have a change in the BRAF gene.

BRAF inhibitors

BRAF is a protein that 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 tissue will be tested for the BRAF gene mutation. Almost half of Irish melanoma patients have a mutated BRAF gene. If you test positive for the mutated BRAF gene, you may be treated with a BRAF inhibitor. These 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 or rashes and they increase your risk of developing non-melanoma skin cancer. Other side-effects include diarrhoea, joint pain, feeling sick (nausea), liver problems and thinning hair.

New targeted therapies

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy as part of a clinical trial (see page 55). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials suitable for you.

Your doctor and nurse will discuss your treatment with you in more detail and tell you about any likely side-effects.

Immunotherapy

Immunotherapy boosts your body's immune system to fight cancer. Immunotherapy works 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. PD-1 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-PD-1 and CTLA 4 inhibitors as a treatment helps the T-cells to keep working and allow your immune system to fight off cancer. Immunotherapy drugs are given to patients through a drip into a vein (intravenously). This is usually done in a specialist cancer centre.

Side-effects

Patients typically have few or mild side-effects from immunotherapy. It is important to understand that any side-effects you have 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, joint pain and headaches. You may feel depressed. If you do, you may need a short course of medication. Usually the side-effects disappear once the treatment is over.

Talk to your medical team about any side-effects you experience, so they can be managed effectively.

For more information on immunotherapy and its side-effects, call our Support Line on 1800 200 700 or visit a Daffodil Centre. Ask for a copy of the free booklet, ***Understanding Chemotherapy and other cancer drugs***.

Chemotherapy

Chemotherapy is a treatment using drugs to kill cancer cells. It is used to treat melanoma if targeted therapy or immunotherapy are not good options for you. Chemotherapy may be given to control metastatic melanoma or to improve symptoms.

You may be given chemotherapy as part of a clinical trial. Clinical trials are research studies investigating the best ways to treat a disease. Your doctor may ask you if you would like to take part in a trial. See page 55 for more details.

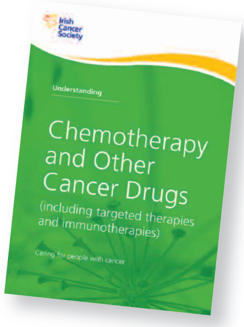
Side-effects

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

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

> 'Your team will prescribe you medications to get you through the side-effects. Take them. Report how you are feeling to your oncologist or oncology nurse, and they will be able to change your drug regimen or offer advice.'

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



Understanding your drug treatment

It's important that you understand the medicine you have been given. Don't be afraid to ask your doctor or specialist nurse for more information about any drugs you are taking, what they are for and any possible side-effects. They should give you a printed sheet to take home with you. If you know the name of your drug, you can visit the Health Product Regulatory Authority's website at **www.hpra.ie** for more information about:

- What the drug is
- How it is given
- Possible side-effects

If you have any questions or need any more information, you can speak to our cancer nurses by visiting a Daffodil Centre or by calling our Support Line on 1800 200 700.

Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells. It is not often used to treat melanoma. Occasionally it is used for recurrent melanoma of 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 the tumour or tumour site.

For more information, see our booklet ***Understanding Radiotherapy*** which you can download from our website, **www.cancer.ie**

Clinical trials

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

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

Because the drugs are still in trial, you'll be very closely monitored for unexpected side-effects and may have extra tests and appointments.

Trials often investigate very specific features of a particular cancer or treatment, so you may not be suitable for a trial, even if it is researching your particular cancer. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For 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 Support Line on 1800 200 700 or by dropping into a Daffodil Centre. You can see a list of current cancer trials at **www.cancertrials.ie**

Cancer and Clinical Trials

Cancer Nurseline 1800 200 700

Treating cancer that has spread (metastatic cancer)

If the melanoma spreads to another part of your body, it is called metastatic, advanced or secondary cancer. The melanoma may be in more than one part of your body when it is first diagnosed.

If your cancer has spread it can still be treated. Treatment in this case is to try to control the cancer rather than to cure it. There is a range of treatment options for most metastatic cancers, and new treatments are being developed all the time.

Often metastatic cancer is treated with immunotherapy, targeted therapies or chemotherapy. See pages 49-54 for more about these treatments. The metastatic cancer is still melanoma even if it is found in another part of your body and will be treated with melanoma treatments. There may also be treatments that you can have as part of a clinical trial (see previous page).

You can also have treatment to help relieve symptoms. You may be referred to the palliative care team, who are experts in managing the symptoms of metastatic cancer.

Thanks to recent advances in research and treatments, many people are living longer with metastatic cancer and with a better quality of life.

Palliative care

Palliative care helps you to manage your symptoms and improve your quality of life. Palliative care includes end-of-life care, but your doctor may also recommend palliative care to relieve symptoms earlier in your illness. The palliative care team can include specially trained doctors, nurses, social workers, physiotherapists, occupational therapists, complementary therapists, pastoral care professionals 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 don't need medical insurance.

Managing side-effects and symptoms

How can I cope with fatigue?

- Fatigue means feeling extremely tired.
- There are things that can improve fatigue, depending on what’s causing it.

It’s common to feel exhausted when you have cancer. This extreme tiredness (fatigue) 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

Usually fatigue starts to improve 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. They may be able to refer you to a physiotherapist who can advise you on how to best manage your fatigue.

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.

Our booklet ***Coping with fatigue*** has more advice. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre for a free copy. It’s also on our website **www.cancer.ie**

Hints & Tips – Fatigue

- Ask your doctor about exercising. Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- Plan your days. 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 with any jobs you find tiring.
- Try to a balanced diet. Eat little and often if your appetite is poor. Our booklet ***Diet and Cancer*** has tips to help.
- Try to avoid stress. Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling (see page 78) may help too.
- If you are not sleeping well, try to get a good bedtime routine and try relaxation techniques. Avoid stimulants like caffeine and alcohol in the evening and try not to use devices for an hour before bedtime. Short naps (less than an hour) and rest periods can be helpful, as long as they don't stop you from sleeping at night.
- Try complementary therapies such as meditation, acupuncture or massage, if your doctor says they're safe for you.

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. You may have concerns about how your partner will react if treatment affects how you look. It can be hard to relax 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. Touching, caressing and holding each other can help you to stay physically close.

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. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. 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. But you may find it will be some weeks before you will feel well enough to have sex again after surgery. Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

If you are having sex and you are fertile, 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 and some targeted therapies.

Many specialists recommend that you wait for up to 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 talking about these matters, so try not to feel embarrassed. You can also call our Support Line 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 supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments for cancer and 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. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Dealing with infertility 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 Support Line on 1800 200 700 or visit a Daffodil Centre for information and support from a cancer nurse.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage, counselling and aromatherapy.

Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their cancer and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Tell them also if you're using or considering using over-the-counter or herbal medications. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your cancer diagnosis.

Integrative care

Integrative care means combining (integrating) your standard cancer treatment with complementary therapies to try to feel as well as possible and to cope better with your cancer.

What's the difference between complementary and alternative therapies?

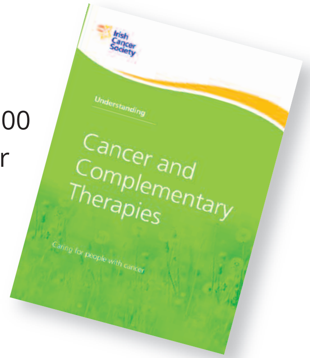
Complementary therapies are used **together with** standard medical treatment.

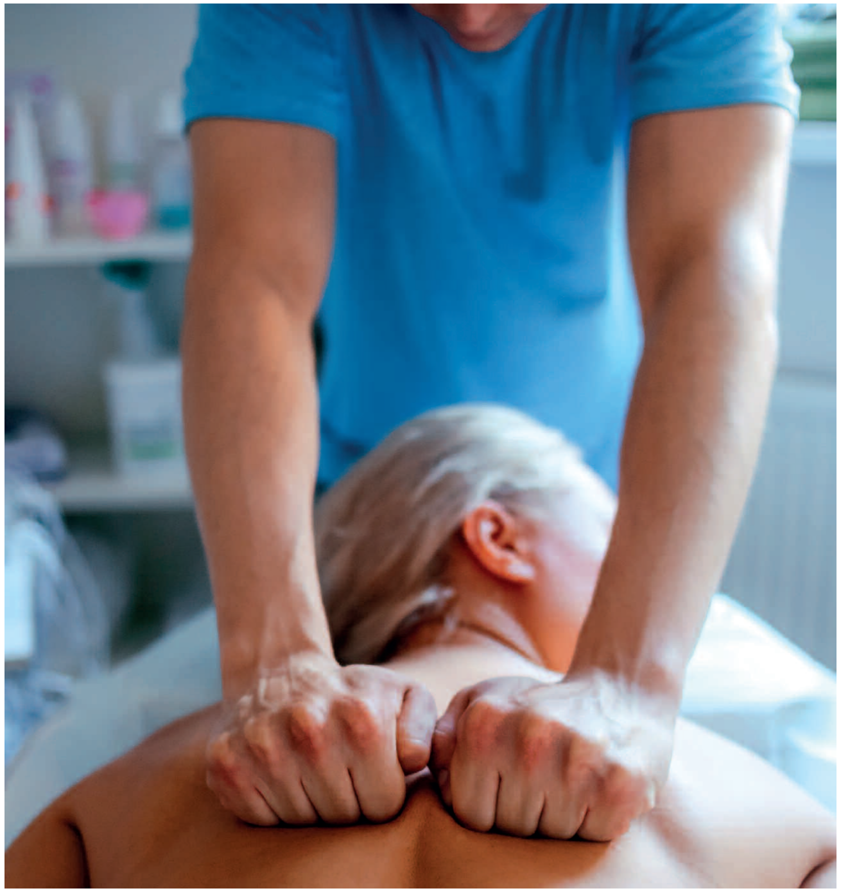
Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective at curing cancer and keeping it under control. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet ***Understanding cancer and complementary therapies***, or download it from our website **www.cancer.ie**





After treatment

What follow-up will I need?

After your cancer treatment has ended you will still need to have regular check-ups. This is called follow-up. At first you will see your consultant every 3-6 months, for at least 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 wound site and 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. It can help to write down what you want to say before you see the doctor. That way you won't forget anything.

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 them as soon as possible.

Life after treatment

It can take some time to adjust to life after cancer treatment. It's normal 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**. You can also call our Support Line or visit a Daffodil Centre to talk to a cancer nurse in confidence. See page 79 for other ways to get emotional support.

Living a healthy lifestyle

Having a healthy lifestyle is important as it can help you to:

- Feel better
- Heal and recover faster
- Keep up your energy and strength
- Reduce your risk of further illness

A healthy lifestyle includes:

- Exercising
- Eating well
- Not smoking
- Avoiding alcohol
- Protecting yourself from the sun

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **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 new lumps. If you find any changes, go to your GP so that they can check them. Remember, melanoma that is treated early has a greater chance of being cured.

Examine the scar site

Check the scar on the surgery site when the scar is healed, as part of your regular skin check routine. Watch out for changes such as lumps, bumps or a change of colour.

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)

Self-exam for melanoma skin cancer

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 soles and the spaces between your toes.
- 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.

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 skin cancer. This includes your brother, 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 skin cancer may have a higher risk of developing another.

It is very important to protect your skin from ultraviolet (UV) rays. Learn how to protect your skin using the SunSmart code on the next page or on **www.cancer.ie**.

If you're not sure, ask your doctor or nurse for advice. You can also speak with one of our nurses in a Daffodil Centre or call our Support Line on 1800 200 700.

The SunSmart Code

Keep your hat and shirt on!

Cover up

- Wear a shirt with a collar and long sleeves.
- Wear a wide-brimmed hat that gives shade to your face, neck and ears.

Seek shade

- Stay in the shade, especially between 11am and 3pm from April to September.

Wear wraparound sunglasses

- Make sure they give you 100% UV protection or are CE marked.

Slap on sunscreen

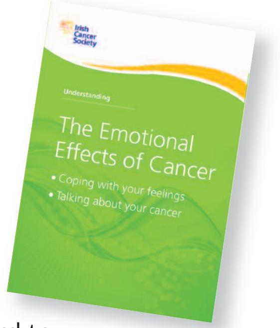
- Use water-resistant sunscreen with sun protection factor (SPF) of at least 30 and 100% UV protection or CE marked. Reapply every 2 hours.

Coping and emotions

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer. You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Emotions like sadness, fear, grief, hopelessness and anger can happen at different times, sometimes months or years after treatment.



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

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family. Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

A cancer diagnosis can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions, and get help if you need it.

Counselling

If you're feeling very distressed or finding it hard to cope, 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.

Free one-to-one counselling is available at many local cancer support centres. To find out more about counselling call our Support Line on Freephone 1800 200 700 or visit a Daffodil Centre. Or email the nurses at supportline@irishcancer.ie

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

> It's not a sign of failure to ask for help or to feel unable to cope on your own.

Ways to get emotional support

> 'Counselling has helped me with every part of my life.'

Find out about cancer support services in your area: Most 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 100 for more about cancer support services.

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

Ask about psycho-oncology services at the hospital: Hospital psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology support services if they are available at your hospital.

Get online support: Special groups called online communities let you ask 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 worries. 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.

Survivor support: Survivor Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has had a cancer diagnosis. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

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

> 'Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better.'

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

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 ***Understanding the Emotional Effects of Cancer*** can help to you find ways to talk about your cancer and to ask for the help and support you need.

Further information and support

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. You could also read our booklet ***Talking to Children about Cancer***, which has practical advice about how to talk to children of different ages.

Talking to Children about Cancer

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out.
Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel.
If you find it hard, ask another family member or friend to talk to them.

Advice for carers

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

Here are some things that can help to make life a little easier:

Learn about cancer

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one’s illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. Visit our website **www.cancer.ie** or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.

Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don’t be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. Free one-to-one counselling is available to friends and family members through many cancer support centres. Talk to your GP or see page 78.

Find out about support for carers

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. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for someone with cancer***, has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres or the Support Line, or download it from our website **www.cancer.ie**

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 Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer***. The booklet has a section on how to talk 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**

Support resources

Money matters

- If you have cancer you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as 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 your illness 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
- Medical aids and equipment (appliances), like wigs

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 don't 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 to check you're covered.

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer's Allowance, Carer's Benefit, 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: 0818 074 000
- **Department of Employment Affairs and Social Protection** – Tel: 0818 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 money problems

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 0818 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 97 for more details of our Volunteer Driver Service and the Travel2Care fund.

You can also call our Support Line 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

More information

Go to **www.cancer.ie** and see our **managing money** page for information on:

- **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 Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

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:

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

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information. The Support Line is open Monday–Friday, 9am to 5pm. You can email us at any time on **supportline@irishcancer.ie** or visit our Online Community at **www.cancer.ie**

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

Email: supportline@irishcancer.ie

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide free confidential advice, support and information to anyone concerned about or affected by cancer.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – you don't need an appointment. Just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

You can email daffodilcentreinfo@irishcancer.ie or visit **www.cancer.ie** to find your local Daffodil Centre.

Survivor Support

Speak to someone who has been through a diagnosis similar to yours. 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 and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them. The Society funds professional one-to-one counselling (including telephone and video-call counselling) and group survivorship programmes in communities across the country.

For information about what's available near you, call our Support Line on 1800 200 700 or go to **www.cancer.ie** and search 'Find Support'.

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 travelling for cancer tests or treatment to one of the national designated cancer centres or their approved satellite centres. Patients must be travelling over 50km one way to access the fund.
- **Irish Cancer Society Volunteer Driver Service** is mainly for patients undergoing chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.

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

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 a unique service in Ireland, providing palliative nursing care at night between 11pm and 7am to cancer patients.

The health professional who is looking after your loved one can request a night nurse for you, so talk to your palliative care team member, GP or public health nurse about this.

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** or call our Support Line for free copies of our publications.

If you would like more information on any of our services, call our Support Line on 1800 200 700 or visit a Daffodil Centre.

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 through many local support services)

- **Support groups**, often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques**, such as mindfulness and meditation

- **Complementary therapies** like massage and reflexology
- **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 Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find Support'.

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.
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 to kill 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.
Malignant	Cancer. A tumour that spreads.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Melanin	A pigment that gives your skin its colour.

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

Questions to ask your doctor

Here is a list of questions that you might like to ask. 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 often will I need treatment and for how long?

Where will I get my treatment?

How will my treatment be given?

Do I have to stay in hospital for my treatment?

What side-effects will I get?

Who do I contact if I develop side-effects?

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?

Questions / notes

Acknowledgments

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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The following sources were used in the publication of this booklet:

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The Irish Cancer Society is a registered charity, number CHY5863.

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 Support Line 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

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