Irish Cancer Society

Understanding

Cancers of the Head, Neck and Mouth

Caring for people with cancer

Understanding

Cancers of the head, neck and mouth

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

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

Specialist nurse	Tel:
Family doctor (GP)	Tel:
Dentist	Tel:
ENT specialist	Tel:
Head and neck surgeon	Tel:
Maxillofacial surgeon	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Medical oncologist	Tel:
Dental specialist/oncologist	Tel:
Speech therapist	Tel:
Dietitian	Tel:
Medical social worker	Tel:
Emergency number	Tel:

If you like, you can also add:

Your name

Address

This booklet has been produced by Nursing Services of the Irish Cancer Society to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those patients, families and professionals whose support and advice made this publication possible.

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- *Manual of Clinical Oncology*, 7th edition. Casciato & Territo (eds). Lippincott, 2012.
- *Squamous Cell Carcinoma of the Head and Neck: EHNS–ESMO–ESTRO Clinical Practice Guidelines for Diagnosis, Treatment and Follow-up.* European Society for Medical Oncology, 2010.
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Introduction

This booklet has been written to help you understand more about head, neck and mouth cancers. Head and neck is a general term that includes cancers of the mouth, lip, nose, sinuses, salivary glands, throat, larynx, thyroid gland and lymph nodes in your neck. It also includes eye and ear cancers, but these are less common.

The booklet is divided into four parts:

- **Part 1** gives an introduction to head, neck and mouth cancers, including causes, symptoms and diagnosis.
- **Part 2** looks at the different treatments used and possible side-effects.
- **Part 3** discusses your feelings and the emotional effects of having cancer.
- **Part 4** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

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

Reading this booklet...

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

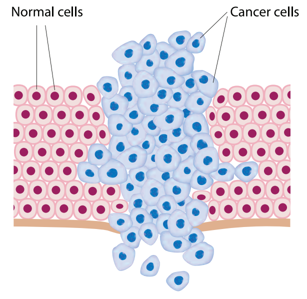
If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline on 1800 200 700. It is open Monday to Thursday 9am–7pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 70 for more about Daffodil Centres.

Helplines Partnership
MEMBER

About head, neck and mouth cancers

What is cancer?

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

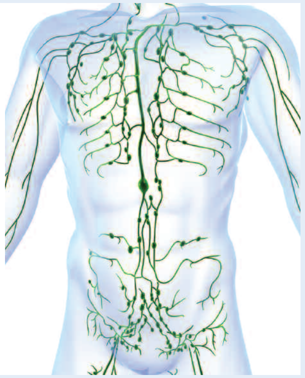


Cancer cells

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

What is the lymphatic system?

The lymphatic system is made up of groups of lymph nodes throughout the body. Lymph nodes are found mainly in the neck, armpit, groin and tummy. Lymph nodes are connected by a network of lymph vessels. These lymph vessels are tiny tubes, which usually lie just under the skin. The lymph vessels transport lymph fluid, which carries extra fluid and waste from body tissues. Sometimes cancer cells spread into lymph nodes or start in the lymph nodes themselves. If this happens the lymph nodes become swollen.



Lymphatic system

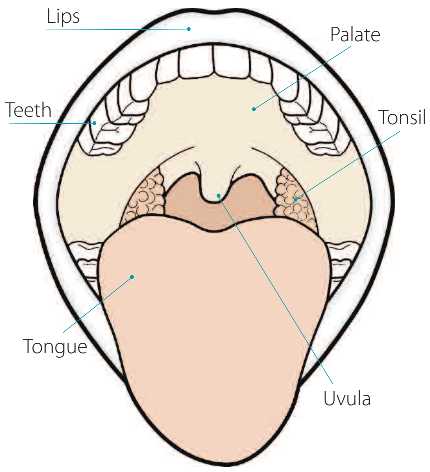
To sum up

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

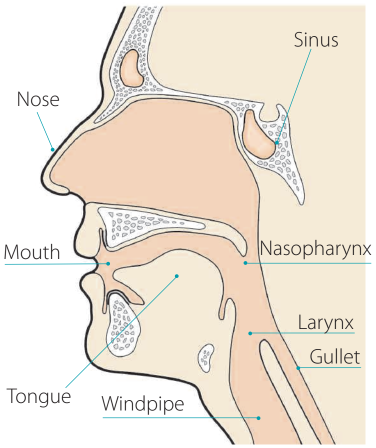
What are head, neck and mouth cancers?

Cancer can develop in any tissue or organ in your head or neck. As they grow, the cancer cells can affect how the organ or tissue normally works:

- **Mouth (oral) cancers** can occur in your lips, tongue, gums, cheeks, roof of your mouth (the hard palate) and the floor of your mouth (under your tongue).

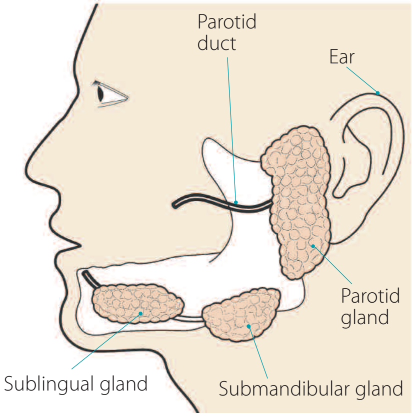


The mouth



The nasopharynx

- **Oropharyngeal cancers** can occur in the soft part of the roof of your mouth, the back and side walls of your throat and the base of your tongue.
- **Cancer of the larynx** can occur. The larynx is also called the voicebox. It is a tube in your throat.
- **Cancer of the nose** can occur in your nasopharynx, nostrils or the lining of your nose. The nasopharynx is the area where your throat joins your nose. Cancer can also develop in the bones around your face or in your sinuses.
- **Cancer of the ear** can occur in and around your ear but is very unusual.
- **Cancer of the eye** can occur but is very rare.
- **Cancer of the salivary glands** can occur but is a rare type of cancer. Benign lumps in the salivary gland are common but need to be checked out. There are also small salivary glands in your mouth, which need to be cared for too.
- **Cancer of the thyroid** can occur as a swelling in the front of your neck above your voice box.



The salivary glands

How common are head and neck cancers?

In general, head and neck cancer is not common. About 400 people are diagnosed with it in Ireland each year.

Cancers of the thyroid, larynx or eye

Thyroid cancer, eye cancer and cancer of the larynx are not discussed in detail in this booklet. For more information, see the booklets *Understanding Cancer of the Larynx* and *Understanding Cancer of the Thyroid* or visit our website **www.cancer.ie**. For free copies of the booklets contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

What are the types of these cancers?

Head and neck cancer covers a wide range of different diseases. They are named after the type of cell where the cancer first started to grow. For example:

- **Squamous cell cancers** (carcinomas) start in the lining of your mouth, nose, throat, tongue or ear. Most head and neck cancers are of this type.
- **Lymphomas** begin in the cells of the lymphatic system and travel to areas of your head and neck.
- **Sarcomas** are tumours in your muscle, cartilage and blood vessels around your head and neck.
- **Melanomas** are cancer cells that grow in the pigment cells that give colour to your skin and eyes. They can also occur in the cells that line your mouth.

What causes these cancers?

The exact cause of head and neck cancer is unknown. Research continues to study possible causes. But there are certain things called risk factors that can increase your chance of getting these cancers. These include:

- **Age:** Your risk increases as you get older. These cancers are more common in people over 50 years of age, but can occur in all ages.
- **Gender:** The cancers are more common in men than women.
- **Smoking:** If you smoke, you are more at risk of developing cancer of the mouth, larynx or lung. If you smoke tobacco pipes, you are more likely to develop cancer of the lip. If you chew tobacco, you have a higher risk of developing mouth cancers.
- **Alcohol:** If you drink a lot of alcohol (more than 10 units per week), particularly spirits, you are 40 times more likely to develop a head and neck cancer.
- **Sun exposure:** If you are exposed to long periods of sunshine, for example if you work outdoors, you are more at risk of cancer, especially around your ear, nose and lips.

- **Diet:** If you eat very little fruit and vegetables, you are more at risk of developing mouth cancers.
- **Chemical exposure:** If you work with and breathe in certain chemicals or dusts, you may have a higher risk of developing cancer in the nose.
- **Human papilloma virus (HPV):** This common virus is passed on through sexual contact and can increase your risk of cancers of the oropharynx – the base of tongue, tonsil and soft palate.

Remember if a member of your family has a head, neck or mouth cancer it does not mean that you have an increased risk.

To sum up

- Head and neck cancer is a general term that includes cancers of the mouth, lip, nose, sinuses, salivary glands, throat, larynx, thyroid gland and lymph nodes in your neck.
- In general, head, neck and mouth cancers are not common.
- Most head, neck and mouth cancers are squamous cell cancers.
- The exact cause of these cancers is unknown. Your risk increases if you are older, male, smoke or drink a lot of alcohol.
- Your risk also increases with sun exposure, exposure to chemicals and dusts in the workplace, a diet low in fruit and vegetables, or if you have a HPV infection.

What are the symptoms of these cancers?

The symptoms of head, neck and mouth cancers depend on where the tumour is found. Some common symptoms include:

- A sore or ulcer that does not heal – longer than 3 weeks
- A swelling or lump in your mouth or neck
- White or red patches in the lining of your mouth or on your tongue
- Difficulty or pain on chewing and swallowing

- Sore throat or difficulty speaking
- Hoarseness
- Unexplained pain in your face, jaw or throat
- Numbness in your jaw, face and mouth for no known reason
- Unexplained loose tooth/teeth
- Earache
- Blocked or bleeding nose
- Changes in your breathing at rest

These symptoms can be caused by conditions other than cancer, but do visit your dentist or doctor if any of these symptoms persist for longer than 2 or 3 weeks and especially if they get worse.

How are these cancers diagnosed?

If you are worried about any symptoms the first step is to visit your family doctor (GP) or dentist. They can examine you and do some blood tests if needed. If your GP or dentist is still concerned about you, they can refer you to a hospital for more tests. You may be seen by a specialist doctor, such as an oral surgeon, maxillofacial surgeon or an ear, nose and throat (ENT) specialist.

The specialist will discuss your symptoms and examine you again. He or she will inspect your mouth, throat, tongue, nose and neck using a small mirror with or without lights. Your neck, lips, gums and cheeks will also be checked for any lumps.

You will need blood tests to check your general health as well. For example, a full blood count and liver and kidney function tests.

The following tests can help to diagnose head and neck cancer:

- X-rays
- Nasendoscopy
- Panendoscopy
- Biopsy
- Fine needle aspiration cytology

X-rays: These can be taken of your jaw and also your chest.

Nasendoscopy: In this test your doctor looks at your nose and throat using a small, thin flexible tube with a light attached. The tube is called a nasendoscope. Your throat will be numbed before the tube is passed into your nose. Then a small mirror will be held at the back of your throat to allow your doctor to look closely at the area. The test is a little uncomfortable but only lasts a few minutes. This test takes place in an outpatients' clinic.

Panendoscopy: For this test your doctor uses rigid and/or flexible tubes called endoscopes to look at your mouth, nose, throat, pharynx, larynx, windpipe and oesophagus. This takes place in an operating theatre while you are asleep.

Biopsy: A biopsy is a sample of cells taken from the affected area to see if they are abnormal. These are then examined under a microscope in the laboratory. The biopsy can be done in the clinic or during a nasendoscopy or panendoscopy using a very small needle. The biopsy can show if the sample contains cancer cells and if so what type. Your doctor may also test for a protein marker called P16. If this is found it means that your cancer is caused by a virus called human papilloma virus (HPV). HPV positive tumours respond well to treatment. Having the test done can help your doctor plan your treatment.

Fine needle aspiration cytology: This test uses a fine needle and syringe to get a sample of cells from a lump. The sample is then sent to the laboratory to see if any cancer cells are present. The test can be uncomfortable and local anaesthetic may be used. The area may be bruised for short while afterwards.

How are these cancers staged?

Staging a cancer means finding out its size and if it has spread to other parts of your body. Staging allows your doctor to decide the best treatment for you.

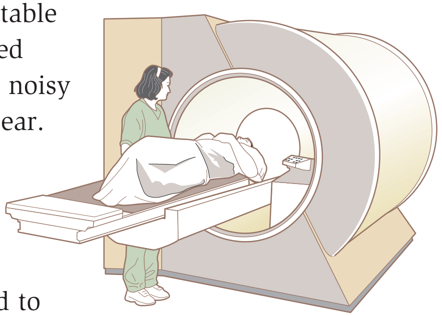
Tests for staging

The following tests may be done to stage head and neck cancer:

- CT scan
- MRI scan
- PET scan
- Ultrasound scan

CT scan: This is a special type of X-ray that builds up a detailed picture of the tissues inside your body. These pictures can then be seen on a computer. For some CT scans you cannot eat or drink for 4 hours beforehand. You may be given a special drink or injection which helps to show up parts of your body on the scan. Before you take the drink or injection, 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. Preparation for a CT scan can vary between hospitals. Your doctor or nurse will let you what to expect. The scan is not painful but you must lie as still as possible during it. Normally it takes between 10 and 30 minutes. Most people can go home afterwards.

MRI scan: This special type of scan uses magnetic energy to build up a picture of the tissues inside your body. During the scan you will be asked to lie as still as possible on a table which will move into the tube-shaped scanner. It does not hurt but can be noisy and you will be given earplugs to wear. You will also have an intercom or buzzer so you can communicate with the technician during the scan. You might also have an injection of a special dye beforehand to show up certain areas of your body. During the scan you cannot wear metal jewellery, hair clips or a metal prosthesis. If you have medical devices in your body, like a pacemaker or metal pin, you will not be suitable for the test. Your doctor will advise you about this. If you have a nicotine patch or other drug patch, you may be asked to remove it to prevent a skin burn. Each scan lasts for around 30 minutes and most people will be able to go home immediately afterwards.



MRI scan

PET scan: PET stands for positron emission tomography (PET). PET uses a low dose of radioactive sugar to measure the activity in your cells. This sugar is first injected into a vein in your arm and travels to all the cells in your body. Because cancer cells absorb large amounts of the sugar, there will be more radioactivity where the cancer cells are found.

The PET scan can show if the cancer has spread to other tissues and organs. You may be told not to eat or drink for a few hours before the test. The scan itself may take up to 1 hour. PET is safe and there are no side-effects.

Ultrasound scan: In this test, a picture is built up of the tissues inside your body using sound waves. Any part of your body can be scanned. Usually you are asked to lie on your back and a gel is spread over the area to be scanned. A small device like a microphone is then used to take the scan. This device makes sound waves that are changed into a picture on a computer. The test does not hurt and only takes about 10 minutes. You can go home afterwards.

Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. It may help to talk things over with the specialist nurse, the team or with a relative or close friend. You may also wish to call the National Cancer Helpline on 1800 200 700 and speak to one of our specialist nurses or visit a Daffodil Centre.

Describing the stages

The staging system normally used in head, neck and mouth cancer is called TNM. This stands for tumour, node, metastasis. It refers to the size and depth of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor and nurse can give you more information about the TNM of your cancer if you wish.

The cancer is very often divided into four stages:

- **Stage 1:** This is a small tumour and found in one place only.
- **Stages 2/3:** The disease has spread to other areas of your head and neck.
- **Stage 4:** The disease has spread to other parts of your body further away. These are known as secondaries or metastases.

Treatment and side-effects

How are head, neck and mouth cancers treated?

The treatment you have will depend on your age, your general health and the type and stage of cancer. Your team of doctors will explain to you if the treatment can cure or control the cancer. Some treatments used are:

- Surgery
- Radiotherapy
- Chemotherapy
- Biological therapies

You may need one or two of these treatments or a combination. The treatment decision made by your doctors will be based on best practice.

Surgery: Surgery is one of the main treatments for head and neck cancer. If found early, the surgery can often cure the cancer. Skin, muscle, bone or lymph nodes in the area may also need to be removed. More surgery may be needed to reconstruct the affected area, perhaps using a skin flap or bone graft. See page 19 for more details on surgery.

Radiotherapy: This is the use of high-energy X-rays to kill or shrink the cancer cells. It can be used alone or with other treatments like surgery or chemotherapy. If given after surgery, it can destroy any cancer cells left behind. See page 23 for more about radiotherapy.

Chemotherapy: This is the use of drugs to cure or control cancer cells. Chemotherapy can be given before, during or after radiotherapy and surgery. Both radiotherapy and chemotherapy can also be given together. See page 39 for more about chemotherapy.

Biological therapies: These are drugs which use your body's immune system to fight cancer. They are also called targeted therapies. They may be given if the cancer has spread to nearby tissues or is advanced. See page 43 for more details.

Specialist centres

In Ireland, head, neck and mouth cancers are treated in specialist cancer centres. The staff at these centres have expertise and experience in managing patients with various types of these cancers. As a result, you may be transferred to another hospital from the one where you received your diagnosis.

Multidisciplinary meeting: In the specialist centre your individual case and test results will be discussed at a meeting with all specialists involved in caring for your type of cancer. Your treatment plan will be agreed at this meeting.

Deciding on treatment

At this time you may be anxious about what is going to happen next. Do not be afraid to ask for more information.

Treatment options: Your doctor and nurse will explain your treatment options. Do ask as many questions as you like, no matter how small or trivial you think they are. It can help to write out your questions beforehand so you can get all the answers you need. You might want to use the fill-in page at the back of this booklet. Do bring a relative or friend with you when you are discussing your treatment with your doctor.

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

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

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

Giving consent for treatment

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

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

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

Before treatment

Dental check-up: Before you begin your treatment, your doctor will advise you to have a dental check-up. This is very important as your treatment may cause your mouth to become sore and irritated. See page 25 for more details.

Smoking and drinking: Your doctor will advise you not to smoke or drink alcohol at this time. Smoking and alcohol can cause your treatment to work less well or make any side-effects worse. If you would like to give up smoking, do speak to your doctor, nurse or pharmacist. The National Smokers' Quitline is also available for advice, support and information at Callsave 1850 201 203 (Monday to Thursday 9am to 7pm and Friday 9am to 5pm). See page 50 for more advice.

Eating and diet: A dietitian may visit you to advise you about how to eat well and keep a healthy weight during and after treatment.

If you are finding it hard to swallow or if you may develop swallowing difficulties you may be recommended to have a small operation to have a PEG feeding tube fitted. A PEG tube is a small tube inserted through your tummy into the stomach. The tube means liquid food can go straight into your stomach. This will be removed when your swallowing improves. Not every patient will require a PEG tube.

Who will be involved in my care?

Some of the following may be involved in your care at the hospital. Usually, a team of cancer care doctors will decide your treatment.

Maxillofacial surgeon	A doctor who specialises in treating injuries and diseases affecting the head, neck, face, mouth and jaw.
ENT specialist	A doctor who specialises in treating injuries and diseases affecting the ear, nose and throat, and head and neck.
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.
Clinical nurse specialist	A specially trained nurse who works in a special cancer care unit. She or he can give you and your family information and reassurance from diagnosis and throughout treatment.
Radiation therapist	A radiotherapist who specialises in giving radiotherapy and advice to cancer patients.
Dental specialist/ oncologist	A dentist who specialises in the dental care of cancer patients undergoing treatment.
Physiotherapist	A therapist who treats injury or illness with exercises and other physical treatments.
Dietitian	An expert on food and nutrition. They are trained to give advice on eating and artificial feeding during your illness and use diet to help your symptoms.
Speech therapist	A therapist who treats speech and swallowing defects and disorders if they are affected by treatment.
Occupational therapist (OT)	A therapist who specialises in helping people who are ill or disabled learn to manage their daily activities.
Medical social worker	A person specially trained to help you and your family with allyour social issues and practical needs. They are skilled in giving counselling and emotional support to children and families at times of loss and change. They can also give advice on benefits, entitlements and services available to you when you go home.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters and can help you make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it difficult to come to terms with your illness.

To sum up

- The main treatments for head, neck and mouth cancers are surgery and radiotherapy.
- Chemotherapy may be given before or after surgery or radiotherapy.
- Biological therapy can also be given. It is also called targeted therapy.
- You may receive one or a combination of treatments.
- You will need a dental assessment before treatment.
- A team of specialists will help you decide which treatment is best for you.

Surgery

Surgery is one of the main treatments for head, neck and mouth cancers. The aim of surgery is to remove the cancer cells and nearby tissue. If the cancer is found early, surgery can often cure it.

Trans-oral surgery

Some early cancers of the mouth, throat and larynx may be treated using laser surgery. This form of surgery takes place in the operating room, but the cancer is removed through the mouth, rather than through a skin incision (cut) in the neck. Your surgeon and care team will decide if you are suitable for this type of treatment.

Surgery for higher stage cancer

Depending on where the tumour is found, your surgeon may need to remove skin, muscle or bone along with your cancer. This can be replaced by a skin or muscle flap or a prosthesis (see page 20). In some cases your surgeon may also remove lymph nodes in your neck.

Your surgeon will explain what to expect after surgery and if any scarring will happen. Do discuss your surgery fully with your surgical team so that you know exactly what is going to be removed and how it may affect you afterwards.

It can be difficult to keep track of all of your cancer treatments and the information you receive at each doctor's appointment. A useful diary to help you keep track of your cancer treatment is called the *Journey*

Journal. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Reconstructive surgery

The surgery might affect how you eat or drink or how you look. As a result, another surgeon (plastic/maxillofacial) might also work with your surgeon to reconstruct the affected area. This can give you the best possible function and appearance after treatment. This type of surgery is called reconstructive surgery.

If your surgeon needs to remove part of your mouth, throat lining or facial skin, it may be replaced by a skin flap. A skin flap is a thick piece of skin taken from another part of your body, usually your forearm or chest. If the cancer is affecting part of your jawbone, your surgeon may need to remove the affected area and replace it with a piece of bone taken from another part of your body. This is known as a bone graft.

Prosthesis

Depending on the type and extent of the cancer, your surgeon may need to remove some of your facial bones. For example, your cheekbone or palate. If you need this type of surgery, you may be offered a prosthesis. A prosthesis is a special soft plastic device which reconstructs the area where bone has been removed and closes the opening. A common type of prosthesis is an obturator. This is like a retainer or denture with an extension to replace the missing section of your upper jaw or palate. This prosthesis is provided by a special dentist called a maxillofacial prosthodontist. During your surgery a temporary obturator will be put in place. Once the area is healed this obturator will be replaced by a new one.

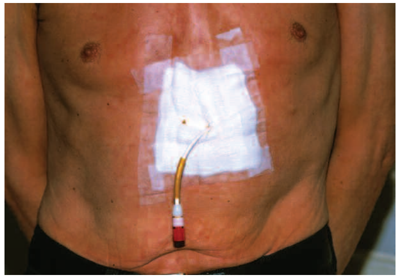
After surgery

Depending on your surgery, you may need to stay in hospital for several days or even weeks. For the first few days after surgery, more than likely you will stay in an intensive care unit or high dependency unit or special ward. It is normal to be attached to tubes and drips after your surgery. For example:

IV fluids/drip: You will need to fast before your surgery and for some time afterwards. A drip giving fluids into your vein (IV) can prevent you from becoming dehydrated.

Nasogastric tube: A nasogastric tube is a thin tube passed down your nose all the way to your stomach. This tube can also be used to feed you and so help your wounds to heal and recover. It can be easily removed once you are ready to eat again.

PEG tube: PEG stands for percutaneous endoscopic gastrostomy. This is a tube passed through the wall of your abdomen into your stomach. It can be used to deliver liquid food directly into your stomach if you cannot eat normally after your surgery. PEG tubes can be left in permanently if needed. Your dietitians will help to make sure you get enough nutrition after surgery. They will discuss your nutritional needs with you and your doctors and prescribe supplements if needed.


PEG tube

Parenteral feeding: Sometimes nutrition can be given directly into a vein after surgery. This is called parenteral feeding.

Urinary catheter: A catheter is a small tube placed in your bladder which drains urine into a bag. It is used to prevent you having to get out of bed to go to the toilet. The tube is usually removed a few days after surgery.

Wound drain: Plastic tubes may be placed beside your wound and stitched into place. These collect any excess blood or oozing from your wound and prevent further swelling. Drains are normally removed a few days after surgery.

Tracheostomy

Sometimes your surgeon may decide to make an opening into your windpipe to help you breathe more easily during and after surgery. This is called a tracheostomy or stoma. A tracheostomy is helpful where there is swelling or bruising around your mouth, which can make breathing uncomfortable.

You may be given special mask to wear over your tracheostomy. This lets you breathe humidified oxygen, which is special air to help keep your airway moist.

A small plastic tube will keep the stoma open. Your nurses and physiotherapists will help you to care for your stoma and do breathing exercises after your surgery. For most patients the tracheostomy is temporary.

More than likely, you won’t be able to talk for a time after a tracheostomy because you are not using your voice box (larynx) in the normal way. Air cannot pass through your larynx to produce your voice. Your doctors, nurses and speech and language therapist will help you to communicate. You might find it easier to write down what you want to say or send text messages on your mobile phone.

Speech

Some surgery to your mouth and throat can affect the way you speak. Your mouth, tongue, teeth, lips, nose, throat (pharynx) and soft palate are all involved in speech. Surgery to any of these areas can affect the way you speak. Some people may not notice a change in the way they speak, but for others speech can be changed temporarily or permanently. See page 46 for more about speech therapy.

Pain

It is normal to have pain or discomfort after your surgery. Pain can be controlled but your team need to know about it. Do tell your nurses and doctors if you feel any pain or if your painkillers are not helping. There are several different types of painkillers that can be used.

If you cannot eat properly you will be given painkillers by injection or in liquid form through your nasogastric or PEG tube. When you can eat and drink again, you will be given painkillers in tablet or liquid form. Being as pain-free as possible will help you to speak, eat, drink and move about.

Physiotherapy

Your physiotherapist will visit you regularly after your surgery. It is important that you do your breathing and leg exercises to avoid developing a clot. For this reason also, your physiotherapist will help you out of bed and start you moving around again as soon as possible.

Going home

If you have any concerns about going home after surgery discuss them with your doctor or nurse. There is an entire team of experts available to you, including dietitians, medical social workers, speech and language therapists and physiotherapists. Remember they are there to help you.

To sum up

- Surgery is one of the main treatments for head, neck and mouth cancers.
- If the cancer is found early, surgery can often cure it.
- Your surgeon may also need to remove skin, muscle, bone or lymph nodes in your neck.
- Another surgeon might work with your surgeon to reconstruct the affected area. You might need a prosthesis to replace any bone or muscle removed.
- You will have several tubes and drains in after surgery. For example, a drip, catheter, feeding tube.
- Most patients go home within a couple of weeks.

Radiotherapy

Radiotherapy is the use of high-energy X-rays to kill or shrink the cancer cells. It can be used alone or with other treatments like surgery or chemotherapy. If given after surgery, it can destroy any cancer cells left behind. The doctor who specialises in radiotherapy is called a radiation oncologist.

There are different types of radiotherapy used for head, neck and mouth cancers:

1. **1** External beam radiotherapy
2. **2** Internal radiotherapy (brachytherapy)

1 External beam radiotherapy
This aims high-energy X-rays at the cancer to cure or control it. These X-rays come from a machine called a linear accelerator. For more information on external radiotherapy see page 25.


Linear accelerator

Conformal radiotherapy (CRT): This is the most common type of external beam radiotherapy for head and neck cancers. It is also called 3D conformal radiotherapy. CT or MRI scans are used to make a three-dimensional (3-D) computer image of your tumour and nearby tissues.

Modern radiotherapy treatments such as CRT are designed to deliver radiation as precisely as possible, shaping radiation beams to match the shape of your tumour to avoid affecting healthy tissues.

This allows a higher dose of radiation to be given to the cancer and a much smaller dose to normal tissue. This helps to reduce the risk of long-term side effects.


Conformal radiotherapy

2 Internal radiotherapy
This involves giving radiotherapy from within your body. Usually an implant containing a source of radiation is put directly into the tumour and left in place for several days. It will release radiation and kill the cancer cells. Internal radiotherapy is also known as brachytherapy. For more information on internal radiotherapy see page 29.

The booklet *Understanding Radiotherapy* has more details about the types of radiotherapy and possible side-effects. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy or to speak to a specialist cancer nurse. You can also download the booklet from our website **www.cancer.ie**

See the Helpful Books section on page 79 for details of other useful publications.

Dental check-up

If you are to receive radiotherapy to your head or neck, you will need a check-up by a dental specialist (dental oncologist) beforehand.

Radiotherapy can affect your sense of taste and the muscles in your mouth. It may also affect your salivary glands, which can cause a dry mouth. This in turn can lead to tooth decay (dental caries). It is also more difficult to extract teeth after radiotherapy as the treatment affects bone health.

Your dentist will give you advice on how to care for your mouth (oral hygiene), on your diet and any physiotherapy exercises that you may need during or after radiotherapy. The dental oncologist will check that your mouth and teeth are healthy and plan for any treatment you might need after radiotherapy. If you have dentures, they will also be checked to make sure they are correctly fitted so that they do not cause damage or infection.

The dental oncologist will also advise you on special mouthcare products you might use during treatment such as gum guards, artificial saliva drops, enzyme gels and mouthwashes, which can help you to cope with side-effects. You will need ongoing check-ups by your own dentist after treatment is over.

X-ray: Before treatment, you are likely to have a special X-ray of your jaw and teeth called an orthopantomogram (OPG).

External radiotherapy

Planning your treatment

Your doctor may decide that radiotherapy is the best treatment for you. Planning your treatment and preparing for it may take some weeks and you may need more than one session. Planning can include:

Physical exam: A physical exam will be done to check the general state of your health. You may need to have some X-rays, scans and blood tests done as well.

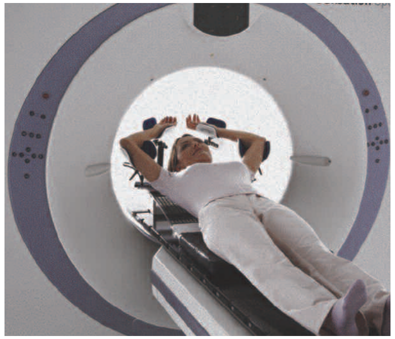
Mask fitting: You will probably need to wear a plastic mould or mask during radiotherapy treatment. The mask makes sure that your head and shoulders are kept perfectly still and the radiation delivered to exactly the right place. You will only have to wear the mask for a few minutes each time you are being treated. Because treatment marks are put on the mask, there is usually no need to put marks on your skin. On your first visit to the radiotherapy unit, you will be taken to the mould room to be fitted for a mask. If you have a beard or moustache you will probably be asked to shave it off, as it might stop the mask from fitting properly.

For the Perspex mask a plaster cast mould is made first. A mould-release cream will be applied to whatever part of your head and neck is to be treated. Next a plaster of Paris bandage will be laid over the top of this to make a mould. This will feel wet and cold. Your mouth and nose will not be covered so you can breathe normally. This takes a few minutes to set and is then removed. When the plaster has set, Perspex is moulded onto the cast and the mask is formed. This mask will fit your face and neck snugly, with holes cut for your eyes, nose and mouth.

If your mask will be made of thermoplastic, warm, wet plastic is stretched over your face and possibly your shoulders. This takes just a few minutes to set. Making the mask may feel a little frightening or claustrophobic, but it only takes a short time. Talk to your nurse or the person making the mask if you are worried about being fitted for your mask.


Thermoplastic mask

Simulation: Before you have radiotherapy your doctor must work out the exact area that needs to be treated. You will need to have a scan to help your doctor plan your treatment. This planning is sometimes called simulation. For this, the radiation therapist uses a special X-ray machine called a simulator or CT simulator to locate your treatment field. This is the exact area of your body where the radiation will be aimed each time. You will be asked to lie very still on a table, so do wear comfortable clothes. The simulator will move around you and can be noisy, but will not touch or hurt you at all. Just lie still and breathe normally. During the planning, the lights in the room will be switched off and laser lights will become visible. These laser lights are harmless. They are used to position your treatment field with precision and accuracy. Simulation can last for up to 45 minutes.


Simulator

Pregnancy test: It is important that you are not pregnant during your treatment. A pregnancy test can be arranged if there is any chance that you could be pregnant.

Planning completed

Once all your tests and planning are completed, you can go home. Your doctor will then meet with the radiation physicists, radiation therapists and other experts. Together they will calculate the dose of radiation you need based on the treatment goals. Do talk to the radiation therapists if you have any worries or concerns. A useful DVD called *Understanding Radiation Therapy: A Patient Pathway* is also available from the Irish Cancer Society. It shows in detail how radiotherapy works and what is involved. Call 1800 200 700 or visit a Daffodil Centre for a free copy. You can also visit the website **www.cancer.ie/cancerInfo/understanding_radiotherapy.php**

Giving radiotherapy

The radiation therapists who deliver the treatment will first explain to you what happens and what to expect. Radiotherapy doesn't hurt at all and the machine does not touch you, but it is natural to feel anxious. If you have any questions or concerns, no matter how small, talk to your radiation therapist.

On the day of your first treatment, you will come to the radiotherapy unit. It is best to wear clothing that is comfortable and easy to put on and remove. Some hospitals may provide gowns. The radiation therapists will help you onto the treatment table and will adjust both the table and the machine to the exact positions that are needed. Because you need to keep still for a few minutes during treatment, they will make you as comfortable as possible.

Special shields or blocks may be put between the machine and certain parts of your body to protect normal tissues and organs. There may also be plaster, plastic or foam pads or vacuum bags to help you stay in the right position. The lights will be turned down while the radiation therapists set up the machine and check the laser lights. The lasers help the therapists to check that you are in the correct position to receive the radiotherapy beam. Relax as much as you can and just breathe normally. If you are very anxious or claustrophobic, do talk to your doctor about this.

Each treatment session will take about 20 minutes allowing time for getting on and off the treatment table and for the machine to be set up. Depending on the hospital you attend, sometimes your appointment can be made for the same time each day. Normally you will not be expected to stay in hospital.

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

How long does treatment take?
Your doctor will decide on the best treatment plan for you. He or she will try to give you the most effective treatment with the least damaging side-effects. The total dose of radiation and the number of treatments you need will depend on:

- The size, location and type of your cancer
- Your general health
- Other medical treatments you are receiving, such as chemotherapy, surgery, or biological therapy

It is common to have radiotherapy treatment for 3-6 weeks if you have head or neck cancer. But the dosage and length of treatment can vary between patients, even those with the same type of cancer. Normally, there is no radiotherapy given at weekends.

Your radiation therapist will give you information on who to contact if you have any problems between sessions.

Internal radiotherapy (brachytherapy)

Your doctor may decide that internal radiotherapy is the best way to treat your type of cancer. Internal radiotherapy is also known as brachytherapy. This is used less often than external radiotherapy. In some cases you may need both internal and external radiotherapy. Usually an implant containing a source of radiation is put directly into the tumour and left in place for several days. It will release radiation and kill the cancer cells. The implant is usually put in under general anaesthetic through soft tubes called catheters, which are placed in the tumour. Wires that are not radioactive are also placed in the tubes. These help to keep the tubes open and allow them to be seen on an X-ray afterwards. Once your treatment dose is decided, you will be taken to the radiotherapy treatment room where the tubes will be attached to the radiotherapy machine.

Normally during treatment you can sit comfortably in a chair. You will receive treatment twice a day, once in the morning and once in the evening. This will happen for 2 to 5 days, depending on the amount of treatment your doctor has prescribed.

The radiation therapist can explain the treatment to you in detail. All the staff will leave the room while the radiation is given. They will monitor you closely during the treatment by video camera and intercom.

When you have received all of your internal radiotherapy, the tubes will be removed in the radiotherapy unit or ward. You may need painkillers for a couple of days and a small dressing on the area where the tube was. For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Side-effects of radiotherapy

Radiotherapy is given directly to the site of the cancer. Therefore, most of the side-effects that occur are related to the part of your body being treated. How severe these side-effects are will vary from person to person, depending on the amount of treatment received.

In general, side-effects may be short term (temporary) or long term. The short-term side-effects tend to develop towards the end of the second week of treatment or as treatment goes on. These usually last for a few weeks. Long-term side-effects may occur after treatment and may sometimes be permanent.

Before treatment, your doctor will discuss any likely side-effects with you. Remember some side-effects are visible while others are hidden. The visible ones may affect your body image and confidence. The radiotherapy staff will give you advice on how to deal with side-effects.

Radiotherapy to the head, neck and mouth

- Radiotherapy to this region can cause a sore mouth and throat because the cells that line these areas are very sensitive to treatment.
- Keeping your teeth, gums and mouth very clean will help to control the soreness and reduce the risk of a mouth or throat infection.
- Keeping your teeth and dentures in good condition will also improve your appearance, comfort and quality of life.
- Do mouth-opening exercises regularly, as instructed by your therapist.

You may experience some of the following side-effects:

- Taste changes
- Voice changes
- Dry mouth (xerostomia)
- Sticky mucus
- Sore mouth and throat
- Dental problems
- Mouth stiffness (and reduced mouth/jaw opening)
- Difficulty with eating and drinking
- Weight loss
- Hair loss of beard, generally not head hair
- Tiredness and fatigue
- Skin reactions

Taste changes: Radiotherapy can affect the taste buds in your mouth. Your sense of taste may be greatly reduced or you may find that food tastes salty, metallic or like cardboard. If this happens, you may lose interest in food and eat less than you did before treatment. It can help to eat little and often. Supplement your meals with high-calorie drinks such as Complan®, Build-Up®, Fortisip® or Ensure®. If your appetite is poor, ask your nurse or radiation therapist to refer you to a dietitian who will check your weight and give you further advice. Your taste and appetite should improve once treatment has ended. But in some cases it may take up to 6 or 9 months to recover after radiotherapy to your mouth.

Voice changes: Radiotherapy can cause make your voice hoarse for a time. Rest your voice as much as possible and avoid smoky places. A speech and language therapist can advise you on voice exercises to help.

Dry mouth: After a week or two of treatment you may notice that your mouth and throat feel dry all the time. This is because radiotherapy may cause the salivary glands to make less saliva (spit) than usual. This is called xerostomia. The amount of dryness will depend on the overall dose of radiotherapy you receive and the areas treated. You may find that your saliva can become thick and stringy making swallowing and speech a little difficult. The dryness may improve with time but can be permanent. Your healthcare team can recommend the best products to help keep your mouth and lips moist. Artificial saliva, enzyme gels, mouthwashes and lubricants are all available. Ask your nurse or doctor for advice. It may help to sip cool drinks during the day. Plain water is best. Avoid sugary, alcoholic or acidic drinks.

Avoid very dry food like crackers and use sauces or gravy to make food moist and easier to swallow. Smoking can make a dry mouth worse, so try to give up or cut down. See page 50 for details.

Sticky mucus: You may also find that you have a lot of sticky mucus in your throat. If the mucus turns green or yellow, tell your doctor. He or she may want to treat you with medication.

>>> Let your doctor or nurse know as soon as possible if your mouth or throat becomes sore.

Sore mouth and throat: Your mouth and throat will probably become red and sore and mouth ulcers may develop (mucositis). Do let your radiation therapist or nurse know if this happens. Your dental specialist will advise you on the use of special products to reduce the discomfort. Sometimes eating food may become difficult and swallowing painful. Your voice might also become hoarse. Let your doctor or nurse know as soon as possible if this happens. They can prescribe painkillers if you need them. Your doctor or dietitian will also advise you on how to change your diet to make eating more comfortable.

Your mouth or throat may occasionally become too sore to eat or drink during radiotherapy. In this case, you may need to be fed by a nasogastric tube or PEG tube for a short while. See page 21 for more details. Within a few weeks of finishing your radiotherapy, your mouth should be far more comfortable and you should be able to eat well.

Dental problems: You will need to take special care of your teeth as they will be more prone to decay because of the lack of saliva. Decay can happen very quickly and can cause your teeth to break. Avoid sucking sugary sweets when your mouth feels dry as it increases your risk of tooth decay. It is better to use water or sugar-free chewing gum or sweets. You will usually be asked to put fluoride gel on your teeth every day to help prevent decay. This can be as a mouthwash, special toothpaste or in a special gum shield made by your dentist.

If you are likely to develop dental problems, a dental specialist will check your progress during radiotherapy. After the course has finished, you will need to have regular dental check-ups (every 4–6 months). If you decide to have any dental work after radiotherapy, do tell your dentist that you have had radiotherapy. It is very important to avoid having teeth taken out (extractions) after radiotherapy, as your gums may not heal well afterwards or you may get a bone infection called osteoradionecrosis (ORN). See page 37 for details.

Mouth stiffness: Sometimes radiation to your head and neck can cause a stiffness in certain facial muscles. This is called trismus. The stiffness can prevent you opening your mouth and jaw fully. You will be shown some simple mouth-opening exercises to keep your mouth as flexible as possible. These should be done at least twice every day. A speech and language therapist may also provide other ways to help. For example, you can check your facial muscles by doing the '3 finger test' – turn your hand sideways and see if you can open your mouth wide enough to fit 3 fingers in. You may also be advised to use an exercise device called a TheraBite®.

TheraBite®

>>> Tips & Hints – mouth care

- Avoid sugary foods and look for the 'hidden sugars' on the labels.
- Gently brush your teeth with a small soft toothbrush five or six times a day, especially after meals and before bedtime. It may help to soften the brush in warm water before brushing.
- Carry a water bottle with you and drink water throughout the day to keep your mouth moist.
- If you have dentures, remove them every night and if your gums are sore.
- Use special mouthwashes recommended by your dentist, radiation therapist or nurse. They will help to keep your mouth clean and ease mild soreness or pain.
- Avoid dry or brittle foods like toast, crisps, nuts and crackers.
- Avoid eating hot, spicy or very cold food and drink.
- Avoid alcohol (especially spirits) and tobacco as they can irritate the lining of your mouth and throat. They can also make side-effects more severe.
- If you need teeth pulled (extracted), tell your doctor before doing so.
- Visit your dentist at least every 6 months.

Difficulty with eating and drinking: Surgery and radiotherapy to your head and neck, for example your mouth or larynx, may cause eating and drinking difficulties. You may notice after a week or two of radiotherapy that you find it hard to swallow. It may feel like you have a lump in your throat all the time. Food or drink may seem to go down the wrong way, making you cough as you try to swallow.

If you have any difficulty eating or drinking, talk to your doctor, radiation therapist or nurse as soon as possible. They can give you advice on how to solve the problem, the best foods to eat or what to gargle with. If the problem gets worse they can also arrange for a dietitian or speech and language therapist to help. Your doctor might also give you medication to take before meals to make swallowing easier. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a free copy of the booklet, *Diet and Cancer.* You can also download it from our website **www.cancer.ie**

It is best to put small amounts of food into your mouth and chew them properly before you try to swallow. You may find it helpful to eat foods combined with liquid, such as thick soups or stews. If fluids go down the wrong way, there is a powder available which, when added to your drink, makes it thicker and easier to swallow. The discomfort usually eases 5 to 8 weeks after you finish treatment.

Tips & Hints – eating and drinking

- Drink about 2 litres of fluid (3 to 4 pints) each day.
- Eat when you are hungry, even if it is not mealtime.
- Eat small snacks during the day rather than large meals.
- Try to limit foods containing sugar.
- Increase calories by adding butter, spreads or cream to your food.
- Vary your meals and try new recipes.
- Keep simple meals in the freezer, ready to use when you feel hungry.
- If you live alone, arrange for a relative or Meals on Wheels to bring food to you. Ask your GP, nurse, medical social worker or community welfare officer if it can be arranged.

Weight loss: If you continue to lose weight due to difficulty in eating, you may need to be fed in another way. This may mean you have to spend a short time in hospital. Liquid food can be given into a vein or by a PEG tube into your stomach until you can eat properly again. A helpful booklet called *Diet and Cancer* gives tips on how to cope with weight loss. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a free copy and advice.

Hair loss (alopecia): Radiotherapy can cause hair loss, but only in the area being treated. For example, it might affect a beard or moustache, if you have one. In general it does not affect your head hair. In other cases hair loss may occur where the beam of radiation enters and leaves your body. For example, at the back of your neck. Your radiation therapist can tell you where your hair will fall out, but ask if you are worried about it.

Most hair loss is temporary. Your hair will start to grow back within 2 to 3 months of finishing treatment. The colour and texture might be a little different. For example, it may not be as thick as before. Hair loss can be upsetting for various reasons. It can be a constant reminder of your illness or you may feel your identity had been lost. If you would like more advice, contact the National Cancer Helpline 1800 200 700 for a free copy of the factsheet, *Hair Loss and Cancer Treatment*. You can also pick up a copy from a Daffodil Centre or download it at **www.cancer.ie**

Tiredness and fatigue: Tiredness is quite common during radiotherapy, especially towards the end of treatment. There may be many reasons for feeling tired or fatigued. Your body uses up a lot of energy for healing during radiotherapy. Travelling to and from the hospital each day for weeks can make you more tired than usual. In general the fatigue may last for some time afterwards. Tell your doctors, radiation therapist or nurse if tiredness becomes a problem for you. They can offer advice on ways to save your energy and cope with everyday activities.

See page 48 for more information on how to cope with fatigue. Call the National Cancer Helpline 1800 200 700 for a free copy of our booklet, *Coping with Fatigue*. You can also pick up a copy from a Daffodil Centre or download it at **www.cancer.ie**.

Skin reactions: People react in all sorts of ways to external radiotherapy. A lot depends on your skin type and the area being treated. If you are light-skinned, you may find that your skin in the treated area becomes red, sore or itchy. If you have dark skin, your skin might become even darker. Or you may have no skin reactions at all.

Skin reactions usually happen after 3 to 4 weeks of treatment. Advice on skin care tends to vary between hospitals. Some hospitals prefer you not to wash the treated area at all while having treatment. Others may advise you to use only tepid water to wash the area. When drying your skin, you may be told to pat it gently with a soft towel. Continue this for a few weeks after treatment.

At the start of treatment, your radiation therapist and nurse will give you all the advice you need on skin care. Ask as many questions as you like, no matter how silly or trivial you think they are. During your treatment, your radiation therapists will also check for any skin reactions, but do let them know as soon as you feel any soreness.

Advice will be given if you have any discomfort. Also, your doctor may prescribe a cream or lotion for you to use. Skin reactions usually settle down 2 to 4 weeks after treatment has finished. After the redness has faded your skin may peel, but it should heal quickly. The skin may also remain a little darker than the surrounding skin. After radiotherapy the treated area is sensitive to extremes of temperature, so make sure you are protected when outdoors.

It is best to avoid tight collars and ties if you receive radiotherapy to your head and neck. Do not wear starched or stiff clothing over the treated area.

Tips & Hints – skin care

- Do not scratch or rub the treated area as it may become sore.
- Avoid soaps, talcum powders, deodorants and perfumes as they may irritate the treated area.
- Moisurise your skin. Only use creams and dressings prescribed or recommended by your doctor.
- Do not wet shave within the treated area or use shaving lotion or hair removal products.
- Wash the area gently with lukewarm water and pat it dry.
- Protect your skin from cold weather by wrapping up well.
- Never expose the treated area to the sun. Always use a total sunblock on the treated area and use a sunscreen (SPF 30) on non-treated skin. Cover treated skin with light clothing when outdoors.
- Do not apply sunscreen before radiation treatment.
- Do not apply heat or cold (heating pads, hot water bottles, ice packs) to the treated area. Avoid saunas and steamrooms.
- Do not use adhesive tape on the treated skin. When bandaging use paper tape outside the treated area.

Osteoradionecrosis (ORN): After radiotherapy your jaw bone can have less blood supply and not heal so well. If the bone is injured by surgery, tooth extractions or denture irritations, a condition called osteoradionecrosis (ORN) can develop. It is much better to keep your teeth in good condition and to treat any tooth decay (cavities) quickly if they occur. If a tooth has to be taken out after radiotherapy, you should see a dentist who is used to dealing with patients who have had radiotherapy. The tooth will need to be removed carefully and extra precautions will be taken to prevent infection, such as prescribing antibiotics.

Tell your doctor or dentist immediately if you develop any problems with your teeth or gums, or swelling, pain, heaviness or numbness of your jaw.

Other side-effects

Nausea and vomiting can sometimes occur on the first day of treatment to the throat area. But it is more likely to occur if you have radiotherapy to your abdomen or pelvis. For more information on the side-effects of radiotherapy, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. Ask for a free copy of the DVD *Understanding Radiation Therapy: A Patient Pathway* or the booklet *Understanding Radiotherapy*. You can also find them on our website **www.cancer.ie**

To sum up

- Radiotherapy is the use of high-energy X-rays to kill or shrink cancer cells.
- It can be used alone or with other treatments like surgery or chemotherapy.
- Radiotherapy can be given externally or internally.
- A lot of careful planning is needed beforehand. For example, for most head and neck cancers, a special mask will be made to keep your head still during treatment.
- Any side-effects you get will depend on which part of your body is being treated and the number of treatments you get.
- Some side-effects include taste changes, dry mouth, sticky mucus, sore mouth and throat, dental problems, mouth stiffness, difficulty with eating and drinking, weight loss, hair loss, fatigue and skin reactions.

Chemotherapy

Chemotherapy is the use of drugs to cure or control cancer. With head and neck cancer, it can also be given before or after radiotherapy or surgery. It may help to prevent the cancer coming back or to control advanced cancer. Chemotherapy can also be given at the same time as radiotherapy.

Chemotherapy drugs can be given on their own or with each other. They are either injected into your bloodstream or given in tablet form. Your doctor will decide the type and dose of your chemotherapy based on the size and location of the tumour, if the cancer has spread, and your general health. Some drugs commonly used for head, neck and mouth cancers are carboplatin, cisplatin, 5-fluorouracil (5-FU), cetuximab (Erbitux®) and paclitaxel (Taxol®).

Where do I go for treatment?

Where you go for chemotherapy can vary. It can be given as a day patient or sometimes as an inpatient, depending on the drugs being used. Your nurse will give you more information about your own treatment. This includes where and how often you will receive it and any possible side-effects. Do ask as many questions as you like so that you know what to expect.

Side-effects of chemotherapy

The side-effects of chemotherapy depend on the individual drug. These unwanted effects happen because the drugs work not only on cancer cells but normal cells too. In most cases, the side-effects go away once the treatment ends or soon after. Some people who have chemotherapy have few or no side-effects.

Before you start your treatment, ask your doctor about any possible side-effects that may occur. Do tell him or her about the way you are feeling during your treatment, as most side-effects can be eased with medication.

Common side-effects may include:

- Sore mouth
- Taste changes
- Loss of appetite
- Nausea and vomiting
- Diarrhoea
- Infection
- Fatigue
- Hair loss (alopecia)
- Numbness or tingling in hands or feet

Sore mouth: Some drugs can cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside your cheeks. Try to keep your teeth, gums and mouth very clean. If you have dentures, remove them if your gums are sore. There are also special mouthwashes that you can use. Your nurse or dental specialist will tell you which ones are safe and how to use them properly.

Taste changes: You may notice that your food tastes different. Normal taste usually returns once treatment is over.

Loss of appetite: It is important to eat well while on chemotherapy to keep your strength up. However, this may be hard in practice. You may find that you have little or no appetite. Eating very small amounts of food often can help. Taking special build-up drinks can give you extra proteins and calories too. Talk to your nurse or dietitian for more advice. You can also call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Diet and Cancer*. You can also pick up a copy from a Daffodil Centre or download it at **www.cancer.ie**

Nausea and vomiting: Not everyone feels sick (nausea) or vomits after chemotherapy. But if you do, take any prescribed medication to stop you feeling sick. If the feeling of nausea carries on let your oncology nurse know. Special build-up drinks can also help give you more calories, if you are not eating. Talk to your dietitian for more advice.

Diarrhoea: Passing more than three watery bowel motions a day is known as diarrhoea. You may also have cramping or abdominal pain. If this happens, drink lots of clear fluids to replace the fluid you are losing. Do tell your doctor or nurse if you get diarrhoea, as there is medication to stop this side-effect.

Infection: Chemotherapy can increase your risk of infection. Most chemotherapy drugs affect the bone marrow. This means the growth of red and white cells and platelets normally produced in the bone marrow can be affected. The white cells normally fight infection. If your bone marrow is affected by chemotherapy you may not have enough white cells. This means even minor infections like a cold or sore throat could make you quite ill. During treatment cycles, you will have blood tests to make sure you have enough white blood cells.

Your doctor will ask you to watch out for signs of infection at all times, especially if your white cells are low. These signs could include feeling shivery and unwell or running a high temperature of 38°C or higher. If this happens, tell your hospital doctor straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. Check this out with your doctor or nurse before you start treatment. If you have a high temperature, you will need a blood test and perhaps antibiotics to treat the infection.

Do avoid close contact with people who have colds or flu or other infections such as chickenpox, shingles or measles. Let your doctor know if you are in contact with these or any other infections. Remember to wash your hands often during the day, especially before you eat and after going to the bathroom.

Tiredness (fatigue): It is normal to feel very tired (fatigued) during chemotherapy. If you do feel tired, pace yourself and balance rest periods with exercise. The tiredness can last for some weeks or months after treatment has ended. Speak to your doctor if you are troubled by fatigue. See page 48 for more about fatigue.

Hair loss (alopecia): This usually starts a few weeks after the first dose of some chemotherapy drugs, although it may happen earlier. Hair usually falls out completely but it may just grow thinner. You may also have thinning and loss of eyelashes, eyebrows and other body hair. This is temporary and your hair will regrow once the treatment is over.

It is normal to feel upset at the thought of losing your hair. Do talk to your nurses about your feelings, as they can give you advice about ways of coping. You can wear a wig when it happens or you may prefer to wear a hat, bandana or scarf. In some hospitals, your medical social worker or nurse will arrange this for you. If your hospital does not provide this service, ask if they know the name of a wig fitter you could visit. Your local hairdresser may also be able to help. If you would like more information on hair loss, call the National Cancer Helpline 1800 200 700 for a copy of the factsheet, *Hair Loss and Cancer Treatment*. You can also pick up a copy from a Daffodil Centre or download it at **www.cancer.ie**

Numbness or tingling in hands or feet: This is due to the effect of some chemotherapy drugs on the nerves in your hands or feet and is known as peripheral neuropathy. You may also notice that you have difficulty doing up buttons or similar fiddly tasks. Tell your doctor if you notice any numbness or tingling in your hands or feet or pain in your feet while walking. It usually improves slowly a few months after the treatment is finished.

Other side-effects

For the effects of chemotherapy on fertility and advice on contraception, see page 47. The drug Taxol in particular can cause other side-effects but they do not last long. For example, aching joints and muscles, an itchy rash and headaches. The first few doses may cause an allergic reaction but you will be closely monitored during this time. Your doctor can prescribe medication to help prevent or treat any of these problems.

If you have any other side-effect or symptom that concerns you, tell your doctor or nurse straight away. He or she will give you advice. If you would like more information on chemotherapy, call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Understanding Chemotherapy*. You can also pick up a copy from a Daffodil Centre or download it at **www.cancer.ie**

Nutritious Snacks

- Cereals – hot or cold
- Beans
- Cheese
- Custards
- Hot chocolate (make with milk)
- Milk puddings
- Milkshakes
- Creamy soups
- Yoghurt or fromage frais
- Smoothies
- Mousses

- Sandwiches
- Nuts
- Omelettes
- Quiche
- Muffins or scones
- Sausages
- Scrambled eggs
- Baked potatoes with beans, cheese, tuna
- Dips made with cheese or yoghurt

LIQUIDS

CLEAR LIQUIDS

- Water
- Fruit juices without fruit pieces
- Clear broth
- Consommé
- Ice pops
- Honey
- Clear fizzy drinks like flat 7-Up or Sprite
- Lucozade
- Sports drinks
- Strained vegetable broth

FULL LIQUIDS

- Milk
- Fruit juices
- Fruit nectars
- Fresh or frozen yoghurt
- Milkshakes
- Fruit purée
- Smooth ice cream
- Liquidised soup
- Tomato juice
- Vegetable juice
- Build-up drinks
- Soft custard
- Drinking chocolate

SOFT DIET

- Omelette or scrambled egg
- Baked egg custard
- Egg mayonnaise
- Creamed soups
- French toast
- Baked beans with grated cheese
- Tinned spaghetti with grated cheese
- Macaroni cheese
- Cauliflower with cheese
- Casseroles or stews
- Shepherd's pie or cottage pie
- Bolognaise sauce
- Lasagne
- Savoury mince
- Pasta with creamy tomato sauce
- Soft poached or flaked fish in sauce
- Salmon mousse
- Fish and potato in a creamy sauce
- Mashed carrots with honey and cream
- Vegetables mashed with butter and melted cheese
- Chicken in cream sauce
- Quiche
- Jacket potato with butter, grated cheese or cream cheese
- Dips like hummus, pesto, guacamole, cream cheese

HOW TO INCREASE CALORIES

- Add butter or margarine to soups, mashed and baked potatoes, sauces, cooked vegetables, rice.
- Add whipped cream to desserts, puddings and fruit. Add it unsweetened to mashed potatoes and puréed vegetables.
- Add milk or cream to soups, sauces, puddings, custards, cereals. Use cream instead of milk in recipes.
- Add cheese to casseroles, potatoes, vegetables, omelettes, sandwiches. Melt where possible.
- Add chopped hard-boiled eggs to salads, vegetables, casseroles.
- Sauté or fry foods if you can tolerate them.
- Add sauces or gravies to your food.

HOW TO INCREASE PROTEIN

- Eat more hard and soft cheeses. Add them to food where possible.
- Use milk instead of water as a drink and in cooking when possible. Use full fat milk.
- Take build-up drinks.
- Add ice cream or yoghurt to drinks, fruit and cereals.
- Add eggs to your food whenever possible. Avoid raw eggs.
- Add chopped meat or fish to vegetables, salads, casseroles, soups, baked potatoes.
- Eat more beans and peas. Add to soups and casseroles.

To sum up

- Chemotherapy is the use of drugs to cure or control cancer.
- With head, neck and mouth cancers, it can also be given before or after radiotherapy or surgery.
- It may help to prevent the cancer coming back or if the cancer is advanced.
- Drugs can be given on their own or in combination with others. They are either injected into your bloodstream or given in tablet form.
- The side-effects of chemotherapy depend on the individual drug.
- Common side-effects may include sore mouth, taste changes, loss of appetite, nausea and vomiting, diarrhoea, infection, fatigue, hair loss, and numbness or tingling in hands or feet.

Biological therapies

Biological therapies are drugs that use your body's immune system to fight cancer. There are many different types, for example, monoclonal antibodies. They often block the growth of cancer cells by interfering with molecules needed for the cancer to grow. In head, neck and mouth cancers, biological therapies can be given if the cancer has spread to nearby tissues or is advanced.

Biological therapies are also known as targeted therapies. This is because they target the cancer cells directly and do not affect normal cells, unlike chemotherapy. This means there are no chemotherapy side-effects like hair loss, vomiting or damage to bone marrow. Targeted therapies can be given on their own or with chemotherapy drugs. They often make chemotherapy drugs work better as well.

Side-effects of biological therapies

Even though the cancer cells are targeted directly, there are some side-effects. The type of side-effects you get will depend on the type of drug, the dose, the duration and your own general health.

The drugs may cause flu-like symptoms when given at first. But in general they cause very few side-effects.

One targeted therapy commonly used in the treatment of head and neck cancer is cetuximab (Erbitux®). Cetuximab is a type of biological drug known as a monoclonal antibody. There are some side-effects that can occur with monoclonal antibodies. For example, rashes, fatigue, blood clots and high blood pressure. These side-effects are usually short term and improve over time. Your doctor can prescribe medication if they become a problem for you.

If you develop facial rashes, they can be treated. Your doctor can prescribe antibiotic creams if needed and give you advice on caring for your face.

For more about targeted therapies, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

To sum up

- Biological therapies are drugs that use your body's immune system to fight cancer.
- They are also called targeted therapies because they target the cancer cells directly and do not harm normal cells.
- In head and neck cancer, they can be given if the cancer has spread to nearby tissues or is advanced.
- The drugs may cause flu-like symptoms when given at first. But in general they cause very few side-effects.
- Cetuximab (Erbitux®) is a commonly used targeted therapy.

How will my lifestyle be affected?

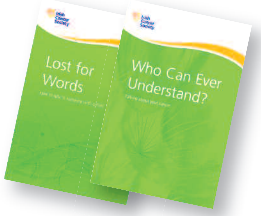
Treatment for head, neck and mouth cancers can sometimes bring big changes to your lifestyle. It can affect how you look, eat, speak and hear. But there will be a team of health professionals ready to help you and your family manage and cope.

It can be difficult to keep track of all of your cancer treatments and the information you receive at each doctor's appointment. A useful diary to help you keep track of your cancer treatment is called the *Journey Journal*. For a free copy, contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Changes to appearance

Treatments such as radiotherapy or surgery can change your appearance. They can affect your body image, which is how you see yourself. Adapting to these changes can take time. But your doctor and nurses can give you advice about prostheses or camouflage make-up. If you have a partner, do discuss these changes together. You may find it helpful to talk to a counsellor as well. Contact the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for more advice. Some websites can offer support as well. See the helpful contacts section on page 78 for details.

Two useful booklets from the Irish Cancer Society are *Lost for Words* and *Who Can Ever Understand: Talking about Your Cancer*. Call 1800 200 700 for free copies.



Changes to eating

Not being able to eat normally is a common problem after treatment for head, neck and mouth cancers. For most people it usually does not last long. But for others it can be a more permanent change. These changes may be due to swelling and bruising after surgery, loss of teeth or a part of your jaw, irritation after radiation, nausea, taste changes or loss of appetite. Your speech and language therapist and dietitian will carefully work out the cause of your eating problems and help you to manage them.

You may need to have a test called a videofluoroscopy done. This is a type of X-ray that looks at the way your swallowing works. The test is recorded on video so your doctor and speech and language therapist can assess it. If the results show that food or liquid is getting into your lungs, you may need to have your food through a tube in your stomach (PEG tube – see page 21). Sometimes this tube can be permanent but usually it is temporary. Your speech and language therapist will teach you exercises to improve your swallow too.

See the booklet *Diet and Cancer* for more information about eating problems. You can download it from **www.cancer.ie**. Or call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for a copy or more advice. There are more recipe books in the 'Helpful Books' section in the back of this book. You can also see the centre of this booklet for menu suggestions.

Changes to speech

Depending on the treatment you receive, you may experience changes to your speech. These changes might be temporary or permanent. Your speech and language therapist will help you manage this side-effect through exercises, aids and prostheses. It can take some time to adapt but it will get easier.

Speech therapy: This can help you learn to speak in the clearest and most effective way. It begins as soon as possible after surgery and usually continues after you go home. This therapy involves learning exercises to improve the range and strength of your mouth and tongue movements. You can also learn to find new ways to produce speech sounds if needed. If you wear dentures these may need to be changed by a dental specialist. Sometimes you may need a specially designed prosthesis or a special aid to help your speech. If this is needed, your speech and language therapist will discuss it with you. Remember it will take time for you and your family and friends to adjust to the change in your speech or voice.

Changes to hearing

If your hearing is affected after treatment, you will need a hearing/ENT assessment. Your doctor will discuss if you need drainage or if an implant is suitable for you. There are also prostheses or hearing aids available.

Will treatment affect my sex life and fertility?

Sex and sexuality

For some people sex is an important part of their relationships, while it is less so for others. During treatment you may lose the desire for sex. This is normal and there can be many reasons for it. Coming to terms with the fact that you have cancer can take quite a while. Your emotions will be turned upside down. It can be hard to relax as well when you have a lot of worries on your mind. You may be worried about your chances of surviving your cancer, how your family is coping with your illness, or about your job and finances. You may also be feeling physically tired from the effects of tests and treatment.

If you have a supportive partner, you may find that talking about your feelings might ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. He or she may refer you for specialist counselling if you feel that would be helpful.

There is no set time for you to be ready to have sex again. It varies from person to person. Once you return to your usual routine your interest in sex should return too. But you may find it will be some weeks before you 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. It is quite safe for you to have sex again with your partner.

Contraception and pregnancy

If you are receiving chemotherapy and you or your partner are fertile, it is best to use a reliable method of contraception during treatment and for some time afterwards. This is because there is a risk of miscarriage or birth defects in babies conceived during or just after treatment.

Many doctors believe it is better for you or your partner not to get pregnant for 2 years after your chemotherapy ends. This time gives your body a chance to get over the effects of the cancer and its treatment.

Fertility

Your fertility may be affected by chemotherapy. Sadly, you may not be able to become pregnant or father a child in the future. If this is the case, do talk to your partner about your feelings. Discuss your worries about infertility with your doctor before treatment starts. He or she can tell you if there are any options open to you at this time. It may be possible to freeze your eggs or sperm before treatment begins. The HARI (Human Assisted Reproduction Ireland) Unit at the Rotunda Hospital in Dublin provides a service where eggs or sperm can be frozen for later use. Talk to your doctor about this service or call the National Cancer Helpline on 1800 200 700 for more information. You can also visit a Daffodil Centre and speak to a nurse there.

Dealing with infertility may not be easy, depending on your age and if you have had children or not. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for more advice.

How can I cope with fatigue?

Fatigue is a common symptom of cancer and is often described as an overwhelming tiredness. You may also find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. It may be caused by worry when a diagnosis of cancer is made or the added stress caused by treatment. Cancer treatments and their side-effects can also cause fatigue.

Even though you may find it hard to identify the reasons for your tiredness, there are still ways to improve it.

How is fatigue helped?

Cancer treatment: For many patients, treatment can relieve symptoms such as pain and nausea. This can also help fatigue and get you back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.

Rest and sleep: Get as much rest as possible. If you are feeling very worried and find it hard to sleep at night, ask your doctor or nurse for advice.

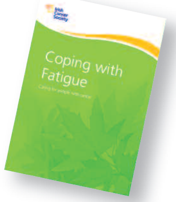
Counselling: If anxiety is a problem, talk to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

Exercise: If you are able to do physical exercise, do some regularly. Ask your doctor or nurse for advice on what type will suit you. For example, a half-hour walk 3 days a week might be a realistic goal and will boost your morale when you achieve it.

Housework/childcare: Get others to help you around the house, with travelling to hospital, at work, with the children or with shopping.

Enjoyment: Save your energy for doing the things you most enjoy. If you are going somewhere special, have a rest before you go out.

A booklet with useful tips called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline on 1800 200 700 for a free copy. You can also pick up a copy from a Daffodil Centre or download it at **www.cancer.ie**



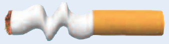
What follow-up do I need?

After your treatment, you will have regular check-up visits with your specialist. This is called follow-up. These check-ups might include seeing your doctor and dentist, having a physical exam and tests such as X-rays, scopes or scans. Blood tests, especially ones that check your thyroid gland and blood count, will also be taken. It is very important for your doctor and dentist to monitor your progress. If you are between check-ups and have a symptom or problem that worries you, let your doctor know without delay.

How can I reduce my risk of further head, neck and mouth cancers?

- Quit smoking.
- Reduce your alcohol intake.
- Visit your dentist for a check-up at least twice a year.
- Eat a well-balanced diet with plenty of fresh fruit and vegetables.
- Wear sunscreen and cover up when outdoors in the sun.
- Talk to your doctor about any special advice.

Should I quit smoking?



It is never too late to quit smoking. If you quit, it reduces your chances of developing other cancers and illnesses. These include emphysema, heart disease, stroke and osteoporosis. Smoking can also affect the treatment of cancer. For example, it can reduce how well chemotherapy or radiotherapy works. It can also make their side-effects worse. Sometimes it may cause rarer side-effects such as breathing and heart problems. This is because radiotherapy can make body organs like the lungs more sensitive to tobacco smoke.

How can I quit?

Like many others, you may find giving up smoking hard. If you would like advice or support on quitting, call the National Smokers' Quitline on CallSave 1800 201 203 or Freetext QUIT to 50100. The Quitline is open Monday to Thursday 9am to 7pm and Friday 9am to 5pm. If you would like further personal support locally, the Quitline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see **www.quit.ie**

Some hospitals also have stop smoking clinics. Ask your doctor or nurse if there is one in your hospital.

What if my cancer comes back?

Many people diagnosed with head, neck and mouth cancers may be cured, but for some the cancer may return some time after treatment. If this happens, your doctor will discuss your options with you and the aim of the treatment. In some cases surgery may be possible. Radiotherapy may be given to the area if it has not already been used before. In other situations, chemotherapy may be given to try to control the cancer for as long as possible.

How is advanced cancer treated?

Advanced cancer is when the cancer has spread to other parts of your body. If this happens, your doctor will discuss the best treatment option for you with a team of healthcare professionals. Your doctor may refer you to specialist palliative care doctors and nurses.

Palliative care is treatment and care given if you are seriously ill. Many people are frightened when they hear the word 'palliative' and think that this means the patient is dying. This isn't necessarily so. The palliative care team are experts in helping patients and their loved ones cope with the emotional and physical effects of advanced cancer. Palliative care is care given to patients when a cure is no longer possible. The aim of their treatment then is to slow down their disease and control their symptoms.

For more information, call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre.

Research – what is a clinical trial?

Research into new ways of treating head, neck and mouth cancers goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. Many patients with cancer take part in research studies today. Even though the word 'research' or 'new drug' sometimes scares people, there is no need for fear. Before a drug or treatment is used on patients, it goes through many stages to make sure it is safe.

Phases of research

There are many stages or phases when research is done. If a drug or treatment looks as if might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated.

If early studies suggest that a new drug may be both safe and effective, further trials are carried out. These aim to:

- Find out if the treatment is better than ones already in use.
- Find out if there are more benefits when the new treatment is given together with current ones.
- Compare the new treatment with current best standard treatments.

Taking part in clinical trials

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully watched during and after the study. You might also receive a treatment that later proves to be better than the current best standard treatment.

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

If you would like more information, call the National Cancer Helpline on 1800 200 700, see our website **www.cancer.ie** or visit a Daffodil Centre

Cancer and complementary therapies

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

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

Conventional therapies

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

Complementary therapies

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

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

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

Alternative therapies

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

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

If you decide to have complementary or alternative treatments…

Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, do talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you. Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present, this area is not fully regulated in Ireland. Make sure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

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

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions can often differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment. Or indeed it may not be until you recover from your illness that your emotions hit hard.

Common reactions include:

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

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. It may take a long time to come to terms with your emotions. Not only do you have to cope with knowing you have cancer, but also the physical effects of treatment. Some helpful booklets that discuss them in detail are *Understanding the Emotional Effects of Cancer* and *Who Can Ever Understand? Talking about Your Cancer*. Call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre for free copies or to talk in confidence.

Shock and disbelief

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

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are totally shocked when it does. Even if your doctor and nurse discuss the cancer with you, the news may not sink in for a while. You may find yourself confused, asking the same questions over and over again. Or else you may accept the news calmly and say nothing because you cannot really believe what is happening to you.

Fear and uncertainty

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

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

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

It is natural for you to be afraid or concerned about the future too. You may wonder if you will be cured or if your cancer will recur. Living with this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions. Do discuss your concerns with your doctor, nurse or medical social worker, as they can advise and help you. If living with uncertainty overwhelms you, it may help to talk to someone in a support group, such as a Survivors Supporting Survivors volunteer. See page 70 for more information. The palliative care team can also offer you support if your cancer is advanced.

Loss of control

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

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

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

Sorrow and sadness

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

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

Denial

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

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

Anger

Why me? I always took care of my health.

Why did this happen now?

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

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

Resentment

How can you talk – you don't have to deal with cancer.

How come I'm not getting better?

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

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

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

Blame and guilt

I should've been more careful.

If only I had a more positive attitude, I wouldn't have got sick.

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

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

Withdrawal and isolation

I just need to be on my own.

It is true that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you may want to be left alone and withdraw from people. It is normal for you to want to be alone to sort out your thoughts and feelings. You will want to take stock of things and work out how best you can cope. However, it is not a good idea to spend long hours on your own every day. Sometimes depression can make you avoid family and friends and stop you wanting to talk. If you isolate yourself, it can be hard for your family and friends, as they will want to share this difficult time with you. They may worry about you needlessly. Let your family and friends know that you will talk to them once you are ready.

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

How can my family and friends help?

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

How can I talk to someone with cancer?

When someone close to you has cancer it can be hard to know what to do. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about. You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, many do not. Be honest with your own feelings too.

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

Be patient

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

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

How can I talk to my children?

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

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

Be honest

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

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

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more. Talk to children in language they will understand and without going into the details of your illness.

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

Coping with children's emotions

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

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer. A Guide for Parents* gives very practical advice. If you would like a free copy call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at **www.cancer.ie**. See page 79 for other helpful books.

What else can I do?

Here is a list of things to help make you feel more involved and more in control of your illness.

- Communicate with your family and close friends.
- Live one day at a time.
- Live well by eating well and taking exercise.
- Expect change in your life.
- Keep an open mind.
- Seek information about your cancer and treatment.
- Find what way of coping works for you.
- Build a support network.
- Seek professional help if you have low moods or strong emotions.
- Consider spiritual care.
- Express yourself through writing, music, dance or art.

Support resources

Who else can help?

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

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

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

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

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

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

Community health services: There are various community health services available from your local health centre. These centres have public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far from your hospital, your community welfare officer can also help with practical issues such as financial problems or exceptional needs. More information on the services is available either from the medical social worker in your hospital before you go home or at your local health centre.

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

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

››› Remember that there are many people ready to help you.

Health cover

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

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

At the end of this section there are also some useful telephone numbers and addresses for further help.

Hospital cover

At present, everyone is entitled to hospital inpatient services in a public ward in a public hospital. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

If you go to the accident and emergency department of a public hospital without being referred there by a GP, you will be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the accident and emergency department first.

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

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

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

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

GP visit card

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

Drugs Payment Scheme

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

Private healthcare cover

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

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

Benefits and allowances

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

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

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

Appliances

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

Travel to hospital

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

See pages 71–72 for information on the Care to Drive and Travel2Care schemes run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

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

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

For social welfare queries, contact:

Dept of Social Protection – Information Service
Oisín House
212–213 Pearse Street
Dublin 2

Tel: 1850 662 244
Leaflet line:
1890 202 325

Email: info@welfare.ie
Website: www.welfare.ie

For queries about local health and social services, contact the HSE. **HSE infoline:** 1850 24 1850 **Email:** info@hse.ie **Website:** www.hse.ie

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

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

If you have financial worries…

A diagnosis of cancer can sometimes bring the added burden of financial worries. You may find that you have a lot more expenses, like medication, travel, food, heating, laundry, clothing and childcare costs. If you are unable to work or unemployed, this may cause even more stress. It may be hard for you to deal with cancer if you are worried about providing for your family and keeping a roof over your head.

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 71 for more details. You can also call the National Cancer Helpline on 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 73 for contact details. A useful book for preparing low-budget nutritious meals is *101+ Square Meals*. See page 79 for more information.

Irish Cancer Society services

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

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

Cancer Information Service (CIS)

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

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

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

Daffodil Centres

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

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

Cancer support services

The Irish Cancer Society funds a range of services set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 74 for more details.

Survivors Supporting Survivors

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

Counselling

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

Night nursing

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

Cancer information booklets and factsheets

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

Financial support

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

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

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

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

Care to Drive transport project

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

If you would like more information on any of the above services, call the National Cancer Helpline on 1800 200 700. You can also visit the website **www.cancer.ie** or a Daffodil Centre.

Useful organisations

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

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

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

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

HARI: The National Fertility Centre
Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Email: info@hari.ie
Website: www.hari.ie

Health Promotion HSE
Website: www.healthpromotion.ie

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

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

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

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

Health insurers

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

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

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

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

National support services

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

ARC Cancer Support Centres Dublin
[See page 75]

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

Cancer Support Sanctuary LARCC
[See page 76]

Connaught support services

Athenry Cancer Care
Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 844 319 / 087 412 8080
Email: athenrycancercare@gmail.com
Website: www.athenrycancercare.com

Ballinasloe Cancer Support Centre
Main Street
Ballinasloe
Co Galway
Tel: 090 964 5574
Email: ballinasloecancer@yahoo.co.uk

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

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

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

Hand in Hand
[Childhood cancer in west and northwest]
Main Street
Oranmore
Co Galway
Tel: 091 799 759
Email: info@handinhand.ie
Website: www.handinhand.ie

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

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

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

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

Leinster support services

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

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

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

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

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

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

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

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

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

Dublin West Cancer Support Group
Generic Social Work Department
Oak Unit
Cherry Orchard Hospital
Ballyfermot
Dublin 10
Tel: 01 620 6273
Email:
martina.mcgovern2@hse.ie/noreen.obrien4@hse.ie

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

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

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

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

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

Rathdrum Cancer Support Group
St Anne's
Lower Street
Rathdrum
Co Wicklow
Tel: 087 292 8660
Email: rathcan@gmail.com

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

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

Munster support services

Cancer Information & Support Centre
University Hospital Limerick
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

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

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

Cuan House Cancer Support Centre
24 Gort Aoibhinn
Cork Hill
Youghal
Co Cork
Tel: 024 92353

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

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

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

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

Suir Haven Cancer Support Centre
Clongour Road
Thurles
Co Tipperary
Tel: 0504 21197
Email: suirhaven@gmail.com

Ulster support services

Coiste Scaoil Saor Ó Ailse
C/O Ionad Niomh Padraig
Upper Dore
Bunbeg
Letterkenny
Co Donegal
Tel: 074 953 2949
Email: ionadnp@eircom.net
Website: www.scaoilsaor.ie

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

Cuan Cancer Social Support and Wellness Group
2nd Floor, Cootehill Credit Union
22–24 Market Street
Cootehill
Co Cavan
Tel: 086 455 6632

Living Beyond Cancer
Oncology Day Services
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674/734) /
074 910 4477
Email: noreen.rodgers@hse.ie

Other support services

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

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

Cúnamh: Bons Secours Cancer Support Group
Bon Secours Hospital
College Road
Cork
Tel: 021 480 1676
Website: www.cunamh.ie

Dundalk Cancer Support Group
Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

Killybegs Cancer Support Group
Kille
Kilcar
Co Donegal
Tel: 074 973 1292
Email: riverbankdunne@eircom.net

Newbridge Cancer Support Group
Tel: 083 360 9898
Email:
newbridgecancerhealinghelp@gmail.com

Purple House – Cancer Support
Aubrey Court
Parnell Road
Bray
Co Wicklow
Tel: 01 286 6966
Email: info@purplehouse.ie
Website: www.braycancersupport.ie

Sláinte an Chláir: Clare Cancer Support
Tír Mhuire
Kilnamona
Ennis
Co Clare
Tel: 1850 211 630
Email: admin@clarecancersupport.com
Website: www.clarecancersupport.com

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

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

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

Useful contacts outside Republic of Ireland

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

American Cancer Society
Website: www.cancer.org

Cancer Focus Northern Ireland
40–44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Buddies Network
Website: www.cancerbuddiesnetwork.org

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

Healthtalkonline
Website: www.healthtalkonline.org

Macmillan Cancer Support (UK)
Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre
Belfast City Hospital Trust
77–81 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancerinfo@belfasttrust.hscni.net
Website: www.cancerni.net

Merseyside Regional Head and Neck Cancer Centre (UK)
Website: www.headandneckcancer.co.uk

Mouth Cancer Foundation (UK)
Website: www.rdoc.org.uk

National Cancer Institute (US)
Website: www.nci.nih.gov

Oral Cancer Foundation (US)
Website: www.oralcancerfoundation.org/

Support for People with Oral and Head and Neck Cancer (US)
Website: www.spohnc.org

Throat Cancer Foundation (UK)
Website: www.throatcancerfoundation.org

Support for changes to appearance

Changing Faces (UK)
Website: www.changingfaces.org.uk

Let's Face It (UK)
Website: www.lets-face-it.org.uk

Helpful books

Free booklets from the Irish Cancer Society:

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

Radiotherapy Treatment to the Head & Neck - A Patient Guide
St Luke's Radiation Oncology Network
Download from www.stlukesnetwork.ie

Meeting the Challenges of Oral & Head and Neck Cancers.
2nd edition.
Nancy E. Leupold & James J. Siubba
Plural Publishing, 2011
ISBN: 9781597564540

Word of Mouth: Coping with and Surviving Mouth, Head and Neck Cancers.
Denise MacCarthy and Lia Mills (Eds)
Word of Mouth Publishing
ISBN 9781909483316
Available from the Irish Cancer Society

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

Brenda's Easy-to-Swallow Cookbook
[Recipes for anyone who has difficulty chewing and swallowing food.]
Brenda Brady, in association with the Mouth Cancer Foundation
Order from
www.easytoswallowcookbook.com/orders/

In Your Face
Lia Mills
Penguin, 2008
ISBN 9780141033334

Explaining cancer to children

The Secret C: Straight Talking About Cancer
Julie A Stokes
Winston's Wish, 2000
ISBN 0-95391-230-2

Why Mum? A Small Child with a Big Problem
Catherine Thornton
Veritas, 2005
ISBN 1-85390-891-6

Helpful DVD

Understanding Radiation Therapy: A Patient Pathway
Call 1800 200 700 for a copy.
Website: www.cancer.ie

What does that word mean?

Alopecia	Loss of hair or no hair where you normally have hair.
Anaemia	A reduced number of red blood cells in your blood. It causes fatigue, weakness and shortness of breath.
Antibodies	Proteins made by white blood cells (plasma cells) in your body. They help protect your body from infection and disease.
Benign	Not cancer. A tumour that does not spread.
Chemotherapy	A treatment that uses drugs to cure or control cancer.
Dental specialist/oncologist	A dentist who plans dental care before, during and after radiotherapy. Also known as a dental oncology specialist.
ENT surgeon	A doctor who specialises in treating injuries and diseases affecting the ear, nose and throat, and head and neck.
Malignant	Cancer. A tumour that can spread.
Maxillofacial surgeon	A doctor who specialises in treating injuries and disease affecting the head, neck, face, mouth and jaw.
Maxillofacial prosthodontist	A dentist who provides rehabilitation of the mouth after cancer surgery. Treatment may involve obturators or implants to restore missing tissue.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
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.
Radiotherapy	A treatment that uses high-energy X-rays to cure or control cancer and other diseases.
Radiation oncologist	A doctor who specialises in treating cancer patients with radiotherapy.
Staging	Tests that measure the size and the extent of a cancer.

Questions to ask your doctor

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

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

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

Answer

6

Answer

Acknowledgements

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

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Would you like more information?

We hope this booklet has been of help to you. After reading it or at any time in the future, if you feel you would like more information or someone to talk to, please call the National Cancer Helpline on 1800 200 700.

Would you like to be a patient reviewer?

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

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

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

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, research and education. This includes patient information booklets. If you would like to support our work in any way – perhaps by making a donation or by organising a local fundraising event – please contact us at CallSave 1850 60 60 60 or email **fundraising@irishcancer.ie**

Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
Tel: 01 231 0500 **Email**: info@irishcancer.ie **Website**: www.cancer.ie

Irish Cancer Society
43/45 Northumberland Road, Dublin 4

T: 01 231 0500
E: info@irishcancer.ie
W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700
Open Monday to Thursday 9am to 7pm
Friday 9am to 5pm

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Follow us on Twitter: @IrishCancerSoc

The National Cancer Charity

Irish
Cancer
Society