

Understanding

Cancer of the Oesophagus

Caring for people with cancer

Understanding cancer of the oesophagus

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

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

Specialist nurse Tel: _____

Family doctor (GP) Tel: _____

Gastroenterologist Tel: _____

Surgeon Tel: _____

Medical oncologist Tel: _____

Radiation oncologist Tel: _____

Radiation therapist Tel: _____

Dietitian Tel: _____

Emergency number Tel: _____

Treatments Review dates

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

- *A Strategy for Cancer Control in Ireland*, National Cancer Forum, 2006.
- *Cancer in Ireland: 1994–2004: A Summary Report*, National Cancer Registry Ireland & Northern Ireland Cancer Registry, 2009.
- *Guidelines for the Management of Oesophageal and Gastric Cancer*, Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland, the British Society of Gastroenterology, and the British Association of Surgical Oncology, *Gut* 50 (Suppl V): v1–v23, 2002.
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First published by the Irish Cancer Society in 2004.

© Irish Cancer Society, 2004, revised 2006, revised 2010

Next revise: 2012



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ISBN 0-95323-690-1

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Introduction

This booklet has been written to help you understand more about cancer of the oesophagus (gullet). It is also known as oesophageal cancer. By reading the booklet you can learn more about its diagnosis, treatment and side-effects, and also any feelings you might have at this time.

We hope it answers some questions you may have. But we cannot advise you about which treatment to choose. You can only make this decision along with your doctors, when all your test results are ready.

At the end of the booklet you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time. You can also call the freefone National Cancer Helpline 1800 200 700 to discuss any queries or concerns you have.



Reading this booklet

It is easy to be overwhelmed by all the information you have to take in. But you do not need to know everything about oesophageal cancer 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 National Cancer Helpline 1800 200 700, if you wish.

If reading this booklet helps you, do pass it on to your family and friends who might find it helpful too.



What does that word mean?

Abdomen	The part of your body that lies between your chest and hips. Also known as your tummy.
Adjuvant	Treatment given soon after surgery when a diagnosis of cancer is made.
Alopecia	Loss of hair or no hair where you normally have hair.
Anaemia	A shortage of haemoglobin in your red blood cells. This causes fatigue, weakness and shortness of breath.
Benign	Not cancer. A tumour that does not spread.
Biopsy	Removing a small amount of tissue from your body to find out if cancer cells are present.
Cells	The building blocks that make up your body. They are tiny and can only be seen under a microscope.
Chemotherapy	A treatment that uses drugs to cure or control cancer.
Fatigue	Ongoing tiredness, often not helped by rest.
Malignant	Cancer. A tumour that can spread.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Metastasis	The spread of cancer from one part of the body to other tissues and organs.
Nausea	Feeling sick or wanting to be sick.
Neo-adjuvant	Treatments such as chemotherapy and radiotherapy given before surgery to reduce the size of a cancer.

Oncology	The study of cancer.
Photodynamic therapy	A treatment that uses light sources and a chemical to kill cancer cells.
Radiation oncologist	A doctor who specialises in treating cancer patients with radiotherapy.
Radiotherapy	A treatment that uses high-energy X-rays to cure or control cancer and other diseases.
Staging	Tests that measure the size and the extent of a cancer.

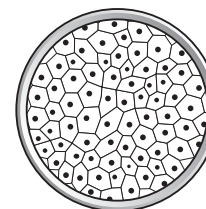
About oesophageal cancer

What is cancer?

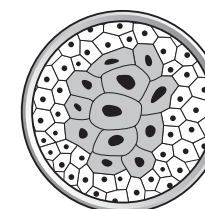
Cancer is a word used to describe a group of diseases. Each one has its own name. For example, skin cancer, lung cancer and breast cancer. Each has an individual type of treatment and chance of being cured.

In your body, your organs and tissues are made up of tiny building blocks called cells. All cancers are a disease of the body's cells. In healthy tissue these cells replace or repair themselves when they get worn out or injured. With cancer, the cells do not behave as normal and keep on growing even when there is no need.

These groups of abnormal cells can form a lump or tumour. Tumours can be either benign or malignant. Benign tumours do not spread to other parts of your body and so are not called cancer. Malignant tumours are made up of cancer cells that can spread from where they first grew. This happens when a cell or group of cells breaks away and is carried by the bloodstream or lymph glands to form a new tumour elsewhere in the body. This is called a metastasis or secondary tumour.



Normal cells



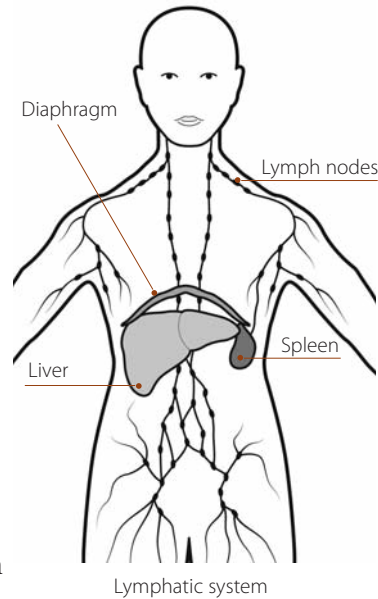
Cells forming a tumour

What is the lymphatic system?

Every day your body defends itself against infection in many ways. The lymphatic system is one way. Like the bloodstream it carries material around your body. It is a network of tiny tubes that pass through most of the tissues in your body. These tubes carry a clear watery fluid called lymph.

Along the network are hundreds of small glands shaped like beans. These are called lymph nodes and remove unwanted material from the lymph like a sieve. They also help white blood cells called lymphocytes to protect your body against infection.

Lymph nodes are found in groups throughout your body, such as in your neck, armpits and groin. Sometimes you may notice these glands if they become swollen. More of these lymph nodes are found in larger groups in your chest and tummy (abdomen). Other parts of the lymphatic system include your spleen, thymus, tonsils and bone marrow. Lymph nodes can also spread cancer cells.



To sum up

- Cancer is a disease of the cells of the 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 blood or lymph somewhere else in the body. This is called a metastasis or secondary tumour.

What is the oesophagus?

The oesophagus is part of your digestive system. Most people know it as the gullet or food pipe. It is a long muscular tube that links your throat to your stomach. In adults it is about 25–30 cm long and runs behind your windpipe (trachea).

The back of your throat divides into two tubes, your windpipe and your

oesophagus. Your windpipe connects your mouth and nose to your lungs and allows you to breathe.

When you swallow food, the muscles in your oesophagus push the food down into your stomach. A muscle valve at the end of your oesophagus prevents food and fluid from going back up. A valve at the top of your oesophagus stops food from going into your lungs.

The wall of your oesophagus has several layers. These include:

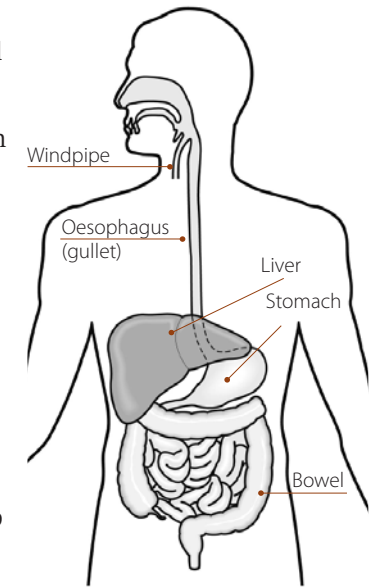
- **Inner layer or lining (mucosa):** The lining of your oesophagus is moist so that food can pass easily into your stomach. It is made up of skin-like cells called squamous cells.
- **Submucosa:** The gland cells in this layer make mucus. Mucus helps to keep your oesophagus moist.
- **Muscle layer:** The muscles in this layer push the food down to your stomach.
- **Outer layer:** The outer layer covers the oesophagus.

Lymph glands are also found near your oesophagus. For example, in your neck, the middle of your chest and where your oesophagus joins your stomach.

What is oesophageal cancer?

When cancer occurs, the cells in the oesophagus change and grow in an abnormal way. Usually the tumour does not cause symptoms at first, but as it grows it can cause difficulty with swallowing (dysphagia). This is because it narrows the oesophagus and makes food lodge or stick there. After that, it can be hard to swallow liquids.

Cancer can develop anywhere in your oesophagus and there are different types. See page 18 for more details on the types.



How common is oesophageal cancer?

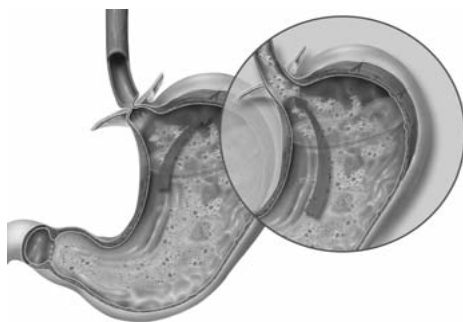
In general oesophageal cancer is not common in Ireland. About 300 people are diagnosed with it each year, but the number is rising. More men than women get the disease.

»»» The exact cause of oesophageal cancer is unknown. But there are certain things called risk factors that can increase your chance of getting the disease.

What causes oesophageal cancer?

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

- **Age:** Your risk increases as you get older. Oesophageal cancer is more common in people over 60 years of age.
- **Gender:** Oesophageal cancer is more common in men than in women.
- **Smoking:** Smoking is a major risk factor for oesophageal cancer. This includes smoking cigarettes, cigars or pipe tobacco.
- **Alcohol:** If you drink a lot of alcohol over many years, you have a high risk. Drinking spirits in particular increases your risk. If you both smoke and drink, your risk of oesophageal cancer is even higher. Scientists believe alcohol and smoking increase the harmful effects of each other.
- **Acid reflux:** Tissues at the lower end of your oesophagus can get inflamed by the backflow of stomach acid into your oesophagus. This problem is called acid reflux (heartburn) and affects about 1 in 3 people. It is also known as gastro-oesophageal reflux disease (GORD).



Acid reflux

- **Barrett's oesophagus:** Over time, the inflamed cells due to acid reflex can change and look like cells in your stomach (columnar cells). This condition is known as Barrett's oesophagus and can lead to oesophageal cancer.
- **Achalasia:** This is a medical condition where the muscles between your oesophagus and stomach cannot open or close properly. This causes a build-up of food in your oesophagus and can sometimes lead to cancer.
- **Obesity:** If you are overweight or obese, you have a higher risk of oesophageal cancer. The reason for this is not yet clear.
- **Poor diet:** Your risk of oesophageal cancer may be raised if your diet lacks certain vitamins and minerals, such as zinc. This can happen if you do not eat a balanced diet with plenty of protein, fresh fruit and vegetables.

Cancer of the oesophagus is not infectious and cannot be passed on to other people. In most cases oesophageal cancer is not inherited. This means your parents cannot pass a faulty gene on to you.

If you feel you could be at risk, visit your family doctor (GP) and discuss your concerns. He or she will advise you what to do.

Can I be screened for oesophageal cancer?

Testing for oesophageal cancer when you have no symptoms is called screening. There is no national oesophageal cancer screening programme in Ireland at present. If you are concerned about oesophageal cancer, talk to your GP. If you do have Barrett's oesophagus or achalasia, you will have routine check-ups.



To sum up

- Your oesophagus is a long muscular tube that links your throat to your stomach.
- When cancer occurs, cells in part of the lining of your oesophagus change to form a tumour.
- Cancer cells may break away and spread to other parts of your body.

- Oesophageal cancer is not common in Ireland. About 300 people are diagnosed with it each year.
- The exact cause of oesophageal cancer is unknown. Your risk increases as you get older, are male, if you drink alcohol and smoke, have acid reflux, Barrett's oesophagus or achalasia, are obese and have a poor diet.

What are the symptoms of oesophageal cancer?

In the early stages of oesophageal cancer, the symptoms may be vague. As the cancer grows, the symptoms can include:

- Difficulty in swallowing, like food catching in your gullet
- Painful swallowing
- Indigestion or heartburn that won't go away
- Weight loss
- Poor appetite
- Pain in your throat, breastbone or back
- Hoarse voice
- Frequent coughing
- Frequent hiccoughs or belching

These symptoms can also be caused by conditions other than cancer. But do have them checked out by your GP, especially if they go on for more than 4–6 weeks. For more information, call the National Cancer Helpline 1800 200 700.

How is oesophageal cancer diagnosed?

If you are worried about any symptoms, visit your family doctor (GP) first. He or she can examine you and do some blood tests. If your GP is still concerned about you, you will be referred to a hospital for more tests.

Sometimes oesophageal cancer is found during a routine check-up for Barrett's oesophagus. In Ireland, rapid access oesophageal clinics are now being developed at specialist centres. Your GP may refer you to this clinic, where you will be seen within one week.

At the hospital, your doctors will ask you questions about your health before examining you. A blood test may be done and a chest X-ray taken to check your general health. The doctors will also arrange special tests of your oesophagus.

Special tests

You may have the following tests done:

- Barium swallow
- Endoscopy
- Biopsy

Barium swallow

A barium swallow is a special type of X-ray of your oesophagus. You will be asked to drink a white chalky liquid called barium. The barium will show up the shape of your oesophagus on the X-ray.



Barium swallow

Before the test: You must fast for 6 hours before the test. Do ask your doctor and nurse any questions you might have about it.

During the test: As you drink the barium, your doctor will watch it on an X-ray screen flow down your oesophagus towards your stomach. X-ray pictures are taken to see if there are any abnormal areas in your oesophagus. The test takes about 15 minutes and does not hurt. Even though the liquid tastes chalky, it should not make you sick. But make sure you arrange for someone to bring you home afterwards.

After the test: Your bowel motions will be white or chalky looking for a few days afterwards. This is normal, as all the barium does not leave your bowel straight after the test. If you feel a bit constipated, drink plenty of clear fluids or take a mild laxative for a couple of days. This will help you to have a bowel motion.

Endoscopy

During an endoscopy, a thin flexible tube will be put into your oesophagus. This tube has a camera and a light attached to it, which lets your doctor see anything unusual inside your oesophagus. The test is also known as an oesophagoscopy. It is usually done under local anaesthetic in an exam room. Sometimes a general anaesthetic is given before the test. If this happens, you may have to stay overnight in hospital.

Before the test: You will have to fast for a few hours beforehand. Your doctor may prescribe a mild sedative for you too. This will help you feel more relaxed. A local anaesthetic will be sprayed onto the back of your throat, while you are lying on your side.

During the test: Once your throat is numb, your doctor will gently pass the tube into your oesophagus. He or she can look through the tube to check for any abnormal areas. Samples of tissue can also be taken at this time. The test may be a bit uncomfortable but does not hurt.

After the test: You cannot eat or drink anything for at least 4 hours afterwards. This is because your throat will be numb from the anaesthetic. You may also feel drowsy and sleepy. But once the sedation wears off, you can go home. Make sure you arrange for someone to take you home. You might have a sore throat for a couple of days but this will soon clear up. If not, contact your doctor at the hospital. Do tell your doctor if you have any problems like chest pain, bleeding or fever afterwards.

Waiting for an endoscopy

If you have been waiting for longer than 3 months for your endoscopy, contact the National Treatment Purchase Fund (NTPF). This is a scheme set up to reduce waiting times for tests and operations. You may be referred to a private hospital for endoscopy free of charge. For more information, contact 1890 720 820 or visit the website www.ntpf.ie

Biopsy

During the endoscopy a small sample of tissue from your oesophagus can be taken. This is called a biopsy. The tissue is then examined under a microscope to see if there are cancer cells. A biopsy is the only sure way of knowing if cancer is present.

>>> A biopsy is the only sure way of knowing if cancer is present.

Tests to stage the cancer

If you have cancer, your doctor may want to do more tests. This is called staging. These tests will show if the cancer has spread to nearby tissues or other parts of your body. The results of the tests will help your doctor to decide on the best treatment for you. You may be referred to another hospital once the diagnosis of cancer is made. If this happens, some or all of the tests already done may need to be repeated.

Further tests may include some of the following:

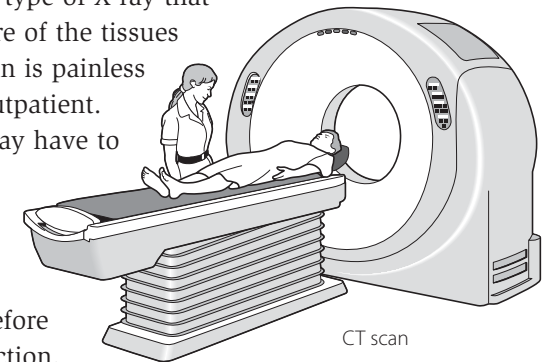
- CT scan
- Endoscopic ultrasound (EUS)
- Liver ultrasound
- MRI scan
- PET scan
- Laparoscopy

CT scan: This is a special type of X-ray that builds up a detailed picture of the tissues inside your chest. The scan is painless and usually done as an outpatient.

For some CT scans you may have to fast for 4 hours

beforehand. You may be given a special drink that helps to show up parts of your body on the scan. Before you take the drink or injection,

do 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. But your doctor or nurse will let you know what will happen.



Endoscopic ultrasound (EUS): This test is like an endoscopy (see page 14). First a small device called an ultrasound probe is joined to the top of the endoscope tube. This probe then makes sound waves that gives your doctor a picture of the tissues inside your oesophagus. By using this probe, your doctor can get deeper views of your oesophagus and nearby areas. He or she can check if nearby lymph glands are enlarged due to cancer or infection. A sample of the lymph glands can also be taken and examined under a microscope.

Liver ultrasound: This scan is done in the X-ray department of the hospital. A picture is built up of the tissues inside your liver and upper abdomen using sound waves. While lying on your back, a gel will be spread over the area to be scanned. A small device like a microphone is used to take the scan. This makes sound waves, which are then changed into a picture by a computer. The test does not hurt and only takes about 10 minutes.

MRI scan: This is a special scan that uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be very noisy. But you will be given earplugs to wear during the scan. You may have an injection before the scan to show up certain areas of your body. During the scan you cannot wear any metal jewellery or hair clips. If you have certain medical devices implanted, like a pacemaker or metal pin, you are not suitable for the test. Your doctor will advise you about this. Most people can go home after the scan.

PET scan: This test is done in the nuclear medicine department of specialist hospitals. You will have to fast for 4 hours beforehand. If you are a diabetic, tell your doctor before the test so you can be given special advice. As part of the test, a blood sample is taken to measure your blood sugar. Then a very small amount of a mildly radioactive sugar is injected into a vein in your arm. After the injection, you must wait for about 60 minutes before the scan can be taken. You might want to bring a book, magazine or music with you or a friend to keep you company.



PET scan

A scan is then taken of your body. Cancer cells absorb more of the radioactive sugar than normal areas, so these areas will show up on the scan. The level of radioactivity used in these scans is very low and is not harmful. It disappears from your body within a few hours. Drinking clear fluids will help to flush it from your body more quickly.

Laparoscopy: This test allows your doctors to look inside your tummy using keyhole surgery. It will help them to decide if you are suitable for major surgery or not. It is done under general anaesthetic and you will need to stay overnight in hospital. Just before the test you may be given sedation to relax you before going to theatre.

While you are asleep, your doctor will make a small cut in your tummy and put in a mini telescope called a laparoscope. By looking through the telescope, your doctor can see the organs close to your oesophagus and check the lining of your tummy for cancer. A small sample of tissue (biopsy) may be taken and examined under a microscope.

During the test, carbon dioxide gas is passed into your abdominal cavity. This can give you uncomfortable wind and/or shoulder pains for 3 or 4 days. Walking about or taking sips of peppermint water often eases the pain. After a laparoscopy you will have one or two stitches at the wound site. Usually they dissolve as your wound heals.

Waiting for results

It may take about 1–2 weeks 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 a specialist nurse or relative or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.

How is oesophageal cancer staged?

The stage of a cancer describes its size and if it has spread to other parts of your body. By knowing the stage of the cancer, it helps your doctors to decide the best treatment for you. The number system is a common way to stage cancer.

- **Stage 0:** This means the cancer is at a very early stage. Cancer cells are found in the lining of your oesophagus but are completely within the lining. This stage is also known as carcinoma in situ.
- **Stage 1:** This also means the cancer is at an early stage. The cancer cells are found only in the surface layers of the lining of your oesophagus. Or it may be found in only a small part of your oesophagus. There is no sign of it spreading anywhere.
- **Stage 2:** Here the cancer has spread to the muscle layer of your oesophagus or to nearby lymph nodes. But it has not spread to any other organs. If the cancer has not spread to nearby lymph nodes, it is stage 2A. If the cancer has spread to nearby lymph nodes, it is stage 2B.
- **Stage 3:** In this stage the cancer has spread beyond the wall of your oesophagus. It may also have spread to nearby lymph nodes and other tissues next to your oesophagus. But there are no signs of it spreading to other parts of your body.
- **Stage 4:** This means the cancer is advanced and has spread to your lymph nodes and other parts of your body. For example, your liver, lungs or stomach. These are known as secondaries or metastases.

>>> Staging refers to the size of the cancer and if it has spread to other parts of your body.

What are the types of oesophageal cancer?

A tumour can grow anywhere along your oesophagus. When diagnosing and treating cancer, doctors think of the oesophagus in three sections: upper, middle and lower. Oesophageal cancers are usually named after the type of cell where the cancer first starts to grow.

- **Squamous cell cancer:** Squamous cells are skin-like cells that line your oesophagus. They are found mainly in the upper and middle

of your oesophagus. About half of oesophageal cancers diagnosed are squamous cell cancers. It is usually due to smoking and alcohol. This type of cancer is becoming less common than before.

- **Adenocarcinoma:** Adenocarcinoma means a cancer that starts in the gland cells that make mucus. This cancer usually starts in the lower part of your oesophagus. It is linked to acid reflux and Barrett's oesophagus. About half of all oesophageal cancers diagnosed are adenocarcinoma. This type of cancer is increasing worldwide.
- **Undifferentiated:** In this type of cancer the doctors cannot tell if the cancer started in the gland cells (adenocarcinoma) or skin-like cells (squamous cells).



To sum up

- The symptoms of oesophageal cancer include difficulty or pain in swallowing, indigestion or heartburn, weight loss, pain in your throat, breastbone or back, hoarse voice, frequent coughing, hiccoughs or belching.
- Oesophageal cancer is diagnosed by barium swallow, endoscopy and biopsy.
- The staging of cancer means finding out its size and how far it has spread in the body.
- Tests to stage the cancer include CT scan, endoscopic ultrasound, liver ultrasound, MRI scan, PET scan, laparoscopy.
- The main types of oesophageal cancer are squamous cell cancer and adenocarcinoma.

Treatment and side-effects

How is oesophageal cancer treated?

The main treatments for oesophageal cancer are surgery, radiotherapy and chemotherapy. They can be used on their own or together. The type of treatment you get will depend on:

- The size of the tumour
- Where it is found
- If it has spread to your lymph nodes or other parts of your body
- Your symptoms
- Your age
- Your general state of health

Surgery: Surgery is the most common treatment for oesophageal cancer. If the cancer is found in only a small section of the oesophagus, it may be possible to remove the entire tumour along with the affected part of the oesophagus. See page 24 for more details about surgery.

Radiotherapy: Radiotherapy can be used alone or with chemotherapy. It may also be used before surgery to reduce the size of the tumour or to prevent it from coming back after surgery. Or it may help to relieve symptoms like pain or difficulty in swallowing. See page 34 for more details about radiotherapy.

Chemotherapy: Chemotherapy may be used alone or with radiotherapy before or after surgery. It can help to either reduce the size of the tumour before surgery or to prevent it from coming back after surgery. It may be used to control the cancer if it recurs after surgery or radiotherapy or to relieve symptoms. See page 41 for more details about chemotherapy.

>>> The main treatments for oesophageal cancer are surgery, radiotherapy and chemotherapy.



Treatments for difficulty swallowing

There are other treatments that can relieve any swallowing difficulties you may have. They include:

Stenting: Putting a tube called a stent into your oesophagus to keep it open.

Dilatation: Stretching and widening your oesophagus.

Laser therapy: Using heat from a laser beam to burn away cancer cells.

Photodynamic therapy: Using light and a chemical to kill the cancer cells.

Alcohol injection: Putting pure alcohol directly into the cancer cells to shrink them.

See page 47 for more details on relieving symptoms.

Cancer treatment

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

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

Deciding on treatment

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

Time to think: When faced with a life-threatening illness, it can be hard to decide what the right treatment is for you. It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You might want more time to think things through. But remember there is always time for you to consider what sort of treatment you want.

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

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully informed of the benefits and risks.

Individual treatment

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

Giving consent for treatment

You may be asked to sign a consent form saying that you give permission for the treatment to take place. No medical treatment can be given without your consent. Before treatment, you should know:

- The type of treatment you are advised to have
- The benefits and risks of the treatment
- Any other treatments that may be available
- Any major side-effects of the treatment

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can always ask for more time to decide about the treatment, if you are unsure when it is first explained to you.

National Cancer Helpline 1800 200 700

Oesophageal cancer and depression

Oesophageal cancer can be hard to deal with, especially if you have trouble swallowing and are losing weight. Not being able to enjoy your favourite food or drink can be upsetting. It is not unusual to get a bit depressed during treatment. If you are feeling low, do talk to your family and friends. Your doctor or nurse can also arrange for you to speak to a counsellor or psychologist, if that would help. See page 57 for more about the emotional effects of cancer.



To sum up

- The main treatments for oesophageal cancer are surgery, radiotherapy and chemotherapy.
- Surgery is the most common treatment for oesophageal cancer.
- Radiotherapy and/or chemotherapy before surgery can reduce the size of the tumour or prevent it coming back after surgery.
- Radiotherapy can help to relieve symptoms like pain or difficulty swallowing.
- Chemotherapy can control the cancer if it comes back or relieve symptoms.
- Do ask your doctor and nurse questions about your treatment.

Surgery

Surgery is the most common treatment for oesophageal cancer. It is mainly done when the tumour is found in one section of your oesophagus only. The aim of surgery is to remove all the cancer cells. The type of surgery you have will depend on:

- The type of tumour
- Where in your oesophagus it is found
- The size of the tumour
- If the cancer has spread to other parts of your body
- Your general health

Sometimes the above information may only become known during surgery. If the tumour is attached to nearby tissues and organs, radiotherapy and/or chemotherapy before surgery can shrink it and make it easier to remove.

Types of surgery

There are many types of oesophageal surgery. Your surgeon may remove the whole oesophagus or just the part that has cancer. Because the oesophagus is a long tube going from one body cavity to another, the surgery may be done in two or three stages. Your surgeon may need to make a cut (incision) or cuts in your chest, tummy (abdomen) or neck to remove the tumour.

- **Oesophagectomy:** The part of your oesophagus with cancer is removed along with lymph nodes and nearby soft tissues. The surgeon pulls up your stomach and joins it to the remaining part of your oesophagus. Or a piece of bowel may be used to join your stomach to the remaining part of your oesophagus.
- **Oesophago-gastrectomy:** If the cancer has spread to your stomach, the upper part of your stomach can be removed, as well as the affected part of your oesophagus. This is called an oesophago-gastrectomy. A piece of bowel is used to join the remaining part of your oesophagus to your small bowel.
- **Total oesophagectomy:** You may need to have your entire oesophagus removed. This is called a total oesophagectomy but is rarely done.
- **Removal of lymph glands (lymphadenectomy):** If the cancer has spread beyond the oesophagus into nearby lymph glands or organs, these may need to be removed during the surgery. This is known as a lymphadenectomy.

Smoking and drinking

Your doctor might advise you not to smoke or drink alcohol at this time. Smoking and alcohol can cause your treatment to become less effective or increase the side-effects. If you would like to give up smoking, do speak to your doctor, nurse or pharmacist.



The National Smokers' Quitline is available for advice, support and information at Callsave 1850 201 203 (Monday–Saturday 8am–10pm). Some hospitals have stop smoking clinics that can give you more advice too. Ask your doctor or nurse if there is one in your hospital.

Getting ready for surgery

Extra tests: To make sure you are fit for surgery some extra tests may be done. These might include a chest X-ray, heart test (ECG), breathing tests, and blood tests to check your liver and kidneys.

Smoking: If you are a smoker, do give up smoking as soon as possible before your operation. This will improve your breathing and reduce the risk of a chest infection after surgery.

Your diet: A dietitian will visit you and explain how best to manage eating before your surgery. He or she will also discuss what dietary changes to expect after surgery. You might have problems with swallowing, which can lead to weight loss. A good nourishing diet high in calories and protein may prevent further weight loss. It will also help you to recover quicker from the effects of surgery. Before your operation, your dietitian or doctor will advise you on ways to:

- Make swallowing easier
- Prevent further weight loss
- How to keep up your strength

>>> A dietitian will visit you and explain how best to manage eating before your surgery.

Dilatation: If needed, your oesophagus can be widened before surgery so there is more space for food and fluids to pass through. This is known as dilatation. Your doctor or dietitian will also advise you on the best consistency of food after your surgery. For example, soft or liquidised food. The improvement in swallowing does not always last and the dilatation may need to be repeated. See page 48 for more details.

Feeding tube: If swallowing becomes very difficult, you may not be able to eat enough food. As a result, you may need to be fed by a tube for a while. Your nurse will pass a thin plastic feeding tube into your nose and down into your stomach. Through this you will be fed liquid supplements high in protein and energy. Your family and friends may find it helpful to meet with the dietitian too. That way, they can learn about any changes to your diet.

Deep breathing and leg exercises: A physiotherapist will show you how to do deep breathing and leg exercises. These exercises will help to prevent a chest infection or blood clot after surgery. You will be given special elastic stockings to wear that can also prevent a blood clot in your legs. Your nurse may also give you an injection of heparin to prevent blood clots as well.

Feeling anxious: It is normal to feel anxious about the prospect of surgery. Do talk to your nurse or doctor, especially if there is something you do not understand.

Community services: If you live alone or have problems getting around at home, talk to your nurse or the medical social worker on your ward. Do this as soon as you are admitted to the ward. That way, he or she can organise any community services you may need after you leave hospital. For example, the public health nurse or home helps.

Before surgery: You cannot eat anything from the midnight before your surgery. On the morning of surgery, your nurse may give you a tablet before you go to theatre. This will make you feel more relaxed and sleepy.

Drips, drains and tubes

After your operation, you will spend about 2–5 days in an intensive care unit or high dependency unit. When you wake up, you might notice some tubes attached to your body. They might look alarming but are normal after an operation like yours. You may be put on a machine called a ventilator that helps you to breathe until the anaesthetic wears off.

- **Drip:** A drip will be put into a vein in your arm. Through this you will be given fluids until you are able to take fluids by mouth again.
- **Nasogastric tube:** A thin plastic tube may be placed in your nose leading to your stomach or small bowel. Your nurses can then draw up fluid to keep your stomach empty. This will stop you feeling sick and allow your wounds to heal more quickly.
- **Urine tube:** A thin flexible tube called a catheter may be put into your bladder to drain urine into a bag. This will save you having to get out of bed to go to the toilet. Also, your nurses can check how much fluid you are passing.
- **Chest drain:** You might have a drainage tube coming from your chest. This tube drains any fluid around your lungs into a bottle beside your bed. It is usually removed after 8–9 days.
- **Feeding tube:** You may have a small feeding tube placed directly into your small bowel. This is called a jejunostomy or J EJ tube. The tube is put in through your tummy during surgery. It can be used to give you all the calories, protein and nutrients you need until you are ready to eat and drink again.
- **Epidural:** You may have a thin tube called an epidural in your back. This is to help relieve any pain you might have.

What happens after surgery?

A team of doctors, nurses, physiotherapists and dietitians will work towards your full recovery. They will help with any problems you have after surgery, such as:

- Pain
- Nausea and vomiting
- Breathing and coughing
- Infection
- Eating and drinking
- Moving around (mobility)
- Wound

Pain: You may have some pain after surgery, especially when you cough or try to move. But you will be given painkillers to ease any pain. If you have a patient controlled analgesia pump (PCA), a nurse will show you how to use it to reduce your pain.



A PCA pump

It can help to take your painkillers before getting out of bed or before other activities. Remember to always ask for help before the pain gets too bad. If the injections do not work, let your nurse know as they can be changed. If you would like more information, call the National Cancer Helpline 1800 200 700 for a copy of the factsheet on cancer pain.

Nausea and vomiting: You might also feel sick (nausea) or vomit after surgery. Your nurses can give you medicine to prevent this, if needed.

Breathing and coughing: A physiotherapist will visit you every day for the first few days. She or he will help you with breathing and leg exercises. By doing these exercises regularly, it will help to prevent a blood clot in your legs or lungs. Even when in bed, you should move your legs and do deep breathing exercises at least once an hour. Your physiotherapist will also help you to clear any build-up of sputum and so prevent a chest infection. You will also feel more comfortable if you can breathe easily.

The physiotherapist can show you other exercises to help loosen up any shoulder stiffness due to surgery as well. You may find it helpful to take your painkillers before you start the breathing exercises. If you would like more information, call the National Cancer Helpline 1800 200 700 for a copy of the factsheet on breathlessness.

>>> After surgery, you should move your legs and do deep breathing exercises at least once an hour.

Infection: After surgery, there is a risk you may get an infection in your wound, around the chest tube or near the feeding tube. Your nurse will check your wound and the tubes twice a day. Let him or her know if any leakage happens at the wound or tube sites or if you feel hot or unwell.

Eating and drinking: For at least 9 days after surgery you cannot eat or drink in the normal way. This time will allow your wound to heal. If you need tube feeding, it usually starts the first day after your surgery and continues for as long as is needed.

Before you can start eating and drinking again, you will be sent for a special X-ray like a barium swallow. The X-ray is usually done between

7 and 10 days after surgery. If the X-ray shows that the joining between the remaining oesophagus and your stomach is healing well, you will be allowed sips of water to drink. Over the next few days the amount of fluids you can take will be increased.

Once you are managing fluids well, you can begin eating again by taking small, frequent amounts of soft foods. Your dietitian will give you plenty of advice to make sure you continue to eat well. Do eat slowly and chew your food well to help regain your confidence with swallowing. Take foods high in calories and protein with nutritional drinks/supplements that are a good source of energy. These will boost your food intake and help your recovery.

Your dietitian will also advise you if you have a feeding tube in place. Once you begin to eat and drink reasonable amounts, the tube feeding may be gradually reduced and then stopped altogether. If you cannot take enough food by mouth, the tube feeding can be continued for as long as needed. Do not worry about managing tube feeding at home as it can be done easily.

Moving around: On the day after surgery, your nurses and physiotherapists will help you get out of bed and take you for a short walk. These walks will become more frequent and longer as you feel stronger. Soon you will be able to go for walks on your own.

Wound: Your medical team will watch for signs of any food leaking from the newly joined parts of your gut. Eating well can help your wound to heal quickly.

>>> For at least 9 days after surgery you will not be able to eat or drink in the normal way.

How long will it take for me to recover?

Every patient is different so the recovery period can vary. If your wound does not heal as quickly as expected, it may delay getting back to normal eating and drinking. Most people are ready to go home 3–4 weeks after surgery. But you will feel very tired at times and plenty of rest is needed. You may feel weak and lacking in energy for at least 3 months or up to a year afterwards.

For at least 3 months, avoid strenuous activity like vacuum cleaning or lifting heavy bags of shopping. Also avoid bending over from the waist. If you need to pick up something from the floor or tie your shoes, bend from the knees and crouch down. You will not be able to drive for 6–8 weeks after surgery. Your doctor and nurse will discuss this with you.

>>> It will take at least 3 months to recover from your surgery and about a year to get back to your normal routine.

Going home

Before you go home you will be given a date to come back for a check-up. It is usually about 4–6 weeks later. You might also have to visit the hospital regularly so your wound can be checked.

Feeding tube: If you need to continue with tube feeding at home, training will be arranged for you before you go home. Your family members can also learn how best to use the tube. Your dietitian will order the tube equipment and give you and the public health nurse all the information you need.

If you no longer are being fed through the feeding tube, it is usually left in place when you go home. But it will need to be flushed through regularly to prevent blockage. Your nurse will show you how to do this. The feeding tube may be removed after your check-up if your doctor is satisfied with your weight and food intake.

Healthcare team: You will be given contact numbers so you can reach the healthcare team if you have a problem. Do contact a member of the team as soon as possible if you:

- Have a problem with the feeding tube
- Have diarrhoea for more than 24 hours or
- Feel unwell

If you have a worry or symptom that is causing you concern before your check-up date, contact your specialist nurse for advice. See page 52 for more about follow-up.

Will I be able to eat and drink normally again?

It may take a while before you get back to normal eating and drinking. It all depends on the type of surgery you have and the time it takes for your wounds to heal. Other problems that may happen due to the surgery include:

- Little or no appetite
- Feeling full and uncomfortable after eating only small amounts
- Weight loss
- Nausea and vomiting

Feeling full and uncomfortable after eating only small amounts happens because of the new position of your stomach after surgery. Your stomach is now higher up in your chest. It can also happen if part of your stomach has been removed. The above problems often last for a few months after surgery. In fact, getting better can be a slow process. But there are things you can do to help reduce these problems.



Hints & Tips – feeling full after eating small amounts

- Eat small portions – half portions at the most.
- Reduce the amount of liquids you drink at mealtimes.
- Eat frequently, about 5–6 times each day.
- Eat slowly.
- Do not lie down flat after eating.
- Take anti-sickness medication if advised by your doctor.



Dietary advice: Your dietitian will advise you on any lack of appetite and feelings of fullness or discomfort after eating. By choosing the right foods to eat and adding nutritional supplements as advised by your dietitian, you will get the most from your diet. Eating well will help your strength and energy levels to improve. Your wounds may heal faster and further weight loss may be prevented. A useful booklet called *Diet and Cancer* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Weight loss: Weight loss may continue after you are discharged from hospital unless you can make the dietary changes. Some weight loss is expected at first. But if you continue to lose weight, let your doctor or dietitian know as soon as possible. You may need more dietary advice, other nutritional supplements or tube feeding. Most likely, you will not get back to the weight you were before your illness.

Finding suitable foods: Finding a pattern of eating and drinking that suits you may take time. You may find that certain foods disagree with you and should be avoided. Remember you will gradually be able to tolerate varied and larger amounts of food.

Examples of small meals:

- Baked potato with cheese or beans
- Macaroni cheese with tomatoes
- Omelette or boiled egg

Examples of snacks:

- Yoghurt
- Mousse
- Milk pudding
- Ice cream
- Custard
- Flapjack
- Chocolate
- Biscuits with butter/cheese

See the middle section of this booklet for more ideas about helpful meals and snacks.



To sum up

- There are many types of surgery for oesophageal cancer. It will all depend on the size of the tumour and where it is found.
- After surgery, you will stay in the intensive care unit or high dependency unit for 2–5 days. You may have many drips, drains and tubes attached to you after surgery.
- Any pain you have will be controlled.
- For at least 9 days after surgery you cannot eat or drink in the normal way.
- Your dietitian will help with eating and drinking after surgery.
- If you need tube feeding, it will start the first day after your surgery.

- Your physiotherapist will help you with breathing and leg exercises.
- Most people go home 3–4 weeks after surgery.
- Some problems due to surgery include poor appetite, feeling full and uncomfortable after eating only small amounts, weight loss, and nausea and vomiting.

Radiotherapy

Radiotherapy uses high-energy X-rays to kill or shrink cancer cells. It can be used alone or with other treatments like surgery or chemotherapy. When it is given to cure cancer, it is called radical radiotherapy. When given to relieve symptoms, it is called palliative radiotherapy.

Radiotherapy can be given at different times. For example:

- **Before surgery:** Radiotherapy may be given before surgery to reduce the size of the tumour and make it easier to remove. It may also improve swallowing.
- **After surgery:** Radiotherapy can be used if there is a risk some cancer cells have been left behind after surgery or that the cancer may return. This is called adjuvant radiotherapy.
- **Relieving symptoms:** Radiotherapy can be used on its own to relieve symptoms such as pain or difficulty in swallowing.

There are two main ways to give radiotherapy. These are external beam radiation and internal radiation (brachytherapy). Sometimes, external radiotherapy is followed by brachytherapy when treating oesophageal cancer.

External beam radiation aims high-energy X-rays at the



External radiotherapy

oesophageal cancer to cure or control it. These X-rays come from a machine called a linear accelerator. The treatment does not hurt but you must lie very still during it.

Internal radiotherapy involves giving radiotherapy from within your oesophagus. Usually a source of radiation is put directly into the tumour and left in place for several minutes. It will release radiation and kill the cancer cells. It causes little or no damage to the nearby healthy tissue. Internal radiotherapy is also known as brachytherapy.

See the booklet *Understanding Radiotherapy* for more details about the types of radiotherapy and side-effects. Call the National Cancer Helpline 1800 200 700 for a free copy.

Planning your treatment

Before radiotherapy, your doctors and other specialists plan how best to give the treatment to you. They work out how to give you the right amount of radiotherapy with the least damage to normal cells. Your first visit to the radiotherapy department will prepare you for treatment only. You may be asked to lie under a machine called a simulator that takes X-rays of the area to be treated. Or you may have a CT scan for planning your treatment. Treatment planning is a very important part of radiotherapy and it may take a few visits before your treatment can go ahead.

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

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

National Cancer Helpline 1800 200 700

Getting your radiotherapy

External radiotherapy is fairly straightforward. You will be asked to come for treatment every day during the week with a rest at weekends. Your treatment can go on for 3 or several weeks. Each treatment session only lasts a few minutes. It does not hurt but you will be asked to lie still. How many sessions you need will depend on the type and size of your tumour. Your doctors will discuss this with you.

Each time you come for treatment you will go into a special room. The radiation therapist will ask you to lie or sit in a certain position under the machine. When you are ready he or she will leave the room. The machine will then be turned on and your treatment given. Even though you are on your own in the room, your radiation therapist can see you all the time through a closed-circuit camera. You can talk through an intercom to the staff if you need to.

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

Will I get any side-effects?

Radiotherapy is given directly to the site of the cancer. The areas that are most likely to be affected by treatment are your throat and chest. How severe these side-effects are will vary from person to person. It all depends on the amount of treatment you need and the exact part of the oesophagus needing treatment.

The effects of radiotherapy may be more severe if you have had surgery as well. Your doctor, nurse or radiation therapist will explain how these effects can be managed before you start treatment. The side-effects may include:

- Sore mouth and throat
- Difficulty swallowing
- Pain
- Poor appetite and weight loss
- Feeling sick (nausea)
- Voice changes
- Ongoing tiredness (fatigue)
- Hair loss in chest area

Sore mouth and throat

Radiotherapy to the oesophagus can make your throat and oesophagus

inflamed. This happens because the cells that line these areas are very sensitive to treatment. You may also develop a sore mouth if you are having both radiotherapy and chemotherapy. If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor will prescribe painkillers if you need them. If you have an infection in your mouth or throat, you may need to be treated with antibiotics or other medication.



Hints & Tips – sore mouth and throat



- Keep your teeth, gums and mouth clean to control soreness and prevent infection.
- Clean your teeth after every meal, using a soft toothbrush.
- Remove your dentures if your mouth is sore.
- Use special mouthwashes to keep your mouth clean and ease mild soreness.
- Only use mouthwashes recommended by your radiation therapist or nurse.
- Choose soft moist foods.
- Take nutritious snacks and drinks between meals, particularly if you are eating smaller portions at mealtimes.
- Avoid very hot foods and drinks, salty and spicy foods and citrus fruit drinks.
- Avoid alcohol, especially spirits, and tobacco during treatment and for a few weeks afterwards. They can irritate the lining of your mouth and throat.
- Take cold foods and drinks to soothe your mouth.

Difficulty in swallowing

After a week or two of treatment your chest might feel tight and you might have difficulty swallowing. 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 difficulty swallowing, ask to see a dietitian. He or she will give you advice on the best foods to eat. Your doctor may also give you

medication to take before meals to make swallowing easier. The discomfort will usually ease 5–8 weeks after your treatment ends. For ways to cope with difficulty in swallowing, contact the National Cancer Helpline 1800 200 700 for a copy of the free booklet, *Diet and Cancer*.

>>> Hints & Tips – difficulty in swallowing

- Eat slowly and chew your food well before you try to swallow.
- Finely chop, mince, mash or liquidise your food as needed.
- When eating, take sips of fluids between mouthfuls to help you to swallow.



Pain

Sometimes radiotherapy to the oesophagus can cause pain when swallowing or pain in your chest. If you are in pain, your doctor can prescribe painkillers. Take them regularly so that the pain can be controlled. The pain normally goes away 4–6 weeks after the treatment has ended. If you would like more information, call the National Cancer Helpline 1800 200 700 for a copy of the factsheet on cancer pain.

Poor appetite and weight loss

If the part of your oesophagus nearest your mouth is treated with radiotherapy, it can affect the taste buds in your mouth. You may get a loss of taste or a metallic taste in your mouth. If this happens, you may lose interest in food and eat less than you did before treatment. Remember eating well can speed up wound healing. Ask your nurse to refer you to a dietitian if you have a poor appetite. He or she will watch your weight and give you advice. Your appetite should improve once treatment is over. For ways to cope with poor appetite and weight loss, contact the National Cancer Helpline 1800 200 700 for a copy of the free booklet, *Diet and Cancer*.

Feeling sick (nausea)

You might also feel sick during treatment. Let your doctor know as he or she can prescribe medication to prevent or reduce nausea. Do take

this medication 30–60 minutes before your main meals or treatment for the best effect. Eat six small meals or snacks a day rather than three large meals. If you have been vomiting, drink plenty of fluids to replace the fluids you have lost. Avoid fatty, spicy, very sweet foods or foods that have a strong smell as these may make the nausea worse.

Voice changes

Sometimes radiotherapy to the oesophagus may cause the sound of your voice to change. Your voice may become quieter or sound hoarse. It may even become sore for you to talk. This common effect of treatment does not last long. The quality of your voice should start to improve about 2 to 3 weeks after treatment.

Skin changes

During radiotherapy the skin in the treated area may become red and sore. It may even look like sunburn. A cream can be used to treat this problem. Only use creams advised by your nurse or radiation therapist. If you need to wash the area, use warm water and pat it dry with a soft towel. Do not rub the skin while washing and drying. If you shave only use an electric razor. It is best to avoid all aftershaves, perfumed creams or powders. Check with your radiation therapist or nurse before putting anything on your skin.

Ongoing tiredness (fatigue)

Feeling very tired can build up over the course of your treatment. It may be due to the treatment itself or because you have to travel long distances for treatment. It can help to cut down on the things you normally do. Rest as much as you can. See page 50 for more about fatigue. You can also contact the National Cancer Helpline 1800 200 700 for a copy of the free booklet, *Coping with Fatigue*.

Hair loss in chest area

Any hair in and around the treatment area will fall out, for example chest hair. The hair loss is usually temporary. But any hair that grows back may be thinner than before treatment. For more about hair loss, contact the National Cancer Helpline 1800 200 700 for a free factsheet on hair loss.

National Cancer Helpline 1800 200 700

Brachytherapy (internal radiotherapy)

Sometimes radiotherapy for cancer of the oesophagus is given internally. This can help to slow down the growth of cancer cells. Different doses can be given but nowadays a high dose rate is given for a very short time.

Treatment: Your doctor will first spray the back of your throat with local anaesthetic. A fine tube is then placed in your oesophagus through your nose. A planning X-ray is taken next. During the treatment, a radioactive source travels through the tube, gives the treatment and then returns safely to the machine. The planning X-ray lasts about 1 hour and the treatment itself takes about 10 minutes. Once the tube is removed, you can return home. No radioactivity will be left in your body so it is safe for you to mix with family and friends. Usually, only one or two treatments are needed.

Side-effects: The treatment may cause nausea and soreness when swallowing. These may happen a few days after treatment and last for a few days. Your doctor can prescribe medication to help with swallowing and ease any nausea and soreness. You will not have any hair loss with this treatment.

More advice: You will be given information on any possible side-effects of treatment. Medication will be prescribed if needed. If you have a problem that concerns you, talk to your doctor or nurse. Most side-effects go away once treatment is over, but do let your doctor know if they continue.

For more information on radiotherapy, see the booklet *Understanding Radiotherapy*. Call the National Cancer Helpline 1800 200 700 for a free copy.



To sum up

- Radiotherapy uses high-energy X-rays to kill or shrink cancer cells.
- It can be used alone or with other treatments like surgery or chemotherapy.
- It can be given at different times, e.g. before or after surgery, or to relieve symptoms.

- There are two ways to give radiotherapy: external beam radiation and internal radiation (brachytherapy).
- External beam radiation uses radiation from a machine outside your body.
- Internal radiotherapy uses radiation from inside your body.
- Radiotherapy is always carefully planned.
- With external radiotherapy, it is given weekdays with a rest at weekends. This can go on for several weeks. Each session only takes a few minutes.
- External or internal radiotherapy to the oesophagus does not make you radioactive.
- Side-effects of radiotherapy include a sore mouth and throat, difficulty swallowing, pain, poor appetite, weight loss, feeling sick (nausea), voice changes, ongoing tiredness (fatigue) and hair loss in your chest area.

Chemotherapy

Chemotherapy is a treatment using drugs that cure or control cancer. These drugs can be used on their own or with each other. The drugs travel throughout your bloodstream to almost every part of your body. Chemotherapy can also be given with other treatments, like surgery and radiotherapy.

When is chemotherapy given?

Chemotherapy can be given at different times. This includes:

- **Before surgery or radiotherapy:** If the cancer has spread, two or three courses of chemotherapy before surgery may reduce the size of the tumour and make it easier to remove.
- **After surgery or radiotherapy:** This is given to kill any cancer cells left behind or prevent them recurring.
- **To relieve symptoms:** If cancer has spread beyond your oesophagus, chemotherapy can help to shrink and control it for a while. The aim of treatment is not to cure the cancer but to improve your symptoms and quality of life.

What drugs are used and how?

A variety of chemotherapy drugs are used to treat oesophageal cancer. They are often given in cycles. For example, you will have 4–5 days of treatment every 3 weeks with a rest period in between. The number of cycles you have will depend on your type of cancer, if you are having other treatments, and how well the cancer is responding to treatment. Some of the drugs commonly used are fluorouracil (5-FU), cisplatin, epirubicin and capecitabine (Xeloda).



The drugs may be given directly into a vein as an injection or in a drip. They may also be given in tablet form. If your treatment is given in a drip, you may need to stay overnight in hospital. But most treatments are given in day care.

>>> Most chemotherapy treatments are given in day care.

What are the side-effects of chemotherapy?

The side-effects of chemotherapy vary from person to person and depend on the drugs used. These unwanted side-effects happen because chemotherapy affects both cancer cells and normal cells. The normal cells affected are usually fast-growing cells like skin, bone marrow, hair and those lining your mouth and gut.

Most side-effects can be well controlled with medication and usually go away when treatment ends or soon after. Before treatment do ask your doctor about any possible side-effects that may happen. During treatment tell your doctor or nurse about how you are feeling, as most side-effects can be eased with medication. Side-effects may include:

NUTRITIOUS SNACKS

- ✔ Cereals – hot or cold
- ✔ Beans on toast
- ✔ Cheese and crackers
- ✔ 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
- ✔ Bolognese 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 nuts, seeds and wheat germ to your food. Add to casseroles, salads, breads, biscuits.
- Add chopped meat or fish to vegetables, salads, casseroles, soups, baked potatoes.
- Eat more beans and peas. Add to soups and casseroles.

- Infection
- Sore mouth
- Bruising
- Feeling sick or vomiting
- Numbness or pins and needles in your hands and feet
- Hair loss (alopecia)
- Ongoing tiredness (fatigue)
- Poor appetite

Infection

Chemotherapy can make you more likely to get infections. This happens because the drugs affect the bone marrow that makes white blood cells. These cells fight infection. If you do not have enough white blood cells, even minor infections such as a cold or sore throat could make you quite ill.

During treatment you will have blood tests to make sure you have enough white blood cells. If your white cell count is low, your doctor may ask you to watch out for signs of infection when at home. These signs could include feeling shivery and unwell or running a high temperature of 37.5°C or higher. If this happens, tell your hospital doctor or nurse straight away. He or she will tell you what to do. Some hospitals prefer you to ring them directly. Check this with your doctor or nurse before you start treatment. If you have a high temperature, you will need to have a blood test. Depending on the results, your doctor may prescribe antibiotics.



Hints & Tips – infection



- If you have a high temperature of 37.5°C or higher, contact the hospital.
- Avoid close contact (such as hugging or kissing) 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 any infections.
- Wash your hands often during the day, especially before you eat and after going to the toilet.

Sore mouth

Some drugs may cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside the cheeks of your mouth. Try to keep your teeth, gums and mouth very clean, as this will

reduce the risk of getting a mouth infection. Clean your teeth after every meal, using a soft toothbrush. If you have dentures remove them if your gums are sore. There are special mouthwashes that you can use too. Your nurse will advise you about these.

Bruising

The drugs can also reduce the amount of platelets in your blood for a short while. This is called thrombocytopenia. If there are not enough platelets, you may bleed or bruise more easily than usual, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily. Or if you notice tiny red spots under your skin that can look like a rash (petechiae). You may need a platelet transfusion.

Feeling sick or vomiting

You may or may not feel sick or vomit during chemotherapy. It all depends on the drugs being used. But if you do, it can happen before, during or after treatment. It may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick. This may be in injection or tablet form. While on treatment it is best to take all medication as advised by your doctor or nurse.

Numbness or pins and needles in your hands and feet

Some chemotherapy drugs can cause tingling or burning sensations in your hands and feet. You might feel some numbness as well. This means it might be difficult to pick up small objects or button up a shirt or cardigan. This side-effect usually goes away once treatment ends. But do tell your doctor if it happens, as changes may need to be made to your treatment. Contact the National Cancer Helpline 1800 200 700 for a free factsheet on peripheral neuropathy.

Hair loss (alopecia)

The drugs may also cause some hair loss. The amount of hair loss depends on the drugs you are given. Your hair might just thin out a little bit. If you do lose your hair, it will happen quite quickly. You may get a tingling sensation in your scalp a day or two beforehand. Try not to worry as your hair will grow again when treatment ends.

It is normal to feel upset at the thought of losing your hair. Talk to your nurse or social worker about your feelings. He or she will help you to find ways to cope with hair loss.

Ask your medical social worker or nurse if you can get financial assistance towards the cost of a wig. For some patients the amount of hair loss is small and a wig may not be needed. For more information, call the National Cancer Helpline for a copy of the free factsheet on hair loss.



Hints & Tips – hair loss

- Brush or comb your hair gently with a soft or baby brush.
- Use gentle hair products.
- Dry your hair by patting it with a soft towel.
- Avoid hairsprays, hair dryers, curling tongs, curlers, dyes or perms.
- Get your hair cut short before it falls out or shave your head. The weight of long hair can pull it out faster.
- If you lose your hair, you can get a wig or hairpiece or wear a hat, turban or scarf.
- Organise a hairpiece before your hair falls out. That way you will get a good match to your hair.
- Ask for the name of a wig fitter you could go to see. Talk to your local hairdresser, who may also be able to help you.
- Use a gentle moisturiser on your scalp if it becomes dry or itchy.



Ongoing tiredness (fatigue)

You may have ongoing tiredness or fatigue during treatment. This tiredness can last for some weeks after treatment has ended. Sometimes it can last for months. If you are fatigued, do take things easier. Do less than you normally would and rest more if you can. Ask your family or friends to help you at work or at home. Some gentle exercise like walking may help you to sleep better at night. Do tell your doctor about the way you are feeling as most side-effects can be eased with medication. See page 50 for more about fatigue. You can also call the National Cancer Helpline for a copy of the free booklet, *Coping with Fatigue*.

Poor appetite

It is best to eat as well as you can while on chemotherapy to keep up

your strength. Eating smaller amounts more often can help. If you do not feel like eating during treatment, ask to see a dietitian who can give you specific dietary advice. See page 47 for more about poor appetite. You can also call the National Cancer Helpline for a copy of the booklet, *Diet and Cancer*.

Other side-effects

If you are concerned about a side-effect not listed above, tell your doctor or nurse straight away. He or she will tell you what to do. For more information on chemotherapy, see the booklet *Understanding Chemotherapy*. Call the National Cancer Helpline 1800 200 700 for a free copy.



To sum up

- Chemotherapy is a treatment using drugs that cure or control cancer.
- These drugs can be used on their own or with each other.
- Chemotherapy can also be given with other treatments, like surgery and radiotherapy. It can be given before or after surgery or radiotherapy.
- It can be given to relieve symptoms such as difficulty swallowing.
- You might have 4–5 days of chemotherapy every 3 weeks with a rest period in between.
- The drugs can be given as an injection into a vein or in tablet form.
- Some common side-effects of chemotherapy are infection, sore mouth, bruising, feeling sick or vomiting, numbness or pins and needles in your hands and feet, hair loss, ongoing tiredness, poor appetite.

How is advanced oesophageal cancer treated?

Advanced cancer is when the cancer has spread to other parts of your body. Your cancer may be advanced when it is first diagnosed. Or it may have come back sometime after you were first treated.

If this happens, your doctor will discuss the best treatment option for you with the healthcare team. Your doctor may refer you to specialist palliative care doctors and nurses.

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

How can my symptoms be relieved?

Some symptoms of oesophageal cancer can be related to the cancer itself or due to treatment. For example, difficulty swallowing and fatigue. If you have any symptoms that are troubling you, let your doctor or nurse know. Sometimes radiotherapy and chemotherapy can be used to help symptoms. But there are other treatments that can help to make your life easier too.

Difficulty swallowing (dysphagia)

Difficulty swallowing can be a problem if you have oesophageal cancer. It can be caused by the tumour itself or if the oesophagus is narrowed after surgery or radiotherapy. Remember do tell your doctor or nurse straight away if you have difficulty swallowing or a poor appetite.



Hints & Tips – difficulty swallowing or poor appetite

- Ask your dietitian for advice on the best foods to eat.
- Make the most of your appetite when it is good.
- Sit upright when you are eating and for 30 minutes after your meal.
- Try having a snack or small meal every 2–3 hours.
- Use a small plate for your meals as large portions can be offputting.
- Do not fill up on drinks that have little nutritional value. This includes tea, coffee, soup or diet minerals.



- Limit fluids at mealtimes as they will only make you feel fuller.
- Take nutritious snacks and drinks between meals, particularly if you are eating smaller portions at mealtimes.
- Take small mouthfuls and chew your food well.
- Eat foods that you can swallow comfortably. Finely chop, mince, mash or liquidise your food as needed.
- Fortify your food and/or use nutritional supplements as well as your diet.

Do ask your dietitian for advice on eating. She or he can advise you on ways to fortify, sift or liquidise foods. This may include trying high protein or calorie supplements.

Sometimes, the cancer can cause the oesophagus to be permanently narrowed. If you continue to have problems with swallowing, your doctor may suggest one or more of the following treatments.

Sometimes they may need to be repeated.

Oesophageal dilatation

Oesophageal dilatation is a treatment that stretches and widens a narrowed area in your oesophagus so food and drink can pass through again. It uses an instrument called a dilator and it can be done quickly under general or local anaesthetic. Sadly, the dilatation may last only a short time and need to be repeated a few weeks or months later. A different type of dilator might be used instead. Your doctor and dietitian can advise you on the best consistency of food to take after the dilatation.

Oesophageal stent

Another way to make swallowing easier is to put a hollow tube called a stent into your oesophagus. The stent is made of plastic or wire mesh tube. It is put in under local or general anaesthetic like during an endoscopy. Once in place, it expands to keep your oesophagus open so you can swallow more easily.

Once you are awake, you can start taking fluids. Gradually you will be given small amounts of soft food to eat. Your dietitian will advise you on the type of foods you should eat. You will need to chew your food

thoroughly before swallowing so the stent does not get blocked. Foods that are soft and moist are generally the most suitable. But you may need to blend your food too. Having drinks with your food and after food can help to keep the stent clean.

Laser therapy

Some patients may be suitable for laser therapy. Here the heat from a laser beam will burn the cancer away. It will not destroy the entire tumour but will allow food to pass down to your stomach and so make swallowing easier. Laser therapy is usually done under general anaesthetic. Once you are asleep, your oesophagus may be dilated so that an endoscope can be passed through. Then a flexible tube is passed through the endoscope so the laser beam can reach the tumour. The laser beam is then turned on and most of the tumour is burned away. Another session may be needed if you have a severe blockage in your oesophagus. It can also be repeated after 4–6 weeks if needed. Your doctor will discuss this with you.

The treatment does not hurt but you might get some swelling in your oesophagus for a short while. You may also find it more difficult to swallow at first but this will pass. There may also be some discomfort in your tummy. Let your doctor know if you have any pain or discomfort.

Photodynamic therapy (PDT)

Photodynamic therapy (PDT) is a newer treatment that may help to ease swallowing. It can also be used with surgery, radiotherapy or chemotherapy. It may be suitable if you have early stage oesophageal cancer or to reduce symptoms like difficulty swallowing. It uses a beam of visible light with a light-sensitive drug to destroy the cancer cells. The light-sensitive drug is first injected into a vein to reach all the cells in your body. More cancer cells absorb the drug than normal cells. After 1–3 days, most of the drug has left the normal cells but remains in the cancer cells.

The treatment is normally done under general anaesthetic. Once you are asleep, an endoscopy is done. A flexible tube is passed through the endoscope so the laser light can reach the tumour. The laser light is then shone onto the cancer for a few minutes. This causes the drug

to interact with oxygen, which then destroys the cancer cells. PDT can be repeated if needed.

You may find swallowing more difficult at first but this will pass. The therapy will also make you very sensitive to light for a few weeks. Do not expose your skin to the sun during this time. Other temporary side-effects are chest pain, swelling of the treated area, and bleeding.

Alcohol injections

Another option is to inject pure alcohol directly into the tumour. This will shrink the tumour making it easier for you to swallow. Not everyone is suitable for this type of treatment. It may work if dilatation cannot be done or if the tumour in your oesophagus is close to your neck. Your doctor will use a special tube with a camera (endoscope) to see exactly where to inject the alcohol. It will take a few days for the cancer to shrink. The alcohol injection can be repeated if needed.

Fatigue

Fatigue is a common symptom of cancer and often described as an overwhelming tiredness. Usually it is not relieved by rest. You may find it difficult to concentrate or make decisions. The reason for the fatigue can sometimes be hard to identify. It may be caused by anxiety over a cancer diagnosis or the added stress caused by treatment. Whatever the reason, there are things you can do that may help.

A useful booklet called *Coping with Fatigue* is available. If you would like a copy, call the National Cancer Helpline 1800 200 700.



Hints & Tips – fatigue

- **Relieving symptoms:** Surgery or other types of treatment may help your fatigue by relieving symptoms like pain or difficulty swallowing. In most cases, there is medication that will make you feel better.
- **Sleeping:** If you find it hard to sleep at night due to worry, tell your doctor or nurse. You could also try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you find ways to relax.



- **Exercising:** Do some physical exercise if your illness allows you. For example, a 10-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. It may also help your fatigue.
- **Eating:** You may have lost weight due to the cancer, surgery or other treatment. It is easy when you are feeling weak and tired to lose interest in your food. Ask for help in preparing your meals. It can also help to eat small meals more often. Ask to see a social worker about getting the 'meals and wheels' service in your area.
- **Helping out:** Get others to help you around the house, with travelling to hospital, with the children or with shopping. Use the extra free time to do something you especially enjoy.

Will treatment affect my sex life and fertility?

Adjusting to a cancer diagnosis can take a while. Your emotions may be turned upside down and you don't know what to think or feel. Not surprisingly, it can be hard to relax when these things are on your mind. You may also feel tired from the effects of treatment. It is normal then to lose interest in sex.

If you have a supportive partner, you may find that talking eases your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship. Do not feel guilty or embarrassed to talk to your nurse or doctor about what is troubling you. He or she will 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 and depends on your treatment. Once you return to your usual routine, your interest in sex should return.

After surgery: It may be some weeks before you will feel well enough to have sex after surgery. It all depends on the type of surgery you have. If you have had all or most of your oesophagus removed, this may change the way you feel about your body. If you have a feeding tube in place, it may affect your body image. You may also have

concerns about the way your partner will react. Try to talk to your partner about the way you are feeling. You may be worrying needlessly and talking might help ease your anxiety.

During and after radiotherapy: Radiotherapy can sometimes cause side-effects such as pain and weight loss. You may also feel quite tired. These may affect your desire for sex. But there is no reason why you cannot have sex while on radiotherapy if you feel like it.

During and after chemotherapy: The side-effects of chemotherapy depend mainly on the type of drugs you receive. These side-effects can vary from person to person. Feeling tired from treatment can reduce your desire for sex. But there is no reason why you cannot have sex while on radiotherapy, if you wish.

Contraception

If you are having sex and still fertile, you should use a reliable method of contraception during chemotherapy and for some time after. This is because the drugs may cause a miscarriage or birth defects.

Fertility

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. Sometimes your fertility can be affected by chemotherapy and you may not be able to have a child in the future. Discuss this possible side-effect with your doctor or nurse before treatment starts. It may be possible to store sperm or eggs for future assisted reproduction at the HARI Unit at the Rotunda Hospital in Dublin. Your doctor or nurse will give you more information. If you prefer, you can contact the National Cancer Helpline 1800 200 700 for advice in confidence.

What follow-up do I need?

Once your treatment for cancer is over, you will need to come back for regular check-ups. This is known as follow-up. During these visits your doctor will examine you and might do tests, such as blood tests, X-rays

or scans. The visit also gives you a chance to talk about any eating problems or symptoms you have, especially difficulty swallowing. Your doctor may check if there is scarring of the oesophagus or where the surgeon has made the joining. You can also meet with the dietitian to discuss any eating problems you might have. If your mobility has not improved or you have trouble breathing, the physiotherapist can help you. If you are feeling a bit low or depressed, do mention this to your doctor at these visits.

At first the check-ups will be quite often. They will continue for a number of years but will become less frequent over time. If you are between check-ups or have a symptom or problem that worries you, let your doctor know without delay.



Research – what is a clinical trial?



Research into new ways of treating oesophageal cancer 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 to use.

Phases of research

There are many stages or **phases** when research is done. If a drug or treatment looks as if it 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.

National Cancer Helpline 1800 200 700

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 monitored during and after the study.

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

If you would like more information, call the National Cancer Helpline 1800 200 700 and speak to a specialist nurse.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them very helpful during their illness. In many countries the way cancer is treated depends on the culture and environment 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 most often use to treat people with cancer. These include surgery, radiotherapy, chemotherapy and biological therapy. They are tried and trusted methods where there is a long history of use. Many of the treatments have been tested in clinical trials.

Complementary therapies

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

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

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

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. Most doctors do not believe that such treatments can cure or control cancer. These therapies include special diet therapy, megavitamin therapy and herbalism. The diet therapy can often be restrictive, as it does not allow you to eat foods that could be nutritious for you. Some restrictive diets can harm your health and may even cause malnutrition.



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, it is important to 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 in Ireland, this area is not fully regulated. Ensure 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 1800 200 700.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer. Reactions can 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 and frustration
- Resentment
- Blame and guilt
- Withdrawal and isolation



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. This can often happen if your prognosis is not good. A helpful booklet that discusses them in detail is *Understanding the Emotional Effects of Cancer*. Call the National Cancer Helpline 1800 200 700 for a free copy 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 still cannot 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. 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. It is true that oesophageal cancer can be painful but it can also 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. 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. You may be afraid of dying and who will look after your loved ones. Living with all this uncertainty can make you feel anxious and fearful. You may not wish to make any plans or decisions.

Discuss your concerns with your doctor, nurse or medical social worker, who will give you advice and help. If living with uncertainty overwhelms you, it may help to talk to someone in a support group. 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 do not know enough about your illness at first, you may rely totally on the advice of your doctors and nurses. You may not feel confident to make any decisions about your treatment. When you experience a loss of control, it can lead to feelings of helplessness. You may also feel that you will be unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope. It takes a while to know what is within your control and what is outside it. Finding out as much as possible about your illness can help you regain some control. Taking an active part in making decisions about your treatment can also help you feel more in control of your illness.

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 long time, depending on how long it takes you to adjust to your illness. Tell your family and close friends that you would prefer not to talk about your illness, at least for the time being. Your doctors and nurses will also understand if you do not want to hear any information about your cancer until you are ready.

Anger and frustration

'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. It is natural to be frustrated at not being able to do the things you normally could. 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 take out your anger on those closest to you.

Indeed being unable to protect the ones you love may frustrate you a lot. But your family and friends may not always be aware that your anger or frustration is really about 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 – even jealous – 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 these feelings of resentment and to express them. Bottling up resentment helps no one. Instead everyone ends up feeling angry and guilty.

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.'

There is no doubt 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 a normal for you to need time 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 copy, call the National Cancer Helpline on 1800 200 700.

>>> Positive emotions

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



How can my family and friends help?

Families 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. Some may gather up-to-date information on cancer to know what you can expect and what you are going through. Others may prefer to help you in a practical way with travelling to and from the hospital, with childcare, cooking, shopping or housework. It may take time to know which way suits you and your friend or relative best.

>>> How to talk to someone with cancer

When someone close to you has cancer it can be hard to know what to do or say. 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 not think you are 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. Call the National Cancer Helpline 1800 200 700 for a free copy.

How can I talk to my children?

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

Every family deals with cancer in a different 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 the children 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 and 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 or the symptoms of oesophageal cancer. For example, if you have severe weight loss or difficulty swallowing, they may wonder why. Try 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, 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 you a sense of relief. Your family may also find new depths of love and inner strength that will boost your life together.

If you need some extra help in dealing with children, talk to your nurse or medical social worker. A useful booklet called *Talking to Children about Cancer: A Guide for Parents* gives practical advice for talking to children about cancer. If you would like a copy, call the National Cancer Helpline 1800 200 700. Another helpful book for children is *The Secret C: Straight Talking about Cancer*. See page 82 for more details.

Support resources

Who else can help?

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

- Medical social worker
- Cancer nurse specialists
- Psycho-oncology services
- Community welfare officer and community health services
- Support groups and cancer support centres
- Irish Cancer Society helpline nurses



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 advice on benefits, entitlements and services available when you go home.

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

Psycho-oncology services: In some larger hospitals there are special units that provide psycho-oncology services. This means that you are given 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. Sometimes patients with oesophageal cancer can find it hard to cope and may feel low or depressed.

Community health services: When you go home, there are various community health services available from your local health centre. These centres have family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. If you live far

from the hospital where you have been treated, your community welfare officer can also help with practical issues such as transport costs, financial worries, etc. All these people in community health services can provide advice and support. More information on the services is available either from the social worker in the 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 oesophageal cancer. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet. Cancer support centres and groups are found in most counties in Ireland and can offer a wide range of services. Some of these are listed at the back of this booklet.

Irish Cancer Society: The staff of the National Cancer Helpline 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 or practical advice about your financial matters, e.g. getting a mortgage or travel insurance. Call 1800 200 700 for information about any of the services outlined above or for support services in your area.

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 all public hospitals. 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 outpatients or A&E unit of a public hospital, without being referred there by a GP, you may be charged €100. There is no charge if you have a medical card or are admitted to hospital because of attending the A&E unit first.

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances. You will have to pay a prescription charge of 50c per item up to a limit of €10 per family.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can 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. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

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.

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families, including spouses and dependent children, pay a limit of €120 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. You can also register for this scheme by filling in a form at 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, Quinn Healthcare, Hibernian AVIVA Health 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, e.g. MRI scan, PET scan. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

- Illness Benefit
- Disability Allowance
- Invalidity Pension
- Carer's Allowance
- Carer's Benefit
- Carer's Leave
- Appliances
- Travel to hospital



Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social Protection,

PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 66. For this allowance, you must satisfy a means test, live in Ireland and be medically suitable. To be medically suitable, you should have an illness that has continued or may continue for at least 1 year.

You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from post offices, social welfare offices or the Disability Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Invalidity Pension

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

Your eligibility will also depend on your PRSI contributions. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a medical card and assistance under

the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

This is an allowance for carers on low incomes who look after someone who needs full-time care and attention. You must be aged 18 or over, live in Ireland, satisfy a means test, not be self-employed or work more than 15 hours a week outside the home, and not live in a hospital or nursing home. You are also allowed a free travel pass and will get extra social welfare benefits, like the household benefits package. This includes allowances for gas, electricity, telephone rental and a free television licence. You are also entitled to a respite care payment every year. For more advice, talk to your social worker and/or the Dept of Social Protection.

Application forms are available from your social welfare office or from the Carer's Allowance Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Benefit

If you are employed but wish to care for a sick relative full time, you might qualify for a carer's benefit. This is a payment made to insured persons who leave the workforce to care for someone in need of full-time care and attention. You must be employed for 8 weeks in the 26-week period immediately before applying for the benefit. You must be aged 16 or over, live in Ireland, not be self-employed or employed while caring for the person, and not live in a hospital or nursing home. More information is available from the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Leave

Under carer's leave legislation, you may be entitled to unpaid temporary leave from your employment. Carer's leave allows you to leave your employment for up to 104 weeks to care for someone in need of full-time care and attention. The leave will be unpaid, but

you will have your job kept open for you while you are on leave. You do not need to be eligible for carer's allowance or carer's benefit to apply for carer's leave. You must have worked for your employer for a continuous period of 12 months to be eligible to apply for carer's leave. The person you are caring for can be a partner or family member, friend or colleague. The family doctor (GP) of the person you are caring for will also need to fill in part of your application form.

You can work while you are on carer's leave for up to 15 hours a week. But you must make sure your income from employment or self-employment is less than a weekly income limit set by the Department of Social Protection. For more information, contact the Carer's Benefit Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Appliances

For patients who have medical cards most appliances are free of charge. For example, you are entitled to a new hairpiece or wig every 6 months.

Travel to hospital

Patients can be faced with many expenses including travelling to and from hospital. If your travel costs are very expensive, discuss it with your social worker at the hospital. Limited help may also be available from your community welfare officer. Some HSE areas provide transport services to hospitals for outpatient appointments and day centres. Sometimes the HSE may assist with transport costs for a person who has to travel a long distance to a hospital.

In general, those who do not have a medical card may be charged for the service. However, the practice varies between HSE areas and often depends on personal circumstances. Charges may be waived in certain cases, like hardship.

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

If you have queries about health and social services, contact the HSE office in your area: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

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

HSE East Coast Area
 [Co Wicklow, South East Dublin]
 Southern Cross House
 Southern Cross Business Park
 Boghall Road
 Bray
 Co Wicklow
 Tel: 01 201 4200

HSE Northern Area
 [North Dublin]
 Swords Business Campus
 Balheary Road
 Swords
 Co Dublin
 Tel: 01 813 1800

HSE South Western Area
 [Co Kildare, West Wicklow, South Dublin]
 Oak House
 Millennium Park
 Naas
 Co Kildare
 Tel: 045 880 400

HSE Midland Area
 [Counties Laois, Offaly, Longford,
 Westmeath]
 Head Office

Arden Road
 Tullamore
 Co Offaly
 Tel: 057 932 1868

HSE Mid-Western Area
 [Counties Clare, Limerick, Tipperary North]
 Head Office
 31/33 Catherine Street
 Limerick
 Tel: 061 483 286

HSE North Eastern Area
 [Counties Cavan, Monaghan, Louth and
 Meath]
 Head Office
 Navan Road
 Kells
 Co Meath
 Tel: 046 928 0500

HSE North Western Area
 [Counties Donegal, Sligo, Leitrim and West
 Cavan]
 Head Office
 Manorhamilton
 Co Leitrim
 Tel: 071 982 0400 / 1850 636 313

HSE South Eastern Area
 [Counties Carlow, Kilkenny, Wexford,
 Waterford, South Tipperary]
 Head Office
 Lacken
 Dublin Road
 Kilkenny
 Tel: 056 778 4100

HSE Southern Area
 [Counties Cork and Kerry]
 Head Office
 Wilton Road
 Cork
 Tel: 021 454 5011

HSE Western Area
 [Counties Galway, Mayo and Roscommon]
 Head Office
 Merlin Park Regional Hospital
 Galway
 Tel: 091 751 131

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

Citizens Information Board (formerly Comhairle)
 Ground Floor, George's Quay House, 43 Townsend Street, Dublin 2
 Tel: 01 605 9000; Locall 1800 777 121
 Email: info@ciboard.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 as well as your normal outgoings, such as medication, travel, food, heating, laundry, clothing and childcare costs. If you are not able to work or unemployed, this may cause even more stress. It may be hard for you to recover from cancer if you are worried about providing for your family and keeping a roof over your head.



There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 76 for more details. You can also call the National Cancer Helpline 1800 200 700 for 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 1890 283 438. 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. See page 78 for contact details.

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)
- Cancer support groups
- Peer-to-peer support
- Counselling
- Night nursing
- Oncology liaison nurses
- Financial aid
- Cancer information booklets



Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services. The **National Cancer Helpline** 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 1800 200 700 runs Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

- All queries or concerns about cancer can be emailed to the CIS at **helpline@irishcancer.ie**
- The **walk-in caller service** allows anyone with concerns about cancer to freely visit the Society to discuss them in private.
- **Message Board** is a bulletin board on our website (**www.irishcancer.ie**) that gives you the chance to post your comments.
- The **CancerChat** service is a live chatroom with a link to a Cancer Information Service nurse.

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 78 for more details.

Peer-to-peer support

Many patients find it helpful to talk to someone who has had a diagnosis of cancer and who has recovered. The Irish Cancer Society can put you in touch with someone who has been trained to provide emotional and practical support for you, the cancer patient. All volunteers have had a personal experience of cancer and understand the emotional and physical impact of the disease. If you would like to make contact with a volunteer, please call the National Cancer Helpline 1800 200 700.

Counselling

Coping with a diagnosis of cancer can be very stressful at times. Patients and their families sometimes find it difficult to come to terms with the illness. Many people also feel that they cannot talk to a close friend or relative. In this case, counselling can provide 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 Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to patients seriously ill at home and give support for their families. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse. Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. ICS night nurses provide care to the patient and support to families in their own home.

Oncology liaison nurses

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

Financial aid

A diagnosis of cancer can bring with it the added burden of financial worries. In certain circumstances, the Irish Cancer Society can provide limited financial help to patients in need. You may be suitable for schemes such as Travel2Care or Financial Aid. If you would like to request this kind of help, contact your oncology or medical social worker at the hospital where you have been treated. He/she should fill in an application form and return it the Irish Cancer Society. If there is no social worker available, another health professional involved in your care may apply on your behalf.

Cancer information booklets

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



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



Useful organisations

Irish Cancer Society

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

Cancer Research Ireland

Website: www.cancer.ie/research/why.php

The Carers Association

Market Square
Tullamore
Co Offaly
Tel: 057 932 2933
Email: info@carersireland.com Website:
www.carersireland.com

Citizens Information Board (formerly Comhairle)

Ground Floor
George's Quay House
43 Townsend Street
Dublin 2
Citizen Information Service:
1890 777 121
Tel: 01 605 9000
Email: info@ciboard.ie
Website: www.citizensinformation.ie

Dept of Social Protection – Information Service

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

HARI Unit (Human Assisted Reproduction Ireland)

Rotunda Hospital
Parnell Square
Dublin 1
Tel: 01 807 2732
Website: www.rotunda.ie

Health Promotion HSE

Website: www.healthpromotion.ie

Irish Clinical 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

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Freefone 1890 283 438
Email: helpline@mabs.ie
Website: www.mabs.ie

National Treatment Purchase Fund

Tel: 1890 720 820
Website: www.ntpf.ie

Oesophageal Cancer Fund

Website: www.lollipopday.com/

Health insurers**Hibernian AVIVA Health**

(formerly VIVAS Health)
One Park Place
Hatch Street
Dublin 2
Tel: 1850 717 717
Email: info@hibernianavivahealth.ie
Websites: www.hibernianavivahealth.ie

Quinn Healthcare (formerly BUPA)

Mill Island
Fermoy
Co Cork
Locall: 1890 700 890
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Voluntary Health Insurance (VHI)

VHI House
Lower Abbey Street
Dublin 1
Tel: 01 872 4499
CallSave 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support groups**Bowel Cancer Support Group**

Irish Cancer Society
43/45 Northumberland Road

Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

CanTeen Ireland

Young Peoples' Cancer Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel: 01 872 2012
Email: canteen@oceanfree.net
Website: www.canteen.net

Lymphoma Support Ireland

Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: info@lymphoma.ie
Website: www.lymphoma.ie

Men Against Cancer (MAC)

c/o Irish Cancer Society
43/45 Northumberland Road
Dublin 4
Freefone 1800 200 700
Email: support@irishcancer.ie
Website: www.cancer.ie

Reach to Recovery

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

Support groups & support centres**ARC Cancer Support Centre**

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

ARC Cancer Support Centre

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

Beacon Cancer Support Centre

Suite 15
Beacon Court
Sandyford
Dublin 18
Tel: 01 213 5654

Bray Cancer Support & Information Centre

36B Main Street
Bray
Co Wicklow
Tel: 01 286 6966
Email: bcsc@iol.ie
Website: www.braycancersupport.ie

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485 163
Website: www.midwesterncancercentre.ie

Cancer Support Centre

St Vincent's University Hospital
Elm Park
Dublin 4
Tel: 01 221 4000
Email: cancersupport@svuh.ie
Website: www.stvincents.ie

CARE – South Tipperary Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 82667
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: karen@corkcancersupport.ie
Website: www.corkcancersupport.ie

Cuisle Centre

Cancer Support Group
Block Road
Portlaoise
Co Laois
Tel: 057 868 1492
Email: cuislecentre@eircom.net

Dóchas – Offaly Cancer Support

Teach Dóchas
Offaly Street
Tullamore
Co Offaly
Tel: 057 932 8268
Email: dochasoffaly@hotmail.com
Website: www.dochasoffaly.ie

Dundalk Cancer Support Group

Community Office
Dundalk Partnership Court
Park Street
Dundalk
Co Louth
Tel: 042 933 0288
Website: www.dconroy@actioncancer.org

Éist – Carlow Cancer Support Group

Tel: 087 767 3240 /
086 316 3838 / 085 144 0510

Éist – East Inishowen Cancer Support Group

Moville
Co Donegal
Tel: 074 938 2874

Gary Kelly Support Centre

Georges Street
Drogheda
Co Louth
Tel: 041 980 5100
Email: services@gkcancersupport.com
Website: www.gkcancersupport.com

Gary Kelly Support Centre

Monaghan
Tel: 086 195 9864

Greystones Cancer Support

La Touche Place
Greystones
Co Wicklow
Tel: 01 287 1601
Email:
greystonescancersupport@eircom.net

HOPE

Enniscorthy Cancer Support &
Information Centre
22 Upper Weafer Street
Enniscorthy
Co Wexford
Tel: 053 923 8555
Email: mary@hopesupportcentre.ie

Inis Aoihbhinn – Cancer Care West

Costello Road
University College Hospital Galway
Tel: 091 545 000
Email: info@cancercarewest.ie
Website: www.cancercarewest.ie

Kerry Cancer Support Group

Kerry Lee
Oakpark Road
Tralee
Co Kerry
Tel: 087 230 8734
Email: kerrycancersupport@live.ie

LARCC Retreat Centre

Ballinalack
Mullingar
Co Westmeath
Tel: 044 937 1971
Callsave 1850 719 719
Email: info@larcc.ie
Website: www.larcc.ie

Listowel Cancer Support Group

Bedford
Listowel
Co Kerry
Tel: 068 21741 / 087 237 0766

Little Way Cancer Support Centre

4 Woods Way
College Road

Clane
Co Kildare
Tel: 045 902 996
Email: littlewayclane@eircom.net
Website: www.littlewaycancersupport.com

Little Way Cancer Support Centre

8 Stanhope Street
Athy
Co Kildare
Tel: 059 863 3725

Living Beyond Cancer

c/o Oncology Department
Letterkenny General Hospital
Letterkenny
Co Donegal
Tel: 074 912 5888 (Bleep 674)

Mayo Cancer Support Association

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

Roscommon Cancer Support Group

Vita House Family Centre
Abbey Street
Roscommon
Tel: 090 662 5898
Email: vitahouse@eircom.net

Sligo Cancer Support Centre

2A Wine Street
Sligo
Tel: 071 967 0399
Email: scsc@eircom.net
Website: www.sligocancersupport.ie

'Solás' – Donegal Cancer Support Centre

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

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Email: infosecf@eircom.net

Suimhneas Cancer Support

Pastoral Centre
Church Road
Nenagh
Co Tipperary
Tel: 067 37403

Tallaght Cancer Support Group

Tel: 087 217 6486

Tuam Cancer Care Centre

Dunmore Road
Tuam
Co Galway
Tel: 093 28522
Email: tccg@eircom.net
Website: www.tuamcancercare.ie

West Clare Cancer Support Group

Tel: 065 905 6327 / 065 905 1517
Tel: 086 357 9055
Email: hlnkennedy@hotmail.com

Wicklow Cancer Support

1 Morton's Lane
Wicklow
Tel: 087 691 4657 / 0404 32696

**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

Barrett's Oesophagus Campaign (UK)

UCL, Division of Surgery and Interventional
Science
Royal Free and University College
Medical School
Rowland Hill Street
London NW3 2PF
Tel: 0044 020 7472 6223
Email: info@barrettscampaign.org.uk
Website: www.barrettscampaign.org.uk

Cancer Network Buddies

www.cancerbuddiesnetwork.org

Cancer Research UK

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

Healthtalkonline

www.healthtalkonline.org

Macmillan Cancer Support (UK)

89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

Belfast City Hospital Trust
79–83 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Email: cancer.info@bch.n-i.nhs.uk
Website: www.actioncancer.org

Mayo Clinic (US)

Website: www.mayoclinic.com

**Memorial Sloan-Kettering Cancer Center
(US)**

Website: www.mskcc.org

National Cancer Institute (US)

Website: www.nci.nih.gov

Oesophageal Patients Association (UK)

22 Vulcan House
Vulcan Road
Solihull, West Midlands B91 2JY
Tel: 0044 0121 704 9860
Email: enquiries@opa.org.uk
Website: www.opa.org.uk/

**Royal Marsden Hospital Foundation NHS
Trust**

Website: www.royalmarsden.org

Ulster Cancer Foundation

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

Helpful books

Free booklets from the Irish Cancer Society:

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



Cancer at Your Fingertips

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1-85959-036-5

Cancer Positive: The Role of the Mind in Tackling Cancers

Dr James Colthurst
Michael O'Mara Books Ltd, 2003
ISBN 1-85479-860-X

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Dr Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1-85959-068-3

Taking Control of Cancer

Beverley van der Molen
Class Publishing, 2003
ISBN 1-85959-091-8

44½ Choices You Can Make If You Have Cancer

Sheila Dainow, Jo Wright & Vicki Golding
Newleaf, 2001
ISBN 0-71713-222-6

What You Really Need to Know about Cancer

Dr Robert Buckman
Pan, 1997
ISBN 0-33033-628-2

Helpful DVDs

Radiation Therapy: A Patient Pathway

Contact the National Cancer Helpline
1800 200 700 for a copy.

The Patient Journey

A DVD about oesophageal cancer from the Medical Illustration Unit of St James's Hospital, Dublin 8. View on www.lollipopday.com or YouTube.

Explaining cancer to children

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1-85390-891-6

The Secret C: Straight Talking about Cancer

Julie A Stokes
Winston's Wish, 2000
ISBN 0-33033-628-2

Questions to ask your doctor

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

- How is cancer of the oesophagus diagnosed?
- Will I have to stay in hospital for the tests?
- How long will I have to wait for the test results?
- What are my treatment choices?
- How successful is this treatment for my cancer?
- What are the expected benefits of treatment?
- What possible side-effects or after-effects will I have?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- How long will it take for me to get over the effects of treatment?
- Should I eat special foods?
- Are there ways to help me swallow easier?

Your own questions

1

Answer

2

Answer

3

Answer

4

Answer

5

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:

Aoife McNamara, Cancer Information Nurse

Eva Copeland, Clinical Nutritionist

Ann Murphy, Clinical Nurse Specialist

Staff at the Brachytherapy Unit, St Luke's Hospital

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 phone the National Cancer Helpline 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. Please fill in the postcard in the pocket inside the back cover, and post it back to us for free.

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 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. 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

The mission of the Irish Cancer Society is to play a vital role in achieving world-class cancer services in Ireland, to ensure fewer people get cancer and those that do have better outcomes. Our goals are focused around prevention, survival and quality of life, with three programme areas to achieve them: advocacy, cancer services and research.

