

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:
Medical social worker	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 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.

OESOPHAGEAL CANCER ADVISERS

Chris Collins, Consultant General and Upper Gastrointestinal Surgery
Dr John Kennedy, Consultant Medical Oncologist
Prof Donal Hollywood, Consultant Radiation Oncologist
Prof John Reynolds, Consultant Surgeon
Aisling McHugh, Clinical Specialist Dietitian
Catherine Corrigan, Senior Clinical Nutritionist

CONTRIBUTOR

Fionnuala Creighton, Daffodil Centre Nurse

EDITOR

Sarah Lane

ILLUSTRATOR

Michael H. Phillips

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.
- *Oesophageal Cancer: ESMO Clinical Recommendations for Diagnosis, Treatment and Follow-up*, M Stahl & J Oliveira. European Society for Medical Oncology, *Annals of Oncology* 20 (Suppl 4): iv32–iv33, 2009.
- *Cancer Nursing: Principles and Practice*, CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 1997.

First published by the Irish Cancer Society in 2004.

© Irish Cancer Society, 2004, revised 2006, revised 2010, 2015

Next revision: 2017

Product or brand names that appear in this book are for example only. The Irish Cancer Society does not endorse any specific product or brand.

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, electronic or mechanical, including photocopying, recording or any information storage and retrieval system, without permission in writing from the Irish Cancer Society.

ISBN 0953236901

Contents

4 Introduction

About oesophageal cancer

- 5 What is cancer?
- 6 What is the oesophagus?
- 7 What is oesophageal cancer?
- 7 What are the types of oesophageal cancer?
- 8 What causes oesophageal cancer?
- 10 What are the symptoms of oesophageal cancer?
- 11 How is oesophageal cancer diagnosed?
- 15 How is oesophageal cancer staged?

Treatment and side-effects

- 17 How is oesophageal cancer treated?
- 20 Surgery
- 30 Radiotherapy
- 37 Chemotherapy
- 42 How is advanced oesophageal cancer treated?
- 43 How can my symptoms be relieved?
- 47 Will treatment affect my sex life and fertility?
- 48 What follow-up do I need?
- 49 Research – what is a clinical trial?
- 50 Cancer and complementary therapies

Coping and emotions

- 53 How can I cope with my feelings?
- 58 How can my family and friends help?
- 59 How can I talk to my children?

Support resources

- 61 Who else can help?
- 62 Health cover
- 67 Irish Cancer Society services
- 69 Useful organisations
- 76 Helpful books
- 77 What does that word mean?
- 79 Questions to ask your doctor

Introduction

This booklet has been written to help you understand more about cancer of the oesophagus (gullet). It is also known as oesophageal cancer. It is divided into four parts:

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

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

>>> Reading this booklet

Remember that 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 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 our Cancer Nurseline on 1800 200 700. It is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also visit a Daffodil Centre. See page 67 for more about Daffodil Centres.



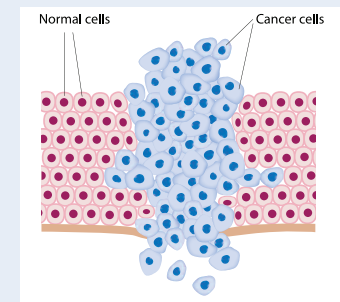
Cancer Nurseline Freephone 1800 200 700

About oesophageal cancer

>>> What is cancer?

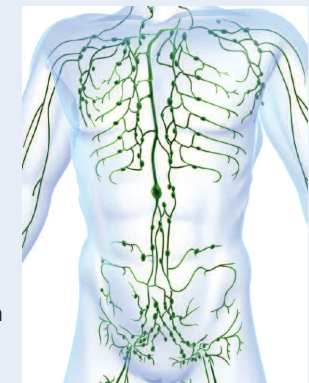
Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells,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

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



What is the lymphatic system?

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





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 to form a tumour somewhere else in the body. This is called a metastasis or secondary tumour.

What is the oesophagus?

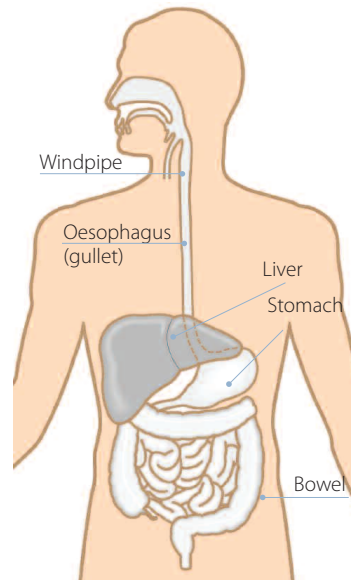
The oesophagus is part of your digestive system. Most people know it as the gullet or food pipe. It is a long muscular tube that links your throat to your stomach. In adults it is about 25–30 cm long and runs behind your windpipe (trachea).

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 below for more details on the types.

How common is oesophageal cancer?

In general oesophageal cancer is not common in Ireland. Around 380 people are diagnosed with it each year. More men than women get the disease.

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.

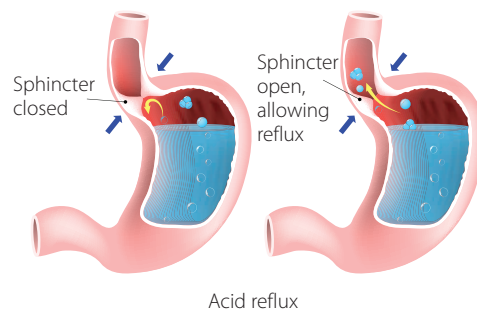
- **Squamous cell cancer:** Squamous cells are skin-like cells that line your oesophagus. They are found mainly in the upper and middle of your oesophagus. This type of oesophageal cancer is usually due to smoking and alcohol.

- **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 (see below).
- **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)

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:** Drinking a lot of alcohol over many years increases your risk of oesophageal cancer. Drinking spirits in particular increases your risk. If you both smoke and drink, your risk 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).



- **Barrett's oesophagus:** Over time, the inflamed cells due to acid reflux 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.

»»» 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.

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 have Barrett's oesophagus or achalasia, you will have routine check-ups.

Cancer Nurseline Freephone 1800 200 700



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 380 people are diagnosed with it each year.
- The main types of oesophageal cancer are squamous cell cancer and adenocarcinoma.
- 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

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.

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.

Before the test: You must fast (not eat) for around 6 hours before the test. Do ask your doctor and nurse any questions you might have.

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. 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 after the test. This is because your throat will be numb from the anaesthetic. You may also feel drowsy and sleepy. Or you may not remember much about having the test, if you were sedated. 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.

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 how big the cancer is and 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 a few hours beforehand. You may be given a special drink or injection 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 12). 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 scan uses magnetic energy to build up a picture of the tissues inside your body. It does not hurt but can be very noisy. 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 don't need to stay in hospital 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 can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to speak to one of our cancer 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. Knowing the stage of the cancer helps your doctors to decide the best treatment for you.

The staging system normally used in cancer of the oesophagus is called TNM. This stands for tumour, node, metastasis. It refers to the size of the tumour (T), if there is cancer in your lymph nodes (N), and if the cancer has spread to other parts of your body (M for metastasis). Your doctor uses this information to give your cancer a stage – from 0 to 4. In general, the lower the number, the less the cancer has spread.

The stages can be hard to understand so do ask your doctor or nurse if you would like them explained in more detail.

- **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. Cancer in another part of your body is called secondary or metastatic oesophageal cancer.



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.
- Staging 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.

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 20 for more details about surgery.

Radiotherapy: Radiotherapy is often used to reduce the size of a tumour. It is used to relieve symptoms like pain and difficulty swallowing. Sometimes it is used to shrink the tumour so a surgeon can remove the tumour. It can be used on its own or with chemotherapy. It is also used sometimes after surgery to prevent cancer coming back.

Chemotherapy: Chemotherapy may be used alone or with radiotherapy before or after surgery. It can help to 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 37 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. The most common treatment is stenting.

Stenting: This means a tube called a stent is put into your oesophagus to keep it open.

Other treatments include:

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 cancer cells.

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

See page 43 for more details on relieving symptoms.

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

Deciding on treatment

Multidisciplinary team meeting: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. For example, surgeons, oncologist, radiation oncologist, pathologist, radiology consultant. They will meet to discuss your test results and decide your treatment plan.

Asking questions: Ask your doctor and nurse as many questions as you like, no matter how small or trivial you think they are. You can use the fill-in page at the back of this booklet to write down your questions and the answers you receive. If you forget to ask a question or would like more explanations, call our Cancer Nurseline on 1800 200 700 and talk to one of our cancer nurses.

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

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

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 understand 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

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

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

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

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 53 for more about coping with your feelings.



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.
- Ask your doctor and nurse if you have any 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 your general health and 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

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 can be done in different ways. Your surgeon may need to make a cut (incision) or cuts in your chest, tummy (abdomen) or neck to remove the tumour, depending on where it is.

- **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 may be 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 it is rarely done.
- **Removal of lymph glands (lymphadenectomy):** During the surgery your surgeon will take out some of the lymph nodes from around your oesophagus. This is called lymphadenectomy. If the lymph nodes contain cancer, removing them can help to stop it spreading. The lymph nodes removed will be looked at under a microscope to give your doctor more information about the stage of your cancer.

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.

How can I stop smoking?

Like many others, you may find giving up smoking hard. If you would like advice or support on quitting, call the HSE Quit Team on CallSave 1800 201 203 or Freetext QUIT to 50100. The Quitline is open Monday to Friday 10am to 7pm and Saturday 10am to 1pm. If you would like further personal support locally, the Quitline can put you in touch with the smoking cessation officer in your area. For more information on giving up smoking, see www.quit.ie



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

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
- Keep up your strength

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

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 43 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.

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 for a few hours before your surgery. Your doctor or nurse will tell you when you should have

your last meal. On the day 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. You may be put on a machine called a ventilator that helps you to breathe until the anaesthetic wears off. 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.

- **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.
- **Drains:** One or more thin tubes called drains will be attached to you near your wound. These help to drain blood and fluid from the operation site to let your wound heal.
- **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 JEJ 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 most patients are very comfortable with the epidural pain relief. If needed, you will be given painkillers to ease any pain. You may have a patient controlled analgesia pump (PCA). This sends pain medication into your blood when you press a button. A nurse will show you how to use it to reduce your pain. 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 your medicine isn't controlling your pain tell your doctor or nurse.



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 fluids (sputum) in your chest to help to prevent an infection. You will also feel more comfortable if you can breathe easily. If you are in pain you may not feel able to do your breathing or leg exercises, so let your nurse or doctor know if you need medication to help with pain.

The physiotherapist can also show you other exercises to help loosen up any shoulder stiffness due to surgery.

»»» 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 may 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.

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

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 leak from the newly joined parts of your gut. Eating well can help your wound to heal quickly.

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 you getting back to normal eating and drinking. Most people are ready to go home 10–14 days after surgery. But you will feel very tired at times and will need plenty of rest. 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.

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.

Even if you are no longer being fed through the feeding tube, the tube may be left in place when you go home. It will need to be flushed through regularly to prevent blockage. Your nurse will show you how to do this. The feeding tube will 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
- Are worried about your wound

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 48 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. Getting better can be a slow process. But there are things you can do to help reduce these problems.

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 our Cancer Nurseline on 1800 200 700 or call into a Daffodil Centre for a free copy. You can also download it at www.cancer.ie



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.

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 eat more varied and larger amounts of food.

See the middle section of this booklet for 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 10–14 days 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.

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. Treatment given before surgery is called neo-adjuvant treatment. Often chemotherapy is given with radiotherapy before surgery. This is called chemoradiation.
- **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 radiotherapy

External beam radiation aims high-energy X-rays at the 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it from www.cancer.ie

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 planning CT scan as part of your treatment planning. 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.

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 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
- Feeling very tired (fatigue)
- Hair loss in chest area

Cancer Nurseline Freephone 1800 200 700

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, call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of the free booklet, *Diet and Cancer* or download it at www.cancer.ie



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.

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 our Cancer Nurseline on 1800 200 700 for a copy of the free booklet, *Diet and Cancer*. You can also pick one up at a Daffodil Centre or download it at www.cancer.ie

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. Eat six small meals or snacks a day rather

than three large meals. Avoid fatty, spicy, very sweet foods or foods that have a strong smell as these may make the nausea worse. If you have been vomiting, drink plenty of fluids to replace the fluids you have lost.

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.

Feeling very tired (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. See page 46 for more about 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 information on radiotherapy and for free booklets and factsheets on radiotherapy and its side effects call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.



Brachytherapy (internal radiotherapy)

Sometimes radiotherapy for cancer of the oesophagus is given by putting a radioactive source inside your body for a few minutes. This can help to slow down the growth of cancer cells. Different doses can be given but often 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 you have any side-effect that is troubling you.



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 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.
- External radiotherapy 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 is often given with radiotherapy, usually before surgery or if surgery isn't possible. This is called chemoradiation.

When is chemotherapy given?

Chemotherapy can be given at different times. This includes:

- **Before surgery:** 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. You may have both chemotherapy and radiotherapy before surgery.
- **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.

Cancer Nurseline Freephone 1800 200 700

How is chemotherapy given?

A variety of chemotherapy drugs are used to treat oesophageal cancer. They are often given in cycles. For example, you might 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.

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, so that they can help with any side-effects. Side-effects may include:

- Infection
- Sore mouth
- Bruising
- Feeling sick (nausea)
- Numbness or pins and needles in your hands and feet
- Hair loss (alopecia)
- Feeling very tired (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 (99.5°F) 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 (99.5°F) 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: Chemotherapy 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 (nausea) or being sick (vomiting): You may or may not feel sick or vomit during chemotherapy. It depends on the drugs being used. Sickness can happen 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.

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 our Cancer Nurseline on 1800 200 700, drop into a Daffodil Centre or visit www.cancer.ie

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
- 👉 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 lemonade drinks
- 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.



>>> 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): It is normal to feel very tired (fatigued) during treatment. This tiredness can last for some weeks after treatment has ended or it may go on even longer,

Tell your doctor or nurse if tiredness becomes a problem for you. They can offer advice on ways to save your energy and cope with everyday activities. More information on how to deal with fatigue is available in a booklet called *Coping with Fatigue*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. See page 46 for more about 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 45 for more about poor appetite.

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre for a free copy. You can also download it at www.cancer.ie



To sum up

- Chemotherapy is a treatment using drugs that cure or control cancer.
- Chemotherapy can be given with other treatments. It is often given with radiotherapy before surgery, or when surgery is not possible. This is called chemoradiation.
- It can be given to relieve symptoms such as difficulty swallowing.
- 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.

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. 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. 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 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 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.



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 and 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.

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it at www.cancer.ie

>>> Hints & Tips – fatigue

- **Relieving symptoms:** For many patients, treatment can relieve symptoms such as pain and nausea. This can also help fatigue and get you back to your normal routine. Ask your doctor before you start treatment what side-effects you can expect.
- **Rest and sleep:** Get as much rest as possible. If you are feeling very worried and find it hard to sleep at night, ask your doctor or nurse for advice.
- **Counselling:** If anxiety is a problem, talk to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.
- **Exercising:** Exercise can boost your energy levels. 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.
- **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.
- **Get help:** Get others to help you around the house, with travelling to hospital, with the children or with shopping.
- **Enjoyment:** Save your energy for doing the things you most enjoy. If you are going somewhere special, have a rest before you go out.

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. 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.

You may find that talking to your partner 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 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 you are having chemotherapy, if you wish.

Contraception

If you are having sex and are still fertile, ask your doctor about contraception. 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. If this is the case, do talk to your partner about your feelings. Also, discuss your worries about infertility with your doctor. He or she can tell you if there are any options open to you at this time.

It may be possible to store sperm or eggs for future assisted reproduction at Rotunda IVF at the Rotunda Hospital in Dublin. Your doctor or nurse will give you more information.

What follow-up do I need?

Once your treatment for cancer is over, you will need to go 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.



Research – what is a clinical trial?



Research into better 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. 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.

Taking part in clinical trials

Your doctor may ask you to try a new way of treating your cancer as part of a trial. Not everyone is suitable to take part in a clinical trial. Some trials want a particular type of person. For example, someone with advanced cancer, a female or someone who has had a particular type of treatment in the past.

Your doctor may refer you to another hospital if he or she feels a clinical trial there may help you. Before a drug or treatment is used on patients, it goes through many phases of research to make sure it is safe to use. 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 the trial 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. If you change your mind at any time you can stop taking part in the trial and will go back to having the standard treatment. 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. For more information, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or see www.cancer.ie for our factsheet, *Cancer and Clinical Trials*.

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard (conventional) medical treatment. For example, yoga or massage. Some people find them very helpful during their illness. The way cancer is treated often depends on the culture of the country in which you live. In Ireland conventional 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.

Alternative therapies

Alternative therapies are generally treatments that are used **instead of** conventional treatments. These therapies include diet therapy, megavitamin therapy and herbalism. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. For example, some diet therapies restrict the types of food you can eat. This can mean you may not get the calories or nutrients that you need. Always talk to your doctor if you are considering an alternative to conventional treatment.



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



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, 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 our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or see our website www.cancer.ie



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. 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 it may not be until you recover from your illness that your emotions hit hard.

Common reactions include:

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

Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. A helpful booklet that discusses them in detail is *Understanding the Emotional Effects of Cancer*. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre a free copy or to talk to a cancer nurse in confidence. You can also email the nurses at cancernurseline@irishcancer.ie

Shock and disbelief

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

Shock is often the first reaction to a cancer diagnosis. In fact, you may feel numb and the situation may seem unreal. Many people think cancer will never happen to them and are 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 many people are cured of cancer or live with it for a long time. Another great fear about cancer is pain. However, some cancers cause no physical pain at all or else can be controlled with good painkillers.

You may also have fears that your experience of cancer will change who you are or that people will reject or avoid you. 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, or to someone who has been through a cancer diagnosis, such as a trained Survivor Support volunteer (see page 67). 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 and taking an active part in making decisions about your treatment may help you feel more in control.

Sorrow and sadness

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

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

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.

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 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it at www.cancer.ie

>>> 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 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. Not talking to your friend or loved one 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.

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

How can I talk to my children?

A cancer diagnosis can affect an entire family. It can bring changes that may be either great or small. Even so, it is best to keep family life as normal as possible. Continue with school and other activities, with birthdays and celebrations or work commitments. It may take a while but families can learn to adjust to 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. If you try to protect them by saying nothing, they may feel isolated or even more worried.

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download the booklet at www.cancer.ie. See page 76 for other helpful books.

Support resources

Who else can help?

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

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

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

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

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

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

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

services is available either from the medical social worker in your hospital before you go home or at your local health centre.

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

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

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

Health cover

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

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

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

Hospital cover

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

Outpatient cover

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

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

Medical card

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

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

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

GP visit card

If you do not qualify for a full medical card, you may be eligible for a GP visit card. This card covers visits to your doctor only and you will have to pay for drugs, outpatient/inpatient charges and medical appliances yourself. It is means tested but will take into account your after-tax income and certain expenses like childcare, rent/mortgage and travel to work. Check with the medical social worker at the hospital or

your HSE office to see if you are eligible. If you wish to apply for a GP visit card, you can download an application form and apply online (www.medicalcard.ie) or at your local health centre. LoCall 1890 252 919.

Drugs Payment Scheme

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

Private healthcare cover

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

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

Benefits and allowances

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

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



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

Appliances

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

Travel to hospital

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

See pages 67 and 68 for information on the Travel2Care and the Volunteer Driving Service run by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

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

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

For social welfare queries, contact:

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

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

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

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

Citizens Information

Tel: 0761 07 4000 **Email:** information@citizensinformation.ie

Website: www.citizensinformation.ie



If you have financial worries...



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

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 67 for more details. You can also call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 69 for more contact details. A useful book for preparing low-budget, nutritious meals is *101+ Square Meals*. See page 76 for more information.

Irish Cancer Society services

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

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

- **Our Cancer Nurseline Freephone 1800 200 700.** Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday to Thursday 9am - 6pm and Friday 9am - 5pm. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at **www.cancer.ie**
- **Our Daffodil Centres.** Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- **Our Survivor Support.** Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.
- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling.
- **Patient travel and financial support.** We provide practical and financial support for patients in need, undergoing cancer treatments. There are three services available through the Society:
 - **Travel2Care** is a fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence.

- Through our **Financial Support** programme, limited, once off financial support is available to patients identified as being in need, who are undergoing cancer treatments nationally.
- **Irish Cancer Society Volunteer Driving Service** is mainly for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments.

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

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

- **Our publications and website information.**

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



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

Useful organisations

Irish Cancer Society

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

The Carers Association

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

Citizens Information

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

Get Ireland Active: Promoting Physical Activity in Ireland

Website: www.getirelandactive.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All Ireland Co-operative Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

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

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 01 812 9350
Helpline 0761 07 2000
Email: helpline@mabs.ie
Website: www.mabs.ie

Rotunda IVF

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

Health insurers

AVIVA Health

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

GloHealth

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

Laya Healthcare

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

Voluntary Health Insurance (VHI)

IDA Business Park, Purcellsinch
Dublin Road
Kilkenny
CallSave: 1850 44 44 44
Email: info@vhi.ie
Website: www.vhi.ie

National support services**Survivor Support**

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

ARC Cancer Support Centres Dublin

[See page 71]

Brain Tumour Support Group

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

Canteen Ireland

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

Cancer Support Sanctuary LARCC

[See page 71]

Connaught support services**Athenry Cancer Care**

Social Service Centre, New Line
Athenry
Co Galway
Tel: 091 845 228 / 087 412 8080
Email: athenrycancer@icm.ie
Website: www.athenrycancer.ie

Ballinasloe Cancer Support Centre

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

Cara Iorrais Cancer Support Centre

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

East Galway & Midlands Cancer Support

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

Gort Cancer Support Group

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

Hand in Hand

[Children's Cancer Support Centre]
Main Street
Oranmore
Co Galway
Tel: 091 799 759
Email: info@handinhand.ie
Website: www.handinhand.ie

Mayo Cancer Support Association

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

Roscommon Cancer Support Group

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

Sligo Cancer Support Centre

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

Tuam Cancer Care Centre

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

Leinster support services**Aoibheann's Pink Tie**

[Supporting children with cancer]
Unit 22, Docklands Innovation Centre
128- 130 East Wall Road
Dublin 3
Tel: 01 240 1300
Email: aoibheannspinktie2@gmail.com
Website: www.aoibheannspinktie.ie

ARC Cancer Support Centre

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

ARC Cancer Support Centre

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

Arklow Cancer Support Group

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

Balbriggan Cancer Support Group

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

Cancer Support Sanctuary LARCC

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

Cara Cancer Support Centre

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

Cois Nore Cancer Support Centre

8 Walkin Street
Kilkenny
Tel: 056 775 2222
Email: coisnorekilkenny@gmail.com
Website: www.kilkennycancersupport.ie

Cuisle Cancer Support Centre

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

Dóchas: Offaly Cancer Support Group

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

Dublin West Cancer Support Group

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

Éist Carlow Cancer Support Centre

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

Gary Kelly Cancer Support Centre

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

Greystones Cancer Support

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

Hope Cancer Support Centre

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

Midlands Myeloma Support Group

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

Tallaght Cancer Support Group

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

Wicklow Cancer Support Centre

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

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

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

CARE Cancer Support Centre

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

Cork ARC Cancer Support House

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

Cuan House Cancer Support Centre

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

Kerry Cancer Support Group

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

Recovery Haven

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

Solas Centre

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

Suaimhneas Cancer Support Centre

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

Suir Haven Cancer Support Centre

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

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

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

Crocus: Monaghan Cancer Support Centre

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

Cuan Cancer Social Support and Wellness Group

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

Other support services**The Bella Rose Foundation**

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

Cancer Care West

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

Cúnamh: Bons Secours Cancer Support Group

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

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

The Forge Cancer Support Service

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

Killybegs Cancer Support Group

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

Newbridge Cancer Support Group

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

Purple House – Cancer Support

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

Rathdrum Cancer Support Group

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

Sláinte an Chláir: Clare Cancer Support

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

Solace: Donegal Cancer Support Centre

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

Useful contacts outside Republic of Ireland**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 Research UK

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

Healthtalkonline (UK)

Website: www.healthtalk.org

Macmillan Cancer Support (UK)

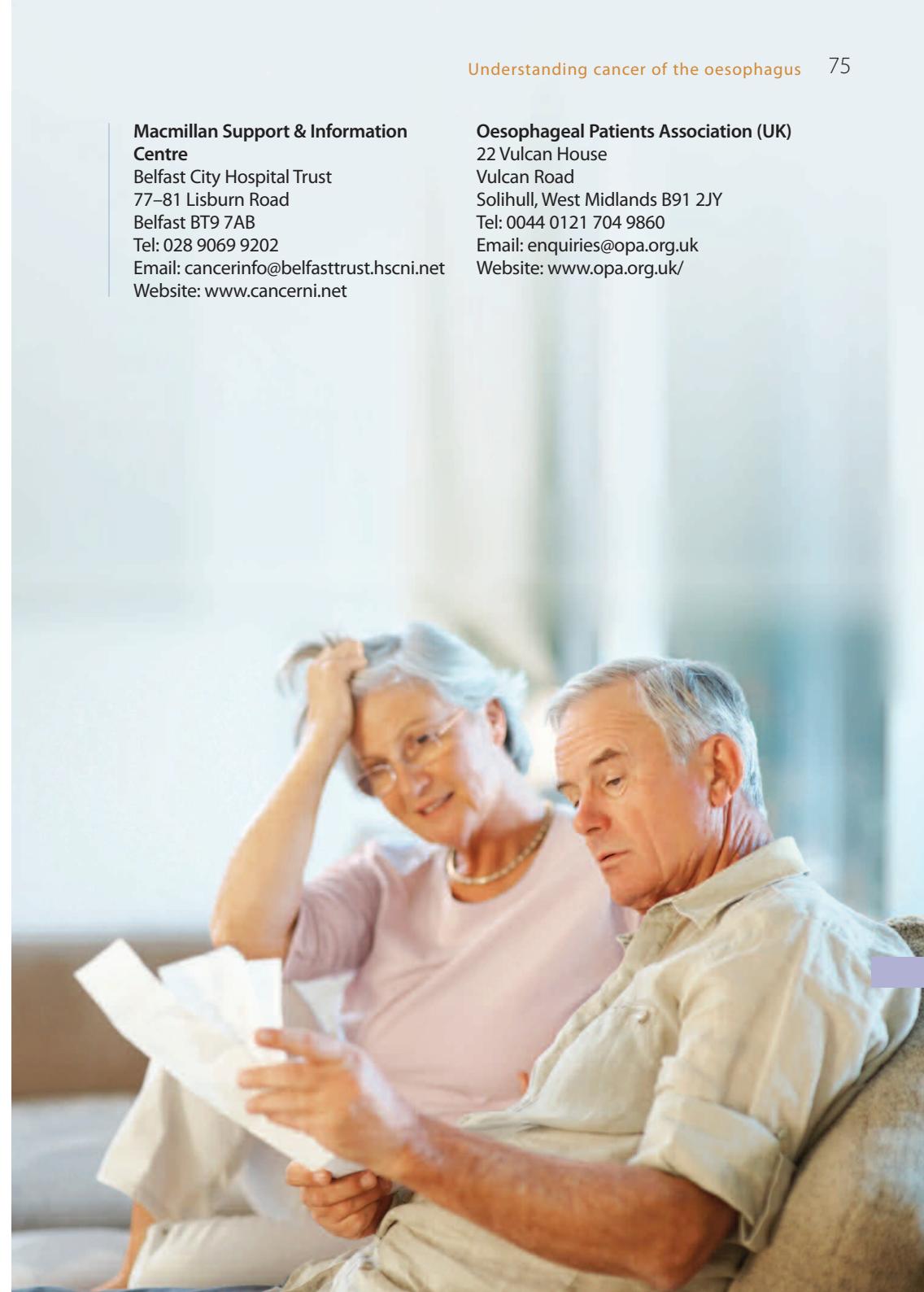
Tel: 0044 20 7840 7840
Email: cancerline@macmillan.org.uk
Website: www.macmillan.org.uk

Macmillan Support & Information Centre

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

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/



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*
- *Managing the Financial Impact of Cancer: A Guide for Patients and their Families*
- *Journey Journal: Keeping Track of Your Cancer Treatment*



Cancer at Your Fingertips

Val Speechley & Maxine Rosenfeld
Class Publishing, 2001
ISBN 1859590365

Cancer Positive: The Role of the Mind in Tackling Cancers

Dr James Colthurst
Michael O'Mara Books Ltd, 2003
ISBN 185479860X

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Dr Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

Taking Control of Cancer

Beverley van der Molen
Class Publishing, 2003
ISBN 1859590918

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

101+ Square Meals [Budget and nutrition]

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

Explaining cancer to children

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

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.



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?

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:

Eva Copeland, Clinical Nutritionist

Ann Murphy, Clinical Nurse Specialist

Staff at the Brachytherapy Unit, St Luke's Hospital

Jenny Moore, Oncology Nurse Specialist

Antoinette Walker, Patient Education Editor

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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre.

Would you like to be a patient reviewer?



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

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

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

Would you like to help us?

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

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

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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Open Monday to Thursday 9am to 6pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

