

Understanding

Cancer of the Pancreas

Caring for people with cancer

Understanding cancer of the pancreas

This booklet has been written to help you understand about cancer of the pancreas. It has been prepared and checked by surgeons, cancer doctors, nurses, dietitians and patients. The information in this booklet is an agreed view on this cancer, its diagnosis and treatment and key aspects of living with it.

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 quickly.



Specialist nurse	Tel:
Family doctor (GP)	Tel:
Surgical oncologist (surgeon)	Tel:
Gastroenterologist	Tel:
Medical oncologist	Tel:
Radiation oncologist	Tel:
Radiation therapist	Tel:
Dietitian	Tel:
Emergency number	Tel:
Treatments	Review dates



Irish Cancer Society, 43/45 Northumberland Road, Dublin 4
Tel: 01 231 0500 Fax: 01 231 0555 National Cancer Helpline 1800 200 700
Email: info@irishcancer.ie Website: www.cancer.ie

If you like, you can also add:

Your name _____

Address _____

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

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Introduction

This booklet has been written to help you understand about cancer of the pancreas. By reading it, you can learn about what it involves, its diagnosis and treatment. We hope that it answers some questions you may have.

We cannot advise you on which treatment to choose. You can only make this decision along with your doctors when all your test results are ready. But we can tell you about some ways to treat this cancer and any possible side-effects.

This booklet also discusses some of the feelings you and those close to you may have when a diagnosis of cancer is made. At the end of the booklet, you will find a list of books that are useful to read. There is also a list of websites and special groups to help and support you at this time. You can also call the freefone National Cancer Helpline 1800 200 700 to discuss any queries or concerns you have.



Reading this booklet

Remember you do not need to know everything about pancreatic cancer straight away. Read a section about a particular item as it happens to you. Then when you feel relaxed and want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call the freefone National Cancer Helpline 1800 200 700.

If you find the booklet helpful, you could give it to your family and friends who might find it useful too.



What does that word mean?

Abdomen	The part of your body that lies between your chest and hips.
Adenocarcinoma	The most common type of pancreatic cancer. It is found in the cells that line the pancreatic tubes (ducts).
Adjuvant treatment	Treatment for cancer given after surgery.
Alopecia	Loss of hair or baldness. No hair where you normally have hair.
Anti-emetic	A tablet, injection or suppository given to stop you feeling sick or vomiting.
Benign	A tumour that is not able to spread.
Biopsy	When a small amount of tissue is taken from your body to find out if cancer cells are present.
Bypass surgery	An operation that bypasses the cancer and relieves a blockage in the bile duct.
Cells	The building blocks that make up the tissues in your body. They are tiny and can only be seen under a microscope.
Chemotherapy	Treatment using drugs that cure or control cancer.
Enzyme	Proteins that cause chemical reactions in the body. For example, they can break down food in the stomach and intestines.
Fatigue	Severe tiredness.
Gastroenterologist	A doctor who specialises in treating diseases of the digestive system.
Jaundice	When your skin and the whites of your eyes turn yellow and your urine dark. It can be caused by a blockage in the bile ducts of the pancreas.
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 your body to other tissues and organs.
Nausea	Feeling sick or wanting to be sick.
Nerve block	A treatment used to relieve pain caused by cancer. It helps to stop the nerves around the pancreas causing pain.
Nutrients	Proteins, carbohydrates, fats, vitamins and minerals found in food. They are needed for you to grow and stay healthy.
Oncology	The study of cancer.
Palliative care team	A team of doctors and nurses and other health professionals who are trained to manage pain and other symptoms caused by cancer. They will also help you cope with emotional distress too.
Prognosis	The expected outcome of a disease. If the pancreatic cancer can be treated and how long you are likely to live.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Radiotherapy	The treatment of cancer using high-energy X-rays.
Staging	Tests that measure the size and extent of cancer.
Stent	A small hollow tube used to relieve a blockage due to cancer cells. It can be either plastic or metal.
Surgical oncologist	A doctor who specialises in treating cancer patients using surgery.
Total parental nutrition	Giving nutrients directly into a vein through a drip.
Tube feeding	Giving nutrients through a feeding tube passed into your stomach or intestine.
Tumour	An abnormal lump of tissue formed by a collection of cells. It may be benign or malignant.

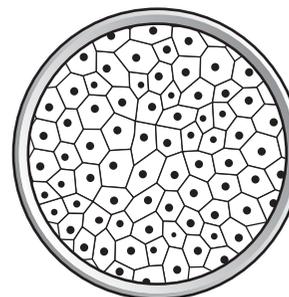
About pancreatic cancer

What is cancer?

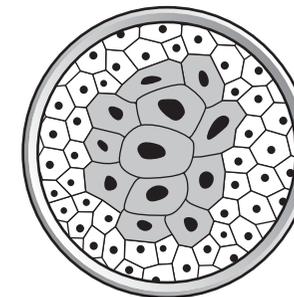
Cancer is a word used to describe a group of diseases. Each one has its own name. For example: skin cancer, lung cancer and breast cancer. Each has an individual type of treatment and chance of being cured.

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

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



Normal cells



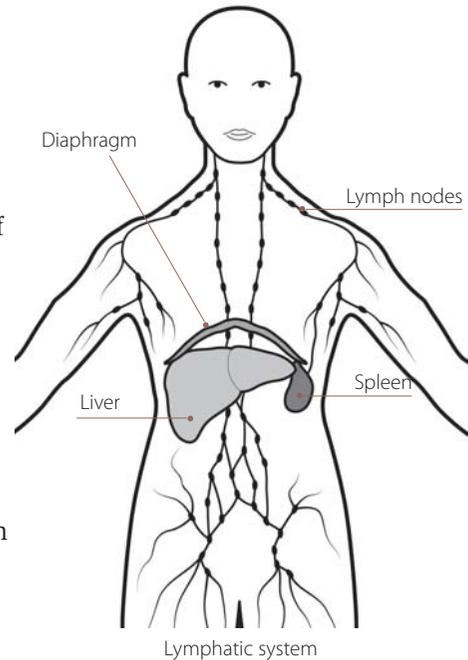
Cancer cells growing

What is the lymphatic system?

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

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

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

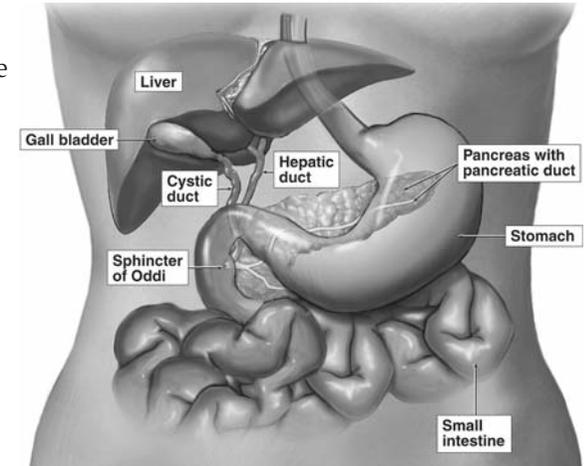


To sum up

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

What is the pancreas?

The pancreas is a gland that is part of your digestive system. It is about 6 inches long and lies deep inside your tummy (abdomen), behind your stomach and in front of your spine. It is shaped like a tadpole and has three main parts: the head, the body and the tail. The head is the broad rounded part near your small bowel. The body lies in the middle and the tail is the thin end below your left ribcage.



The pancreas makes digestive juices (enzymes) and hormones such as insulin and glucagon. **Digestive juices** are chemicals that help to break food down so it can be absorbed into the lymph and bloodstreams. **Insulin** is a hormone that controls the level of sugar in your blood. **Glucagon** is a hormone that is released if your blood sugars are low.

Once food reaches the small bowel (called the duodenum), the digestive juices flow through the pancreatic duct (tube). These then mix with the food to break it down into very small parts. Near the duodenum another tube called the bile duct joins the pancreatic duct. It drains bile from the liver and gallbladder.

Many important blood vessels run near your pancreas so that food can be absorbed. Once the food is absorbed, insulin controls the level of sugar in your bloodstream. If you do not have enough insulin, you get the condition called diabetes.

What is cancer of the pancreas?

Most pancreatic cancers start in the cells that line the ducts in the head of the pancreas. These cancer cells may cause very few symptoms in the beginning. But as they grow they may cause discomfort or pain in your tummy area. Cells may break away from the pancreas and spread to lymph nodes, to nearby tissues or other parts of your body. It is common for the bile duct to be blocked due to cancer cells. This causes bile to leak into the bloodstream and cause jaundice.

What causes pancreatic cancer?

The exact cause of pancreatic cancer is unknown. It is not a common cancer and affects about 370 people in Ireland each year. But the number is likely to increase during the next 20 years due to lifestyle habits. Most cases occur in adults over the age of 60.

Some things can increase your chance of getting a disease. These are called risk factors. Some of the risk factors for pancreatic cancer are:

- Smoking
- Diet high in fat and sugar
- Diabetes
- Chronic pancreatitis
- Family history and inherited conditions
- Occupation

Smoking

You are three times more likely to develop pancreatic cancer if you smoke. This is especially true if you have a relative who has had pancreatic cancer. The chemicals in cigarettes, cigars and chewing tobacco can damage healthy cells and allow cancer cells to grow.

Diet

Recent research suggests that diets high in sugar or animal fat can cause pancreatic cancer. A lack of fresh fruit and vegetables in your diet may increase the risk. Lack of exercise and being overweight

(obesity) may be risk factors too. India has a very low rate of pancreatic cancer and the use of the curry spice curcumin in the diet there could be one reason why. Curcumin is also known as turmeric.

Diabetes

There is some research to suggest that people with diabetes have a slightly higher risk of pancreatic cancer. But remember that diabetes is a very common disease and most people with the condition do not get pancreatic cancer.

Chronic pancreatitis

Chronic pancreatitis is an inflamed pancreas over a long period of time. It can be caused by the heavy drinking of alcohol over many years.

Family history and inherited conditions

If there is a family history of pancreatic cancer, you may be more at risk. Some medical conditions with faulty genes can also lead to pancreatic cancer. These conditions can be passed on from family members. They include:

- Hereditary pancreatitis
- Breast and ovarian cancers with BRCA2 genes (and possibly BRCA1)
- Bowel conditions such as familial adenomatous polyposis (FAP), hereditary nonpolyposis colon cancer (HNPCC/Lynch syndrome) and Peutz-Jeghers syndrome
- Mole skin conditions like familial atypical multiple mole melanoma syndrome (FAMMM)

Your risk of pancreatic cancer is higher if you or your parents, uncle, aunt or brother and sister have or had the above conditions.

Occupation

Some types of chemicals in the workplace and radiation may increase your risk of developing pancreatic cancer. If you are exposed to radiation, aluminium or acrylamide, it may cause adenocarcinoma of the pancreas. But more research is needed to prove it for certain. Acrylamide is used in dyes, wastewater treatment, papermaking and ore processing.

Can I be screened for pancreatic cancer?

Checking for pancreatic cancer when you have no symptoms is called **screening**. Because pancreatic cancer is not common and there is no simple screening test, screening is not done for the general public at present. Screening may cause anxiety too as it can pick up small growths that are not cancer. More tests will then need to be done to out rule cancer.

If you are in the high-risk group for pancreatic cancer, your doctor may decide to get you tested at a specialist centre. People in the high-risk group are those that have a strong family history of pancreatic disease or cancer and those that have faulty genes that increase their risk. Screening usually starts at the age of 40. If you are worried about your risk, do talk to your GP.

Screening tests can include a CT or MRI scan and an EUS (endoscopic ultrasound) every 3 years. See page 14 for more about these tests. You may be offered genetic counselling if you have a strong family history of pancreatic disease or cancer. You may also be advised to quit smoking, if you are a smoker.

If you are referred to a specialist centre, you may be asked to take part in research studies with EUROPAC (European Register for Familial Pancreas Cancer and Hereditary Pancreatitis). See page 40 for more about research.

Preventing and finding pancreatic cancer early

Research continues on ways to prevent or find pancreatic cancer early. Many of these studies look at special genes in your body to understand why they change (mutate) and cause cancer. Some of these genes are K-ras, MUC and BRCA2. Other studies are trying to make a vaccine that will prevent those in the high-risk group from getting pancreatic cancer.



What are the symptoms of pancreatic cancer?

Pancreatic cancer can be hard to diagnose because there may be no signs or symptoms in the early stages. Sometimes symptoms may be vague or common to many other illnesses. Some of the symptoms include:

- Pain or discomfort around your stomach area, which may spread to your back
- Weight loss
- Jaundice – yellow, itchy skin; dark urine; pale stools
- Loss of appetite
- Feeling full very quickly
- Nausea (feeling sick)
- Vomiting
- Diabetes, especially if diagnosed within previous 2 years
- Low mood

Jaundice is when your skin and the whites of your eyes look yellowish. Your urine becomes darker and your bowel motions might be lighter in colour. This happens when the cancer in the head of the pancreas blocks the bile duct, causing bile to be absorbed into the bloodstream.

Even though the above symptoms can be caused by conditions other than cancer, you should get them checked out by your doctor. Jaundice for example is a common symptom of many liver and gallbladder diseases.



To sum up

- Cancer of the pancreas is not a common cancer.
- The cause is unknown in most cases but the main risk factors include smoking, a diet high in fat and sugar, chronic pancreatitis and inherited conditions.
- Symptoms include pain, jaundice, weight loss, and loss of appetite.

How is pancreatic cancer diagnosed?

Usually a symptom like pain or jaundice brings you to see your family doctor (GP). He or she will examine you and check your urine and blood. After that, you are likely to be referred to a hospital specialist for more tests. He or she will do a physical exam and ask you about your symptoms and lifestyle as well as your family medical history.

There is a range of tests to check for pancreatic cancer. Many of them have long difficult names so abbreviations are often used. You do not need all of the tests listed below but some may be done:

- Blood tests
- Ultrasound of liver, pancreas and bile duct
- CT scan
- ERCP
- Endoscopic ultrasound (EUS)
- MRI / MRCP / MRA scans
- Laparoscopy
- Biopsy (sample of tissue)

Some of the above tests are also used to stage the cancer. This means finding out the size and extent of the cancer and if it has spread. These may be done, depending on your general health and your likely treatment. Some of the tests are done in the outpatient department, while you may be admitted to hospital as a day patient for others.

Tests in detail

Blood tests: Bloods tests may be done to check your general health, such as a full blood count and liver function tests. There are other more special tests that check for certain substances in your blood. These are called biomarkers and are raised if cancer is present. For example, one biomarker for pancreatic cancer is CA 19-9. But remember a blood test is not enough to diagnose pancreatic cancer and other tests are also needed.

Ultrasound of liver, pancreas and bile duct: This scan uses sound waves to look at your pancreas and liver. It is very like the scan that

pregnant mothers get when checking their babies in the womb. First, some gel is put on your tummy and then the area is scanned. The scan is very accurate and can show up abnormal tissue like cysts or cancer. It can help your doctor to decide if you need a biopsy. The scan only takes a few minutes.



An ultrasound

CT scan (CAT scan): This special X-ray gives a detailed picture of the tissues inside your body. The scan is painless. It is the most important test in the diagnosis of pancreatic cancer. For a CT scan of your abdomen, you may be asked to fast from 12 midnight before the test. You may be given a special drink which helps show up parts of your body on the scan. Preparation for a CT scan can vary. Your doctor or nurse will tell you what to do. The test is usually done as an outpatient. Some people feel anxious about this test and are afraid they may feel claustrophobic during it. If you think you will be, do ring and tell the radiographer the day before. They may be able to give you a tablet to relax you.

A special type of CT scan might be done instead. This is known as a multi-detector CT scan (MDCT). It can give quick and high-quality images of your pancreas.

MRCP: This stands for magnetic resonance cholangiopancreatography. It is an MRI scan that shows up the tissues of the pancreatic duct, bile ducts and gallbladder in more detail. It takes about 20 minutes.

ERCP: ERCP stands for endoscopic retrograde cholangiopancreatography. This test is used less often today. Before this test, you will be asked to fast for a number of hours. You will then be given sedation to relax you. Next, a thin tube called an endoscope will be passed down your throat to your tummy. It has a light and camera

on one end so your doctor can see the inside of your small bowel (duodenum) and can inject dyes into the pancreas and its ducts. These can then be seen on X-rays and will show up any signs of cancer. Your doctor may also be able to take samples of the cancer (biopsy). These can then be examined in the lab. If the cancer is blocking the bile duct, it may be possible to unblock the duct at this stage with a stent.



An ERCP

EUS: EUS is an endoscopic ultrasound. It can also help to find very small cancers in the pancreas. It is like an ERCP except your doctor puts an ultrasound tube down through the endoscope tube. By doing this, your doctor can take an ultrasound from inside your body. The pictures of your pancreas and liver can be more accurate as a result. By using a fine needle, a more accurate biopsy can be taken as well.

MRI scan: This special scan uses magnetic energy to build up a picture of the tissues inside your body. These pictures can then be seen on a computer. The scan does not hurt but can be very noisy. You will be given earplugs to wear during it. You may have an injection before the scan to show up certain parts of your body. During the scan, you cannot wear metal jewellery and if you have any medical device implanted, like a pacemaker, the test cannot go ahead. Aside from that, the test is harmless and you can go home afterwards.

A special type of MRI can be used to look at the blood vessels around the pancreas and liver. This is called magnetic resonance angiography (MRA).

Laparoscopy: This is a test done under general anaesthetic that allows your doctor to look inside your tummy. For this you will need to be admitted to hospital for one day. Just before the test you will be put to sleep with a general anaesthetic. While you are asleep, your doctor will make a small cut in your abdomen and carefully put in a tiny telescope called a laparoscope. By looking through the laparoscope, he or she can

see your pancreas and nearby organs. A small ultrasound probe can also be put inside your tummy.

A small sample of tissue (biopsy) may be taken and examined in the lab. The result of the laparoscopy will help your doctor to decide what kind of surgery is possible.

During the operation, carbon dioxide gas is passed into your abdomen. This can cause uncomfortable wind and/or shoulder pain for 3 or 4 days. Walking about or taking sips of peppermint water often eases the discomfort. You will have one or two stitches at the wound site. These stitches do not need to be removed as they usually dissolve once the wound heals.



A laparoscopy

Biopsy: One way to confirm a diagnosis of pancreatic cancer is with a biopsy. This is a sample of the pancreas tissue which is examined in the lab under a microscope. There are many ways to take a biopsy. Your doctor will consider the best way for you. It may be done during an ERCP, a EUS, a laparoscopy or by putting a needle through the skin in your tummy area, guided by an ultrasound or CT scan.

A biopsy is not always done before surgery and may depend on your age.



To sum up

The following tests are used to diagnose cancer of the pancreas:

- Blood tests
- Ultrasound scan
- CT scan / MDCT scan
- ERCP or EUS and/or biopsy

Depending on the results of the above tests, you may need some of the following:

- MRI / MRCP / MRA scans
- Laparoscopy with or without ultrasound

Waiting for results

It may take some time for all the test results to come back. Naturally, this can be an anxious time for you. Fear of the unknown can overwhelm everything. It may be frustrating as well, especially if new tests are ordered or scans redone. You may be anxious to start treatment straight away and afraid that delays are letting the cancer spread. But it is important that your doctor gets as much information as possible about your cancer before it is treated.

It may help to talk things over with the specialist nurse or a family member or close friend. You may also wish to call the National Cancer Helpline 1800 200 700 to speak to one of our specially trained nurses.

What are the types of pancreatic cancer?

The most common type of pancreatic cancer is adenocarcinoma. These cancers are found in the head of the pancreas in the ducts. About 9 in 10 patients will have adenocarcinoma. Cancers can also be found in the body and tail of the pancreas.

Some rare types of pancreatic cancer are:

- Cystic tumours (that may be benign or malignant)
- Neuroendocrine tumours that make hormones
- Lymphoma of the pancreas (similar to non-Hodgkin lymphoma)
- Pancreatic sarcomas (connective tissue tumours)

Remember these are rare types of pancreatic cancers. But if you would like more information, contact the National Cancer Helpline 1800 200 700 to speak to one of our specialist nurses.

»»» Staging allows your doctor to decide the best treatment for you.

What are the stages of pancreatic cancer?

Staging means finding out the size of the tumour and if it has spread. Your doctor will arrange some tests to stage the cancer. Some of these tests are mentioned in previous pages. Sometimes a special scan called a PET scan might be used as well. Staging is very important as it allows your doctor to decide the best treatment for you. Sometimes it may only be possible to find out the stage during surgery.

There are a few ways to describe the stage of the cancer but the simplest is the number system.

- **Stage 1:** This means the cancer is at a very early stage. The tumour is 2cm in size or less and found within the pancreas. There is no sign of it spreading anywhere.
- **Stage 2:** Here the tumour is more than 2cm in size. It is now found outside the pancreas in nearby tissues like the bile duct and/or the small bowel (duodenum). There is no sign of cancer in the nearby lymph nodes.
- **Stage 3:** Here the cancer has spread outside the pancreas to nearby tissues. It is also in the lymph nodes and may have spread to other body organs through the lymphatic system or bloodstream.
- **Stage 4:** This stage can be divided into 4a and 4b. In 4a the cancer has spread to nearby organs and vessels. This includes the stomach, spleen, large bowel or large blood vessels. The cancer is also found in lymph nodes. In 4b, the cancer has spread to the liver and/or the lungs. Your doctor may refer to stage 4b as advanced cancer.



To sum up

- The most common type of pancreatic cancer is adenocarcinoma.
- Staging finds out the size of the cancer and if it has spread.
- Staging helps your doctor to decide the best treatment for you.
- There are four stages of pancreatic cancer.



Treatment and side-effects

How is pancreatic cancer treated?

Pancreatic cancer is a rare cancer and is only treated in a few specialist cancer centres in Ireland. The staff at these centres have great expertise and experience in managing patients with pancreatic cancer. As a result, you may be transferred to another hospital from the one where you receive your diagnosis.

Surgery for pancreatic cancer is even more specialised and the service is currently being rearranged in Ireland. If it is possible to remove your cancer, you may be referred to a specific centre for surgery. If this happens, your doctor will explain why. Your doctor will still work closely with the surgeon in the centre.

If it is not possible to remove your cancer, you may receive other treatments such as chemotherapy or surgery to relieve a blockage. No matter what treatment you get, your doctor will discuss the treatment plan with you beforehand and explain your options.

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

Types of treatment

Pancreatic cancer can be hard to treat because it is usually diagnosed at a late stage. Once all the test results are ready, your doctor will discuss your treatment options with you. Sometimes it may not be possible to find out how advanced the disease is until keyhole surgery has been done.

Surgery: The main treatment for early stage pancreatic cancer is surgery. By looking at all your test results, your surgeon will decide if it can be removed. This is called a resection and aims to cure your cancer. Sometimes, despite all the tests, it is only during surgery that the surgeon can find out if the cancer can be resected or not. Only a small number of patients can be cured by surgery.

Your doctor will also consider your general state of health so that you are fit for surgery. There are a number of operations that can be done, depending on where the tumour is found. See page 26 for more details.

Bypass surgery: In a lot of cases, pancreatic cancer is not diagnosed early enough to cure it by surgery. Surgery might be done instead to ease your symptoms and relieve a blockage caused by the tumour. See page 28 for more about bypass surgery.

Chemotherapy: Chemotherapy is sometimes given to patients with pancreatic cancer. It can be given before or after surgery or on its own. Normally, chemotherapy does not cure the cancer but it can help to shrink it or relieve your symptoms. A new type of drug therapy called tyrosine kinase inhibitors is also now being used. See page 32 for more details.

Radiotherapy: Radiotherapy can sometimes be used to treat pancreatic cancer. If your tumour is causing pain, a small dose of radiotherapy may help to relieve it. Sometimes radiotherapy and chemotherapy are used to shrink the tumour before surgery can be done. See page 37 for more details.

Supportive or palliative care: This is treatment that is given to help relieve your symptoms, especially if you have advanced cancer. Surgery, chemotherapy or radiotherapy may be needed as part of the palliative care. A special team called the palliative care team may be involved in your care too. See page 43 for more details.

Treatment or no treatment: Unfortunately, your doctor may not be able to guarantee a cure for your cancer. But some treatment might prolong your life and give you a good quality of life. In some cases, you may not benefit from treatment at all. The treatment may not shrink the tumour or improve your quality of life. In fact, the side-effects of treatment may be greater than the benefits. Either way, your doctor and nurse will discuss this with you in more detail.

Why is pancreatic cancer hard to treat?

- It is usually diagnosed at a late stage.
- It is close to important organs and vessels, so it is hard to remove.
- It can spread very easily.
- It can make you feel very sick and weak, so you are less suitable for surgery and other treatments.
- It is less sensitive to treatments, unlike other cancers.

Who will be involved in my care?

A team of doctors, nurses and other health professionals will care for you. This team might include the following:



Gastroenterologist	A doctor who specialises in diseases of the digestive system.
Surgical oncologist	A doctor who specialises in surgery and who can remove a tumour from your body.
Endocrinologist	A doctor who specialises in diseases of the endocrine system such as diabetes.
Medical oncologist	A doctor who specialises in treating cancer patients using chemotherapy and other drugs.
Radiation oncologist	A doctor who specialises in treating cancer patients using radiotherapy.
Pancreatic nurse specialist	A specially trained nurse who cares for patients who have pancreatic cancer.
Liaison oncology nurse / clinical nurse specialist	Other specially trained nurses who work in a cancer care unit. They can give information and reassurance to patients and their families from diagnosis and throughout treatment.
Diabetic nurse specialist	A specially trained nurse who cares for patients who have diabetes.
Palliative care team	A team specially trained to manage pain and other symptoms and help you and your family cope with any emotional distress. They are sometimes known as the 'homecare team', if you are based at home.
Radiation therapist	A radiotherapist who specialises in giving radiotherapy and advice to cancer patients.

Dietitian	An expert on food and nutrition. They are trained to give advice on diet and other forms of nutrition support during illness and may suggest changes to your diet to help symptoms.
Medical social worker	A person specially trained to help you and your family with all your social and practical needs. They are skilled in counselling and giving emotional support to children and families. They can give you advice on benefits, entitlements and services available to you when you go home.
Psychologist	A specialist who can talk to you and your family about emotional and personal matters. They can help you make decisions.
Counsellor	A person specially trained to give you emotional support and advice when you find it hard to come to terms with your illness. The Irish Cancer Society provides a counselling service. For details, phone the National Cancer Helpline at 1800 200 700.

Deciding on treatment

At this time you may be anxious about what will happen next. You may still be in shock from the diagnosis and forget what you have been told. Do not be afraid to ask your doctor or nurse for more information. They will discuss your treatment options with you. Sometimes, depending on the stage of your cancer, you may have fewer choices. So do ask as many questions as you like, no matter how small or trivial you think they are. You might like to use the fill-in page at the back of this booklet to write down your questions and the answers you receive.

Some patients like to get a second opinion from another cancer specialist. If you feel this way, do discuss it with your doctor. He or she or your GP may be able to recommend another specialist.

>>> No treatment will be given without your consent.

If you need treatment, you may be asked to sign a consent form saying you give permission for it to be given. In some cases you may give verbal permission. No treatment can be given without your consent. Also, you should be told the likely benefits and risks of the treatment. You are also free to choose not to have the treatment. But you will need to discuss it in detail with your doctor or specialist nurse. The helpline nurses on the National Cancer Helpline 1800 200 700 can also discuss it with you.



To sum up

- Treatment for pancreatic cancer depends on the stage of the disease.
- Surgery is the main treatment for early stage pancreatic cancer.
- Surgery may be done if the tumour can be removed.
- Bypass surgery may be done to relieve a blockage in your bile duct or small bowel and ease jaundice and pain.
- Chemotherapy or radiotherapy may be used to relieve your symptoms.
- Treatment can be given to ease your symptoms like jaundice, pain or pressure.
- A team of doctors, nurses and other health professionals will care for you.



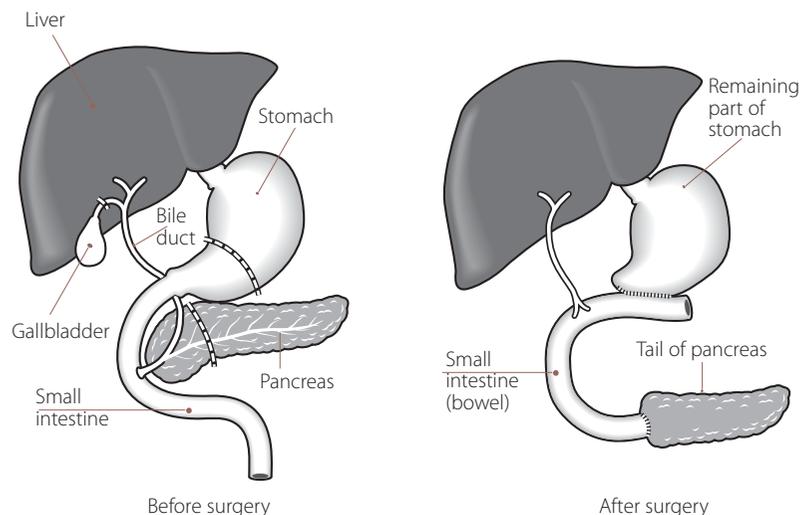
Surgery

The aim of surgery is to remove the cancer and the area close to it. Surgery is only suitable if you have early stage pancreatic cancer. This means about 1 in 5 patients. The surgery is major because the pancreas lies deep inside your body and is surrounded by many large organs and blood vessels. Unless your surgeon hopes to remove all of the cancer, he or she is unlikely to do major surgery.

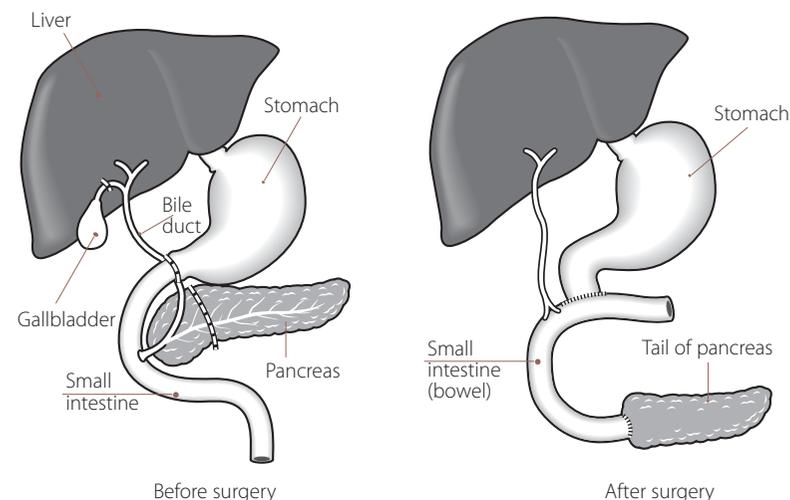
Only about 1 in 20 patients who have cancer at the head of the pancreas are suitable for surgery. If surgery is considered, you will be referred to a specialist centre where the surgeon has more experience with these operations.

There are about three different types of surgery, depending on where the cancer is found:

- **Whipple's operation:** This is done for cancer at the head of the pancreas. Part of your pancreas is removed and part of your small bowel, some of the bile duct and your gallbladder as well as part of your stomach.



- **Pylorus preserving pancreaticoduodenectomy (PPPD):** This is also done for cancer at the head of the pancreas. Part of your pancreas is removed as well as part of your small bowel (duodenum), some of the bile duct and your gallbladder. Your stomach is left intact.



- **Total pancreatectomy:** Usually this is done for cancer in the body or tail of the pancreas. All of your pancreas is removed as well as some of your small bowel, part of your stomach, your gallbladder, part of the bile duct, your spleen and nearby lymph nodes.

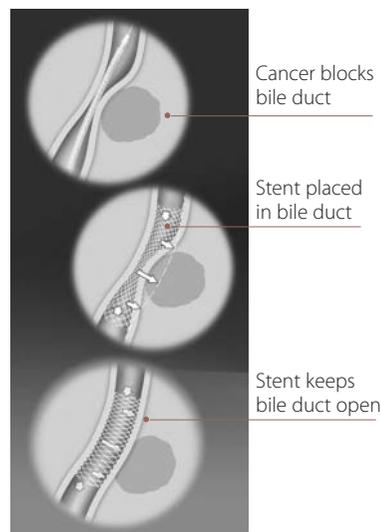
Bypass surgery

Bypass surgery is done to relieve your symptoms when the tumour cannot be removed. For example, you may be vomiting due to a blockage in your small bowel (duodenum) caused by the cancer. In this case, your surgeon might connect your small bowel to your stomach. This operation is called a **gastrojejunostomy**.

It is also quite common for the bile duct to be blocked if you have pancreatic cancer. This is caused by a build-up of bile because it cannot drain into your small bowel. In this case you might have a **stent** put in. This is usually a small metal tube but sometimes plastic

tubes may be used in the short term. The wire mesh of the metal tube keeps the bile duct open. A dye may be injected to see if the bile can flow freely.

Having a stent put in does not need an operation as such. A doctor called an endoscopist may do it during an ERCP (see page 15). It can also be put in through your skin by a method called PTC (percutaneous transhepatic cholangiogram). This is done by a doctor called a radiologist in the X-ray department. For this, the doctor will put some local anaesthetic on your tummy beforehand. A stent can also be put in surgically at the same time as a gastrojejunostomy. Your doctor and nurse will give you more information about bypass surgery if you need it.



A stent to keep the bile duct open

Before surgery

Your doctor and nurse will give you advice on any preparations before surgery. For example, your bowels may need to be empty and you must fast from 12 midnight the night before. If you need extra nutrition for a few days beforehand, your dietitian will advise you. There are other special medications that your doctor may prescribe as well.

After surgery

Because the surgery is major, you will be nursed in an intensive care unit or a high dependency unit (HDU) for a day afterwards. You may have an oxygen mask over your face when you wake up and for a short while later.

Drips, drains and tubes: You may be aware of many drips and drains around you. The drips will give you fluids into your vein. There may be

a central line in a large vein in your neck to give you fluids and antibiotics. A tube going into your nose will drain any juices from your stomach. You are also likely to have a tube into your bladder (catheter) to drain your urine.

Pain: You are likely to have some pain, especially when you move or cough. Your nurse will give you medication regularly to control any pain. Or you may be attached to an epidural or a small pump where you can press a button to give yourself some pain relief safely into a vein. Always tell your nurse if you are in pain.

Wound site: You will have a large dressing over your wound site. This will be checked regularly for any signs of bleeding or leakage.

Replacing insulin and enzymes: If you have had part or all of your pancreas removed, you may need to take insulin. This is normally made by the pancreas. Also, you may need to take extra digestive enzymes, which are normally made by your pancreas. If all your pancreas is taken away, it is certain you will need both of these treatments. If you have the Whipple's operation, you may need vitamin B12 every 3 months. The diabetic nurse specialist will visit you and give you advice if you become a diabetic due to surgery.

Eating and drinking: You will be unable to eat and drink for a few days to allow your gut to heal inside. As a result, you will get fluids through a drip. Your dietitian along with your team will decide if you need help with nutrition after surgery. When you can eat, at first you will be offered light snacks. Gradually you will be allowed to eat more as you tolerate it.

With pancreatic cancer, you are likely to have some weight loss. Your dietitian will give you advice on suitable foods and meals as well as supplements if you need them. Advice on changes to your diet to reduce your symptoms can also be given.

Getting up and about: Your physiotherapist will show you how to do deep breathing and leg exercises. These will help to prevent a chest infection or blood clot after your operation. The nurses and physiotherapists will also help you to take short walks on the ward the day after surgery.

Going home

Your doctor, nurse and dietitian will give you advice when going home. If you live alone or have problems getting around the house, talk to the medical social worker or nurse on your ward as soon as you are admitted to the hospital. That way, he or she can organise any community services you may need after you leave hospital. On the day you go home, you will be given a date to come back for a check-up. This is usually for about 6 weeks later.

Should I stop smoking and drinking?

Smoking: If you reduce or stop smoking it can help your symptoms and your general well-being. Even if your cancer is advanced it can still benefit you. If you would like to quit, there is help available. Ask your doctor or nurse if there is a stop-smoking clinic at the hospital. If not, the National Smokers' Quitline offers support and assistance for smokers all over the country. You can talk to a specially trained stop-smoking counsellor who will help you prepare a plan and support you during this time. The Quitline can also put you in touch with the smoking cessation officer in your area. For more information, call the Quitline 1850 201 203: Monday–Saturday, 8am–10pm. You can also visit the special HSE website: www.giveupsmoking.ie

Alcohol: Ask your doctor if it is safe for you to drink alcohol. If you have a history of chronic pancreatitis or familial pancreatitis, it is best to avoid alcohol.

Should I change my diet?

Your dietitian will give you advice on what foods to avoid or eat. In general you will be told to eat little and often. You may be told to eat high-energy foods, if you find it hard to eat well, and if losing weight. You also may need to take pancreatic supplements (enzymes) as a tablet. These tablets replace the enzymes usually made by your pancreas to help you digest your food.

If your duct is blocked by the cancer, taking these tablets will help your digestion as well. There are other symptoms that might suggest

you are not absorbing or digesting your food. These include fatty diarrhoea, bloating, wind and failure to gain weight. Your dietitian will advise you about taking enzymes to match your diet.

Depending on your surgery, you may be advised to eat small meals regularly. It may take a while for your stomach to get back to normal. It may delay emptying food or else 'dump' it into the small bowel quickly. Your dietitian will give you advice about preventing these problems. If you develop diabetes due to the surgery, you will need to make changes to your diet. Your dietitian and diabetic nurse specialist will give you more advice about this. You will also be referred to a doctor who specialises in diabetes called an endocrinologist.



To sum up

- Surgery is only suitable for early stage pancreatic cancer.
- Bypass surgery may be done to relieve your symptoms, like jaundice or pain.
- You will have many drips, drains and tubes in after the surgery.
- The staff will help you to be pain-free, get you moving around the day after surgery, and encourage deep breathing exercises.

Chemotherapy

Chemotherapy is a treatment using drugs to control cancer. These drugs travel through your bloodstream to almost every part of your body. Chemotherapy can be used for any stage of pancreatic cancer: for advanced cancer, before surgery or after surgery, or if the cancer comes back. But chemotherapy alone is unlikely to cure pancreatic cancer. It can help to control or improve your symptoms and give you a better quality of life.

How is chemotherapy given?

Chemotherapy is usually given into a vein or as a tablet. If given into a vein, it can be as an injection or through an infusion or drip. Usually you receive the treatment as a day patient at the hospital. Your doctor called a medical oncologist will let you know how many courses you need. You will have a rest period between each course. This allows your body to recover from the drugs.

Some drugs used for pancreatic cancer are:

- Gemcitabine (Gemzar)
- 5-Fluorouracil (5-FU)
- Cisplatin
- Capecitabine (Xeloda)
- Oxaliplatin
- Erlotinib (Tarceva)

The drugs listed above may be used on their own or in combination. For example, gemcitabine may be used with erlotinib. Gemcitabine is often used for advanced cancer. Erlotinib is one of a group of new drugs called **tyrosine kinase inhibitors**. They are different from regular chemotherapy drugs in that they target the cancer cells directly and have less side-effects. They are also known as targeted therapies.

If you would like more information on drugs used for pancreatic cancer, see the Irish Cancer Society website:

www.cancer.ie/cancerInfo/chemotherapydrugs_list.php

Some research studies called clinical trials are being done to find out if the drugs can improve the treatment results. Your doctor may ask you to take part in a trial. These studies are quite safe. See page 40 for more details.

Side-effects of chemotherapy

The side-effects of chemotherapy vary from person to person and depend on the drugs used. Many of the drugs used in pancreatic cancer have less side-effects than those used for other cancers. Side-effects happen because chemotherapy can affect both cancer cells and normal cells. The side-effects can be short term or long term. In most cases the side-effects go away once the treatment ends or soon after. Your doctor or nurse can give you medication to stop most side-effects or make them easier to cope with.

The more common side-effects include:

- Infection
- Sore mouth
- Bruising
- Nausea and vomiting
- Rash
- Eye problems
- Diarrhoea
- Loss of appetite
- Hair loss
- Fatigue

Infection: Chemotherapy can make you more likely to get infections. This happens because the drugs can affect the bone marrow where white blood cells that fight infection are made. Regular blood tests will be done to check your blood count. If you feel shivery or unwell or have a high temperature of 38°C, contact the hospital straight away. Sometimes you may need antibiotics.

»»» If you feel shivery or unwell or have a high temperature of 38°C or higher, contact the hospital straight away.

Sore mouth: Some drugs used to treat pancreatic cancer may cause a sore mouth. They can also cause little ulcers to appear on your tongue, gums and inside the cheeks of your mouth. Keeping your teeth, gums and mouth very clean will reduce the risk of infection. If your mouth or throat becomes very painful, let your doctor or nurse know as soon as possible. Your doctor will prescribe painkillers or other medication to treat the infection if needed. There are also special mouthwashes, gels and toothpastes, like Biotène or BioXtra, that can help.

Bruising: Chemotherapy can also affect the number of platelets in your blood. If you have fewer platelets (thrombocytopenia), you may bleed or bruise more easily, even from a minor injury. Let your doctor or nurse know straight away if you are bruising easily.

Nausea and vomiting: Not everyone feels sick (nausea) or gets sick with chemotherapy. It all depends on the drugs being given. But if you do, it can happen before, during or after treatment and may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick. This may be as an injection or tablet.

Rash: Erlotinib may cause a rash usually on your face and neck. It develops about 8–10 days after getting treatment and usually improves after a few weeks. Do not treat this rash like acne but tell your doctor and nurse if it gets worse. There are special creams and antibiotics to treat this rash if needed.

Eye problems: Erlotinib can also cause eye problems. You might get dry sore eyes from taking the drug. Do tell your doctor as he or she may need to prescribe eye drops.

Diarrhoea: The drugs may also affect the cells lining your bowel. If you get diarrhoea, drink lots of clear fluids to prevent dehydration. Do tell your doctor or nurse if you have diarrhoea for more than 24 hours. There is medication that can stop this side-effect of treatment. It might help to talk to a dietitian who can offer more advice too.

Loss of appetite: It is often hard to eat well due to the cancer and effects of treatment. But do try to eat as well as you can to keep your strength up. Eat smaller amounts more often. Getting some fresh air and exercise may help to boost your appetite.

>>> Hints & Tips – poor appetite

- Make the most of your appetite when it is good. Eat when and what you want.
- Take small meals and snacks about every 2–3 hours.
- Take snacks high in calories and protein.



- Keep snacks handy. Try cheese and crackers, sandwiches, muffins or scones.
- Use a smaller plate for your meals. Large portions can be offputting if your appetite is small.
- Eat slowly and chew your food well.
- Take plenty of drinks like milk, yoghurt, juices and soups.
- Do not fill up on food and drinks that are not high in energy. For example, tea, coffee, water, thin soups and diet drinks. These may stop you from taking more nutritious foods.
- Try nutritional supplements, like Complian®, when it's hard for you to eat food. Special high-calorie drinks can help to keep your strength up too. Your dietitian will let you know if these are suitable for you. Your doctor can then give you a prescription for these drinks.
- Take only small sips while eating, as drinking might make you full.

Hair loss (alopecia): The amount of hair loss depends on the drugs you are given. It can vary from person to person. You may notice that your hair just thins out a little bit. If you do lose your hair, it will happen quite quickly. You may get a tingling sensation for a day or two beforehand. Try not to worry, as your hair will grow again when treatment stops. You might like to wear a wig or hairpiece when this happens or you may prefer a hat, turban or scarf.

>>> The amount of hair loss depends on the drugs you are given.

Feeling very tired (fatigue): It is normal to feel tired during treatment. This tiredness can last for some weeks after treatment is over. If this happens, take things easier and rest more if you can. Ask your family or friends to help you at work or at home. Do tell your doctor and nurse if fatigue is a problem for you. See page 48 for more about fatigue. You can also call the National Cancer Helpline 1800 200 700 for a free copy of the booklet *Coping with Fatigue*.



Will chemotherapy affect my sex life and fertility?



Sex life: It is not unusual to lose interest in sex because of the stress of your diagnosis. If your prognosis is not good, this can add to the stress and worry too. As a result, it can be hard to relax and enjoy sex. You may also feel tired or fatigued from the cancer and/or its treatment. Talking to your partner about your feelings may ease your anxiety. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. There is no set time for you to be ready to have sex again. Often when you accept the fact that you have cancer, things can be a little easier.

Remember cancer cannot be passed on to your partner during sex. If you are having chemotherapy, it is best to avoid getting pregnant as it may harm your baby. Do use a barrier method of contraception, like condoms.

Infertility: Your fertility may be affected by the chemotherapy drugs. Sadly, you may not be able to have a child or more children. If your prognosis is not good, you may wonder if there is any chance to have a child before it is too late. 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.

Dealing with infertility may not be easy, depending on your age and if you have had children or not. It can bring feelings of sadness, anger and loss of identity. It can help to talk through your concerns with someone who is a good listener.

Other side-effects: If you have a side-effect or symptom from those listed above and it concerns you, tell your doctor or nurse straight away. They will give you advice. For more information on chemotherapy, contact the National Cancer Helpline 1800 200 700 for a copy of the free booklet *Understanding Chemotherapy*. For advice on what foods to eat if you have poor appetite, nausea, vomiting or diarrhoea, ask for a copy of the booklet *Diet and Cancer*.

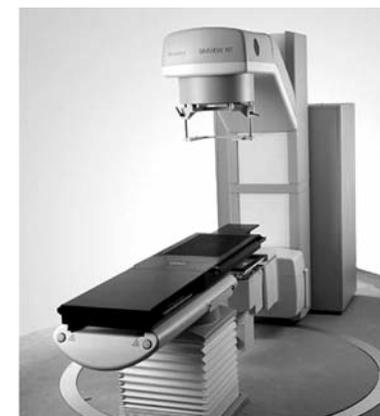


To sum up

- Chemotherapy is a treatment using drugs to control or shrink pancreatic cancer.
- Chemotherapy can be given as a tablet or directly into a vein as an injection or through an infusion (drip).
- The side-effects vary from person to person and depend on the drugs used.
- Some common side-effects are infection, sore mouth, bruising, nausea and vomiting, loss of appetite, diarrhoea, hair loss, and fatigue.
- Most side-effects are well controlled with medication.

Radiotherapy

Radiotherapy is a treatment that uses high-energy rays to kill cancer cells and shrink a tumour. These rays are like X-rays. Radiotherapy is sometimes used for pancreatic cancer to ease pain or pressure caused by the tumour, especially if the cancer is advanced. This is given as part of palliative treatment. Or if you have surgery to remove the cancer, sometimes radiotherapy is given with chemotherapy to reduce the risk of it coming back. Or it may be given with chemotherapy before surgery to shrink the tumour.



A linear accelerator

Giving radiotherapy

Radiotherapy is usually given as external beam radiation. This is where a beam of radiation is aimed at your cancer directly from a machine. A lot of preparation is needed before the actual radiotherapy can be given. Using a machine called a simulator, the doctors work

out exactly where to aim the rays and then mark your skin. This is so the beam goes to the same area each time you get radiotherapy. This area is called the treatment area.

The treatment itself only takes a few minutes and does not hurt. Your doctor and radiation therapist will tell you exactly when to come for treatment each time. Radiotherapy can be given 5 days a week for several weeks, but usually for pancreatic cancer it is a few short treatments.

Side-effects of radiotherapy

The side-effects of radiotherapy depend on the part of the body being treated. Usually they are mild to moderate. They can be managed with simple medications and you do not have to be admitted to hospital. These side-effects can include feeling sick or vomiting, skin redness, loose bowels or hair loss on the treatment area only. You may feel tired or fatigued for some time as well. If you would like more information on radiotherapy, call the National Cancer Helpline 1800 200 700 for a free copy of the booklet *Understanding Radiotherapy*. If you prefer, you can get a copy of the DVD called *Radiation Therapy: A Patient Pathway*.



To sum up

- Radiotherapy is a treatment using high-energy X-rays.
- External beam radiation is usually used. The rays are aimed at the cancer to shrink it or ease pressure and pain.
- Radiotherapy does not hurt and only takes a few minutes.
- For pancreatic cancer the treatment may be a few short sessions.
- Side-effects to radiotherapy depend on the area being treated and the type of radiotherapy given. They include nausea, vomiting, loose bowels, skin redness, hair loss to the area only, and tiredness.

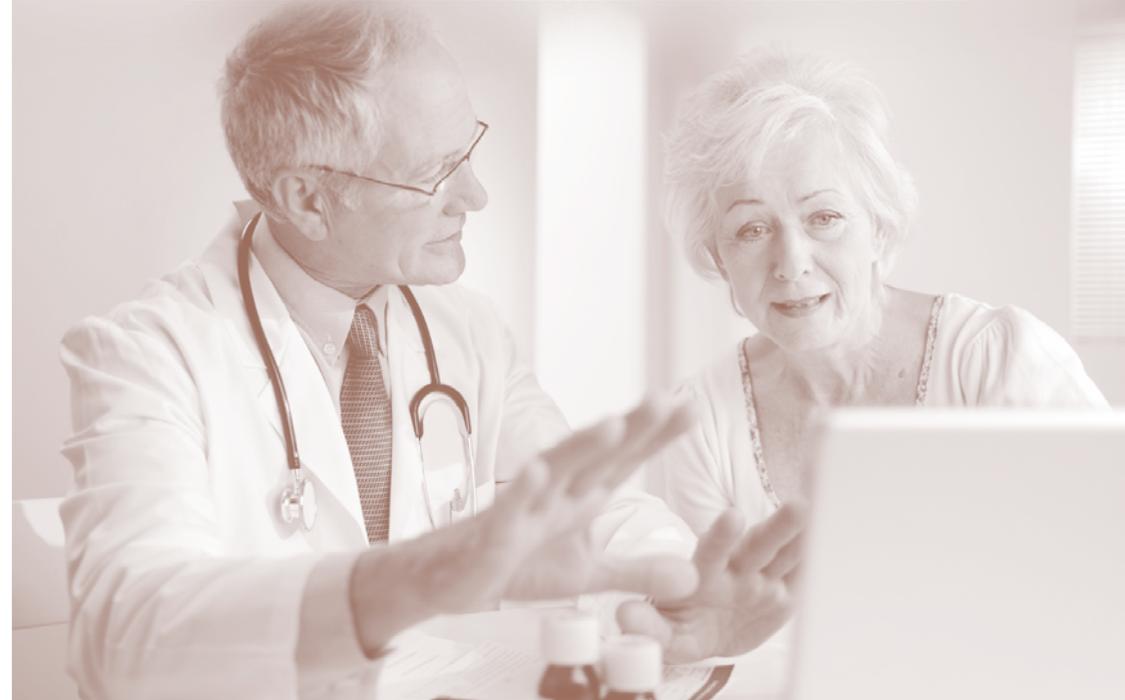
What follow-up do I need?

No matter what type of treatment you get, you will still need check-ups once it is over. These check-ups are called **follow-up**. After you leave hospital, your specialist nurse may telephone you regularly to see how you are getting on. If you have any concerns or questions, he or she can give you advice.

You will also need to visit your doctor at the outpatient clinic. Your doctor will let you know how often you need to see him or her. Usually this is every 3 months for 3 years. If you've had surgery, your first visit is usually 6 weeks later.

The follow-up may involve having a physical exam, a weight check, blood tests and a CT scan. The dietitian at the clinic can also give you advice. If you have a worry or symptom that is causing you concern before your check-up, do not ignore it. Contact your doctor, cancer nurse specialist or hospital ward for advice.

»»» If you are between check-ups and have a problem worrying you, let your doctor know.





Research – what is a clinical trial?



Research on pancreatic cancer goes on all the time. There are many types of research. Some may look into the causes of pancreatic cancer and how it can be diagnosed early and managed. One research study in Ireland is called the PanCam study.

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

There are many stages or **phases** when research is being done. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called **clinical trials**.

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

Your doctor may ask you to try a new treatment. There are many benefits to this. You will be helping to improve knowledge about cancer and new treatments. There is no need for worry as you will be carefully monitored during and after the study.

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

As part of the research into the causes of cancer, your doctors may ask your permission to store some samples of your cancer cells or blood. If you would like more information, call the National Cancer Helpline **1800 200 700**.

Cancer and complementary therapies

There is great interest today in complementary treatments for cancer. Some people find them helpful and beneficial during their illness. In many countries the way cancer is treated depends on the culture in which you live. In Ireland, cancer treatments are based on scientific research, which allows the response to treatment, side-effects and the general effect of treatment to be predicted. You may hear about the following types of treatments or therapies.

Conventional therapies

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

Complementary therapies

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

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

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

Some therapies can also help with physical problems. For example, acupuncture can help nausea and vomiting due to chemotherapy, and also a severely dry mouth due to radiotherapy.

Alternative therapies

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

You may read about therapies that claim to cure pancreatic cancer. For example, producers of the herb *Sarcandra glabra* claim it can cure pancreatic cancer but there is no evidence to prove this.



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. Make sure that the practitioners you plan to visit are properly qualified and have a good reputation. Check to see if they belong to a professional body or not. If you are unsure but would like to know what other patients have found helpful, contact your doctor or a patient support group. Also, it is important to make sure that the practitioner is charging a fair price for your treatment.

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

Advanced pancreatic cancer

Supportive care

If your cancer is at an advanced stage, you will still get the best treatment available to ease your symptoms. This will help to give you a better quality of life for as long as possible.

The most common symptoms of pancreatic cancer are

- Pain
- Jaundice
- Eating problems
- Weight loss
- Vomiting
- Fatigue

Other symptoms such as fluid that collects in your abdomen (ascites) can also cause problems. Some symptoms can be helped by surgery, chemotherapy and radiotherapy. The palliative care team can also help with any symptoms that are causing you problems.

»»» Tell your doctor if you have symptoms that are troubling you.

Pain

Pancreatic cancer can cause pain. If the cancer has spread, there may be more pain in your tummy area (abdomen) and around your back. Do tell your doctor and nurse about any pain as there are ways to treat it.

Treatment: Your doctor will try to find out first what is causing the pain, e.g. a blockage or pressure on the nerves. Surgery, radiotherapy or chemotherapy can all help to ease pain. Your doctor will decide if these treatments can help you. There are also a lot of good painkillers like morphine available today. If the medication does not work, tell your doctor or nurse. You may need to try other painkillers before you find one that suits you best. There are also other ways to treat pain such as nerve blocks and epidural injections. The coeliac plexus block is often used for pancreatic pain. It is important that your pain is under control so that you can enjoy your normal activities.

What you can do: If you are in pain, tell your doctor or nurse about it straight away. Be honest about the level of pain that you are in. Don't suffer in silence or play down the amount of pain you have. Do take your painkillers regularly as they will help to keep your pain under control.

Some painkillers have side-effects, especially the strong ones. These side-effects may include constipation, feeling sick (nausea) and drowsiness. If you have constipation it's a good idea to take a laxative every day. This and drinking plenty of clear fluids such as water and fruit juice between meals will help to keep your bowel habit regular. Your doctor or nurse will give you something stronger if your bowels have not opened for 2 or 3 days.

If you are feeling sick, your doctor may give you anti-sickness tablets. These should be taken 30 minutes before your painkillers. This nausea often improves as you get used to your medication. Drowsiness may happen when you take a stronger painkiller. But it usually wears off after a few days. Do not drive or work machinery if you feel drowsy.

More information: Talk to your doctor or nurse or call the National Cancer Helpline 1800 200 700 for more advice.

Jaundice

Jaundice happens when the cancer blocks the bile ducts in your pancreas or if it has spread to your liver. This causes the bile to be absorbed into your bloodstream instead. In turn it causes your skin and whites of your eye to become yellow in colour. Your skin then gets dry and itchy, your urine becomes dark in colour and your stools pale. You may feel sick, weak and tired, and have windy pains.

Treatment: Bypass surgery can help to remove the blockage. This blockage can also be helped by putting in a small metal tube (stent). See page 28 for more about bypass surgery. A special tube to drain the bile can also be put in through your skin if needed. The bile flows into a drainage bag outside your body that can be emptied each day. If your skin is very itchy, your doctor may prescribe antihistamines to relieve it.

What you can do: Calamine lotion or cool water on your skin can help to ease the itching. Baking soda can help to soothe and soften your skin too. Add a half cup of baking soda to a bath of warm water and soak in it. When washing, use a mild soap on your skin. Add moisture to your skin with soothing lotions such as cocoa butter.

More information: Ask your doctor or nurse or call the National Cancer Helpline 1800 200 700 for more details on jaundice.

Eating problems

You may find it hard to eat well due to the effects of cancer and its treatment. But there are many ways to help you boost your appetite and make sure you are getting enough calories.

Treatment: Your doctor may prescribe pancreatic enzymes in tablet form to help you digest your food so it can be absorbed. He or she may prescribe anti-sickness tablets for you to take before eating if you have nausea. You may be given a laxative if you are constipated or medication to stop diarrhoea, if these are a problem. Your dietitian can advise you on nutritious snacks, high-energy foods to take, and how best to take your pancreatic enzymes.

What you can do: You may find it easier to eat small snacks throughout the day rather than three main meals. Try to eat foods that are high in protein and calories. These can help you to feel better and give you more energy. Drinking plenty of fluids can help if constipation and diarrhoea are a problem.

More information: Talk to your dietitian or nurse for more advice or call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Diet and Cancer*.

Nutritious snacks high in calories and protein

- Baked potatoes with beans, cheese, tuna, crème fraîche
- Breakfast cereal – hot or cold
- Beans
- Cheese and crackers
- Creamy soups or broth
- Custards
- Dips made with cheese or yoghurt
- Hot chocolate
- Ice cream



- Milk puddings
- Milkshakes or smoothies
- Mousse
- Muffins or scones
- Nuts
- Omelette
- Quiche
- Sandwiches
- Sausages
- Scrambled eggs
- Creamy soups or broth
- Yoghurt or fromage frais

Weight loss

Pancreatic cancer can cause a lot of weight loss. This can leave you feeling weak and tired and not able to eat. Your dietitian can discuss ways to increase calories so that you can feel stronger and improve your quality of life.

Treatment: In rare cases a special feeding tube may be put into your gut to give you nutrients in liquid form. This may be done if you cannot take in enough calories by mouth. If your gut is not working at all, your doctor may decide to give you nutrients directly into a vein. This is called total parenteral nutrition (TPN). TPN is usually only given if there is a blockage in the bowel. Your dietitian and doctor will decide if these forms of nutrition are suitable for you.

What you can do: Eat little and often and choose nourishing foods. This can include nutritious snacks and build-up drinks. Adding butter or cream to foods is one way to increase calories.

More information: Talk to your doctor, dietitian or nurse for more advice. You can also call the National Cancer Helpline 1800 200 700 for a free copy of the booklet, *Diet and Cancer*.



Tips & Hints – weight loss

- Make the most of your appetite when it's good. Eat when you want.
- Take nourishing snacks high in calories and full of protein.
- Take snacks about every 2–3 hours. Do not skip meals.



- Add calories to food, for example, by adding milk, butter or cream.
- Avoid drinking liquids before meals.
- Take only small sips at mealtimes, as fluids may make you full.
- Do not put too much food on your plate. It can be offputting if your appetite is small.
- Try nutritional supplements when you find it hard to eat food.
- Keep snacks handy. Try cheese and crackers, sandwiches, muffins or scones.
- Take special high-calorie drinks to help keep your strength up. Your dietitian will advise you and your doctor prescribe them if suitable.
- Encourage your family to eat together and make mealtimes relaxing and enjoyable.

Vomiting

Vomiting can sometimes happen if the cancer is blocking your small bowel (duodenum). Food builds up where the blockage is and makes you feel sick (nausea) or vomit. It can affect your appetite as well so that you do not feel like eating.

Treatment: Bypass surgery may be done or a stent put in to unblock the area so that food can pass normally. Your doctor can prescribe anti-sickness tablets to ease the nausea and vomiting.

What you can do: Do not eat anything until the vomiting has stopped and is under control. Then try small amounts of clear liquids like water. Carry on taking small amounts of liquid as often as you can keep them down. Changing your diet may help, like eating small meals regularly. For example, try six to eight small meals every day of nourishing drinks – milk, milkshakes, Complan® – and softer food like ice-cream, custard, milk puddings and yoghurt.

More information: Talk to your doctor or nurse or call the National Cancer Helpline 1800 200 700 for more details.

Fatigue

Fatigue is a common symptom with cancer and is often described as an overwhelming tiredness. You also may find it hard to concentrate or make decisions. The reason for this fatigue can be hard to identify at first. It can be caused by the cancer itself or the worry of a cancer diagnosis or the stress of treatment.

Treatment: Treatment may help to relieve symptoms such as pain and nausea, allowing you to get back to your normal routine.

What you can do: If you are feeling very worried, you may find it hard to sleep at night. Do tell your doctor or nurse, who may be able to help. Also, try talking to your family or close friends about your concerns. If you find this difficult, ask to see a counsellor. He or she will help you to find ways to cope.

If your illness allows you to do physical exercise, get some regularly. For example, a 20-minute walk 3 days a week might be a realistic goal and will boost your morale when you achieve it. Get others to help you around the house, with travelling to hospital, with the children or with shopping. Use the extra free time to do something that you especially enjoy.

More information: A helpful booklet called *Coping with Fatigue* is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



Tips & Hints – fatigue

- Keep your energy for eating. Eat little and often and use ready-made meals or snacks.
- Build rest periods into your day. If you are going somewhere special, have a rest before you go out. Save your energy for doing the things you most enjoy.
- Wear clothes that are easy to put on and take off.
- Sit down when getting dressed or doing household jobs such as ironing, etc.



- Ask for help at work or at home, especially with cooking, housework or childcare.
- Do some gentle exercise each day. Ask your doctor or nurse for advice.
- If you find it hard to sleep, make sure your bedroom is quiet and not too hot or cold.
- Go to bed each night at the same time. Each morning get up at same time and do not lie in.
- Use relaxation techniques to get to sleep: gentle exercise, relaxation tapes, etc.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.

Who can help me at home?

If your family or friends decide to care for you at home, there are many health professionals who can give you practical advice and support. Some work in the community or are attached to hospitals or hospices. Others work between the hospital and your home.

Depending on where you live, services can vary from one Health Service Executive (HSE) area to another. Before you go home, you can get more information from the medical social worker in the hospital or at your local health centre. Your GP or public health nurse can also tell you what special palliative care services are available in your area. For more advice, call the National Cancer Helpline 1800 200 700 and ask for the booklet, *A Time to Care: Caring for Someone Seriously Ill at Home*.

Sometimes it may not be possible for someone to care for you at home, if your cancer is advanced and your symptoms are causing you problems. You and your family may need to think about hospice care. The palliative care team can give you and your family advice in this situation.

The following can help you at home:

- Family doctor (GP)
- Specialist palliative care service
- Clinical nurse specialist in palliative care (homecare nurse)
- Public health nurse or registered general nurse in the community
- Irish Cancer Society Night Nursing Service
- Care attendant (carer)
- Home help
- Medical social worker
- Community welfare officer
- Community dietitian
- Community physiotherapist
- Occupational therapist
- Community pharmacist
- Cancer support groups
- Carer's organisations



Who else can help?

There are many staff that can support and advise you when in hospital or during your outpatient visits. There are also other forms of support if you are at home.

Specialist nurses: The major cancer centres have pancreatic nurse specialists can give you all the help you need. The centres also have oncology liaison nurses and/or cancer nurse co-ordinators. These nurses are specially trained to give support to you and your family from the time of diagnosis and throughout treatment. They work alongside other members of the medical team to meet your needs.

Psycho-oncology services: Sometimes your illness may cause distress and anxiety that you might find hard to deal with. In some larger hospitals, there are special units that provide psycho-oncology services. This means that you can get special psychological care and support from a team of experts, if you need it. Usually the team consists of psychiatrists, clinical psychologists and nurses working closely together.

Helpline nurses: The Irish Cancer Society Helpline nurses can give you advice on any aspect of cancer care. Often you or your family or partner might need practical advice about financial matters. The nurses will be happy to discuss any concerns you or your family may have, at any

stage of your illness. The helpline can also put you in touch with cancer support centres and counsellors if you feel it would help.

Support groups: Joining a support group can put you in touch with people who have or had cancer. They can give you practical advice about living with cancer or if your recovery is not going well. You may find it easier to share your thoughts and feelings with someone who has a similar experience than with anyone else. There are a range of support groups that will support you and your family at time of diagnosis, throughout treatment and afterwards. A list of support groups is given at the back of this booklet.

Internet: The internet can help you find out information about pancreatic cancer too. But be careful to visit sites that give reliable and accurate information. Look for the HON Code logo on websites that give health information. This is a sign that the information is reliable.

Some useful websites:

- **American Cancer Society:** www.cancer.org
- **Cancerbackup/Macmillan Cancer Support (UK):** www.cancerbackup.org.uk
- **Cancer Research UK:** www.cancerhelp.org.uk
- **EUROPAC:** www.europac-org.eu
- **Irish Cancer Society:** www.cancer.ie
- **National Cancer Institute (US):** www.nci.nih.gov
- **Pancreatica:** www.pancreatica.org
- **Pancreatic Cancer Action Network:** www.pancan.org
- **Pancreatic Cancer Research Fund:** www.pcrf.org.uk
- **Pancreatic Cancer UK:** www.pancreaticcancer.org.uk



For more websites, see pages 75-79 at the back of the booklet.

Advice for carers

Being a partner, carer or friend of someone with pancreatic cancer can be both a challenging and a rewarding experience. But it can also be tiring, frustrating and distressing. If you are to keep your strength and your spirits up, it is important to take good care of yourself.

- **Learn about cancer:** Learn more about pancreatic cancer and the emotional effects it can cause. This will help you to understand how you can support your partner and have realistic expectations of treatments.
- **Share worries:** Make sure you share your worries with someone else. Stay in touch with your own friends and get out when you can. Visit a friend for a chat or go shopping. Take every chance to get out and meet other people, even if you sometimes don't feel like it.
- **Take regular breaks:** If you live with someone who is anxious or depressed, try to make time for a break each day, even if it is just a walk to the shops or a trip to the library. This will give you something to look forward to each day. Ideally, you should also try to organise a longer break, such as an evening out with friends or a trip to the cinema each week. If you have young children, organise for your family or a babysitter to mind them for an hour or two, if possible.
- **Have little treats:** If you don't want to take a break, then at least give yourself little treats to keep yourself going. Order your favourite magazine each week and give yourself an hour to sit down with a cup of tea or coffee to read it. Or make sure that you can watch your favourite TV programme, have a long soak in the bath after a difficult day, or an early night with a good book.
- **Seek professional help:** If you find it difficult to cope, get help. If you have a close friend, talk through how you are feeling. If this is not possible or you feel you don't have anyone you trust, talk to your doctor. He or she can talk through your frustrations and feelings and can suggest other sources of help.
- **Look after physical health:** Protect your physical health too. See your doctor sooner rather than later if you have any niggling health concerns of your own.
- **Join self-help groups:** Find out about self-help groups, especially for carers of people with cancer. There are a number of voluntary organisations in the country that may provide help and support for you as a carer. In your situation, they can offer a variety of practical support and give advice. Your GP, public health nurse or specialist palliative care service can inform you of local groups too.

Coping and emotions

How can I cope with my feelings?

There are many reactions when told you have cancer of the pancreas. Reactions can differ from person to person. In fact, there is no right or wrong way to feel. There is also no set time to have one particular emotion or not. Some reactions may occur at the time of diagnosis, while others might appear or reappear later during your treatment or care.

Common reactions include:

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



Sometimes a cancer diagnosis can bring greater distress and cause anxiety and depression. This can often happen if your prognosis is not good. A helpful booklet that discusses them in detail is *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.

Shock and disbelief

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

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

Fear and uncertainty

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

There is no doubt that cancer is a scary word. Not surprisingly, you may have many fears when first told of your diagnosis. Often the first thing people think about is dying. It is true that if some cancers are diagnosed late, people can die. But nowadays some

treatments can control cancer for a good while. Another great fear about cancer is pain. The fear of pain can sometimes overwhelm everything else. It is true that pancreatic cancer can be painful but it 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. The palliative care team can also offer you support if your cancer is advanced.

Loss of control

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

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

unable to cope with your treatment or that you will 'fall to pieces' or 'go crazy'. You may even lose hope.

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

»»» Learning more about your illness and treatment can help you feel more in control.

Sorrow and sadness

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

It is natural to feel sad when told you have cancer. You may feel sad for a variety of reasons: for the loss of your good health, for the plans that are put on hold, for the people you feel you've let down, and for any changes to your body due to treatment.

Depending on your type of cancer, your fertility or body image may be affected by treatment. In this case, the sadness or sorrow can come from feeling as if a part of you has died. These feelings may not be there all the time and may come and go, but will gradually fade.

Denial

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

Sometimes after being told their diagnosis, people deny they have cancer. While this may seem unusual, it is a valid way of coping. As a result, you may not wish to mention or discuss your illness. Or else you may talk as if your illness is nothing serious. Denial may last for a short or 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 vent your anger on those closest to you. Indeed being unable to protect the ones you love may frustrate you a lot.

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

Resentment

'How can you talk – you don't have to deal with cancer.' 'How come I'm not getting better?'

It is natural that you might be resentful and unhappy – even jealous – because you have cancer while other people are well. During the course of your illness, similar feelings of resentment may occur for many reasons. You may resent that another patient receiving the same treatment as you has responded quicker

than you have. You may resent your healthy relatives or having to change your lifestyle in some way.

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

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

Blame and guilt

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

When diagnosed with a serious illness such as cancer, it is natural to want to know what caused it. Sometimes people blame themselves or others for their illness. As cancer experts rarely know exactly what has caused cancer, there is no good in blaming yourself. Other times, people feel guilty

because they delayed going to the doctor with their symptoms, fearing the worst. No matter what the reason, don't torture yourself at this time.

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

Withdrawal and isolation

'I just need to be on my own.'

There is no doubt that a cancer diagnosis is stressful. It can leave you feeling confused and overwhelmed with so much information to take in. At times during your illness you

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

If you would like more information on how to talk about your cancer, there is a useful booklet available called *Who Can Ever Understand?: Talking about Your Cancer*. If you would like a copy, call the National Cancer Helpline 1800 200 700.

Advanced cancer

You may have many emotions if faced with the prospect of dying. Naturally, this will be a difficult time for you and your family. The palliative care team can help to ease your cancer symptoms so that you can live your remaining life to the full.

You may like to spend time with your family and friends by going on holidays or doing things you most enjoy. You might like to set goals for yourself that you can realistically achieve. The palliative care team can also help you talk about dying. A booklet called *A Time to Care: Caring for Someone Seriously Ill at Home* can offer advice and useful tips if you are in this situation. Call the National Cancer Helpline 1800 200 700 for a free copy.

Positive emotions

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



How can my family and friends help?

Families and friends can support you through your cancer journey in different ways. Some family members and friends can offer a listening ear and give 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. Their welfare may be a priority for you, but you might still be unsure when to visit or what to talk about.

You may be afraid of upsetting them or saying the wrong thing. So it may seem best to pretend that everything is okay and carry on as normal. Sadly, by not talking to your friend or loved one, it can make them feel even more lonely and isolated. Try not to withdraw because you're afraid of their illness or what might happen in the future. Although some people do die from cancer, others do not. Be honest with your own feelings too.

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

Be patient

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

Lost for Words – How to Talk to Someone with Cancer is a useful booklet written for relatives and friends of people with cancer. Call the National Cancer Helpline 1800 200 700 for a free copy.

How can I talk to my children?

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

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

Be honest

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

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

How much you tell children will depend on their age and level of maturity. Very young children do not understand illness and need a simple reason why their parent or friend is sick and has to go to hospital regularly. A story about good cells and bad cells usually works well. Most children over 10 years of age can take in fairly full explanations of why you are sick. Adolescents can understand far more.

It is best to prepare children about the symptoms of pancreatic cancer and any side-effects of treatment before they happen. For example, if you have severe weight loss and jaundice, they may wonder why. Do 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. If your prognosis is not good, it is best to prepare your children for this as well.

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 cancer 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 too. Your family may also find new depths of love and inner strength that will boost your life together.

If you need 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. It also can help to prepare children for the loss of a parent as well. If you would like a free copy, call the National Cancer Helpline 1800 200 700.

What else can I do?

Everyone experiences cancer in a different way. And how each person copes with cancer varies too. There is no right or wrong way to cope, only your way. During your illness there are many things that you can learn, not only about cancer itself but also about you as a person. Here is a list of things to help make you feel more involved and more in control of your illness. They can help to boost your self-esteem and well-being, making it easier to deal with cancer.

- **Communicate with your family and close friends:** Do not keep your worries or symptoms secret from the people closest to you. This includes physical or emotional problems. Ask the person closest to you to come with you when visiting the doctor and when treatments will be discussed.
- **Live one day at a time:** Don't think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.
- **Live well:** Try to eat as well as you can. Eat little and often, using lots of different types of foods with plenty of fresh fruit and vegetables. Do some regular exercise that you enjoy. Take it easy at first, building up the amount you do as you feel stronger.
- **Expect change in your life:** Even though you may want to stick to your old routines, sometimes this may not be possible. It may take

a while for you to adjust to your new routine. Remember that change may bring new opportunities and blessings.

- **Keep an open mind:** Don't feel you have to be positive all the time. Expect ups and downs during your cancer journey. There will be times when you feel low but don't feel guilty about it, as it will pass.
- **Seek information:** Be sure to ask your doctor as many questions as you can and get involved in decisions about your treatment. Always ask for information that is personal to you. Ask what side-effects you can expect so you can prepare for them. Build up as much information about your cancer and treatment as possible. Follow your doctor's instructions carefully. Take your medication. If you forget and are not sure what to do, ask your doctor or nurse. Keep a notebook of all your dates for blood tests, X-rays, scans, treatments, symptoms, side-effects, medications, and your general health. Keep a record of any emotions you are feeling too, especially strong ones.
- **Find what works for you:** It can help to use whatever way of coping that has helped you solve problems in the past. Some people are comfortable talking about their illness, others are not. You may prefer relaxation, meditation, walking, listening to music, or other approaches helpful. Do whatever suits you. But if it's not working, be open to finding a new way to cope.
- **Build a support network:** Be realistic about what you can manage by yourself. No man is an island, so seek help from those who want to support you. Talk to your family, friends, nurses or doctors. Meet with other patients in support groups and self-help groups as they can understand what you are going through. If the group does not suit you and is not helping, leave it.
- **Seek professional help:** If you have any low moods or strong emotions, talk to your close friends and family – or someone who is a good listener. If your emotions are still getting the better of you, discuss them with your nurse and doctor. They may advise you talk to a trained counsellor or other specialist.

- **Spiritual care:** When faced with a cancer diagnosis and treatment, you may start thinking about the meaning of life and the afterlife. For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation can help you to focus on what has value and meaning in your life. Even if you do not consider yourself a religious or spiritual person, it is still possible to get support from prayer or meditation. Some complementary therapies that have a spiritual dimension may also help you to focus on being positive and hopeful.
- **Express yourself:** Keep a diary or journal if you need to express yourself without holding back. It can help you to make sense of your cancer journey and can bring great healing and relief. Other forms of creative expression, such as music and art, may help too.

A useful booklet called *Understanding the Emotional Effects of Cancer* has been written for people with cancer and is available from the Irish Cancer Society. Call the National Cancer Helpline 1800 200 700 for a free copy.



Support resources

Health cover

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

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



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

Hospital cover

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

Outpatient cover

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

Medical card

A medical card usually allows you, your spouse and any child under 16 to free GP services, prescribed drugs and medicines, inpatient public hospital services as well as outpatient services and medical appliances.

To qualify for a medical card depends on a means test. If you are over 70 and your weekly income is €700 or less, you can apply for a card.

Financial guidelines are set out each year and are available from your local Health Service Executive (HSE) office. If your means are above but close to the guidelines, you should apply for a card anyway as a card may be granted in some situations. For example, if you have a large amount of medical expenses. Also, you may qualify for a medical card because you have a cancer diagnosis. In this case, your spouse and children will not be covered if your means are over the limit.

GP visit card

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

Drugs Payment Scheme

Under the Drugs Payment Scheme (DPS), individuals and families including spouses and dependent children pay a limit of €120 each month to cover the cost of prescribed drugs, medicines and appliances. You can apply for cover under the scheme by contacting your local HSE office. You can also register for this scheme by filling in a registration form at your local pharmacy.

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Quinn Healthcare, Hibernian AVIVA Health and other schemes. They provide cover for day care/inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services. If you have private insurance, you may not always be able to have your tests done as quickly as you would like. Your health insurer has to approve some

tests in advance, e.g. MRI scan, PET scan. In some cases, it may take 24–48 hours to get approval from your health insurer.

Benefits and allowances

Information on the following is given in this section:

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



Illness Benefit

This is a benefit for insured people. Your eligibility will depend on your PRSI contributions. You must be under 66 and unable to work due to illness. Each week you must send a social welfare medical certificate signed by your doctor to the Dept of Social and Family Affairs, PO Box 1650, Dublin 1. Tel (01) 679 7777. These certificates are available from your GP and from the hospital you attend during inpatient care. You should send your claim to the Department within 7 days of becoming ill and unable to attend work. A delay might result in loss of payment. The benefit lasts for 2 years.

Disability Allowance

You might qualify for disability allowance if you are not eligible for illness benefit and not able to work for at least 1 year. Disability allowance is a weekly allowance paid to people with an injury, disease or a disability who are aged between 16 and 65. For this allowance you must satisfy a means test, normally live in Ireland and be medically suitable. To be medically suitable you should have an illness that has continued or may continue for at least 1 year.

You are allowed a free travel companion pass and a household benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme.

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

Invalidity Pension

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

Your eligibility will also depend on your PRSI contributions and you must normally live in Ireland. You are allowed a free travel pass and a household benefits package – including an electricity or gas allowance, telephone allowance and free television licence – and a fuel allowance. You are also entitled to a medical card and assistance under the Supplementary Welfare Allowance Scheme. Application forms are available from the Invalidity Pension Claims Section, Social Welfare Services Office, Government Buildings, Ballinalee Road, Longford. Tel: (043) 334 0000 or Locall 1890 927 770.

Carer's Allowance

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

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

Carer's Benefit

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

Appliances

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

Travel to hospital

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

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

Further information

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

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

For social welfare queries contact:

Information Service Tel: 01 7043 000
 Dept of Social and Family Affairs Leaflet line: 1890 202 325
 Oisín House Email: info@welfare.ie
 212–213 Pearse Street Website: www.welfare.ie
 Dublin 2

If you have queries about health and social services, contact the HSE office in your area. The Health Service Executive is based in four regions: HSE Dublin North East, HSE Dublin Mid-Leinster, HSE South, and HSE West. For more information contact:

HSE infoline: 1850 241 850; **Email:** info@hse.ie; **Website:** www.hse.ie.

HSE East Coast Area

[Co Wicklow, South East Dublin]
 Southern Cross House
 Southern Cross Business Park
 Boghall Road
 Bray
 Co Wicklow
 Tel: 01 2014 200

HSE Northern Area

[North Dublin]
 Swords Business Campus
 Balheary Road
 Swords
 Co Dublin
 Tel: 01 8131 800

HSE South Western Area

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

HSE Midland Area

[Counties Laois, Offaly, Longford, Westmeath]
 Head Office
 Arden Road
 Tullamore
 Co Offaly
 Tel: 057 9321 868

HSE Mid-Western Area

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

HSE North Eastern Area

[Counties Cavan, Monaghan, Louth and Meath]
 Head Office
 Navan Road
 Kells
 Co Meath
 Tel: 046 9280 500

HSE North Western Area

[Counties Donegal, Sligo, Leitrim and West Cavan]
 Head Office
 Manorhamilton
 Co Leitrim
 Tel: 071 9820 400 / 1850 636 313

HSE South Eastern Area

[Counties Carlow, Kilkenny, Wexford, Waterford, South Tipperary]
 Head Office
 Lacken
 Dublin Road
 Kilkenny
 Tel: 056 7784 100

HSE Southern Area

[Counties Cork and Kerry]
 Head Office
 Wilton Road
 Cork
 Tel: 021 4545 011

HSE Western Area

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

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

Citizens Information Board (formerly Comhairle)

7th Floor, Hume House, Ballsbridge, Dublin 4

Tel: 01 605 9000

Citizen Information Service: 1890 777 121

Email: information@ciboard.ie

Website: www.citizensinformationboard.ie

There are also some booklets available that may help you. These include:

- *Information Guide to Health Services* (published by the Dept of Health and Children). Copies are available from your local HSE area office. Tel: 01 671 4711 for local HSE numbers.
- *Guide to Social Welfare Services* (published by the Dept of Social and Family Affairs). Copies available from the Dept of Social and Family Affairs. Tel: 01 874 8444. Email: info@welfare.ie. Website: www.welfare.ie
- *Entitlements for People with Disabilities* (published by Comhairle). Available from Citizens Information Board. Tel: 01 605 9000 / 1890 777 121. Website: www.citizensinformationboard.ie

If you have financial worries...

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

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses arising due to your illness. See page 74 for more details. You can also call the National Cancer Helpline 1800 200 700 for ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline 1890 283 438. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. See page 76 for contact details.

Irish Cancer Society services

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

- Cancer Information Service (CIS)
- Cancer support groups
- Counselling
- Night nursing
- Oncology liaison nurses
- Homecare nurses
- Cancer information booklets
- Financial aid



Cancer Information Service (CIS)

The Society provides a Cancer Information Service with a wide range of services: the **National Cancer Helpline** is a freefone service that gives confidential information, support and guidance to people concerned about cancer. It is staffed by specialist cancer nurses who have access to the most up-to-date facts on cancer-related issues. These include prevention of cancer, risk factors, screening, dealing with a cancer diagnosis, different treatments, counselling and other

support services. The helpline can also put you in contact with the various support groups that are available. The helpline 1800 200 700 operates Monday to Thursday from 9am to 7pm, and every Friday from 9am to 5pm.

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

Cancer support groups

The Irish Cancer Society funds a range of support groups set up to support you and your family at time of diagnosis, throughout treatment and afterwards. See page 76 for more details.

Counselling

Coping with a diagnosis of cancer can be very stressful. Patients and their families sometimes find it difficult to come to terms with the illness. Many people feel that they cannot talk to a close friend or relative. Counselling can provide emotional support in a safe and confidential environment. Call the helpline to find out about counselling services provided by the Irish Cancer Society and services available in your area.

Night nursing

The Irish Cancer Society can provide a night nurse, free of charge, for up to 70 hours (mainly at night) to families who are caring for a seriously ill person at home. If you need help, you can find out more about this service from a member of the homecare team, your GP or local public health nurse.

Oncology liaison nurses

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

Homecare nurses

Homecare nurses are specialist palliative care nurses who offer advice on pain control and other symptoms. These nurses work with GPs and public health nurses to form homecare teams bringing care and support, free of charge, to patients in their own homes. Based in local hospitals, health centres and hospices, they can be contacted through your GP or public health nurse. The Irish Cancer Society contributes financially to this service.

Cancer information booklets

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



Financial aid

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



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



Useful organisations

Irish Cancer Society

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

The Carer's Association

Prior's Orchard
John's Quay
Kilkenny
Tel: 056 772 1424
Freefone 1800 024 0724
Email: ceo@carersireland.com
Website: www.carersireland.com

Citizens Information Board (formerly

Comhairle)
7th Floor, Hume House
Ballsbridge
Dublin 4
Citizen Information Service: 1890 777 121
Tel: 01 605 9000
Email: information@ciboard.ie
Website: www.citizensinformationboard.ie

Dept of Social and Family Affairs –

Information Service
Oisín House
212–213 Pearse Street
Dublin 2
Tel: 01 704 3000
Email: info@welfare.ie
Website: www.welfare.ie

HARI Unit (Human Assisted Reproduction Ireland)

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

Health Promotion HSE

Website: www.healthpromotion.ie

Irish Nutrition & Dietetic Institute

Ashgrove House
Kill Avenue
Dún Laoghaire
Co Dublin
Tel: 01 280 4839
Fax: 01 280 5082
Email: info@indi.ie
Website: www.indi.ie

Irish Patients Association

Unit 1, 21 Church Road
Ballybrack
Co Dublin
Tel: 01 272 2552
Out-of-hours emergency: 087 652 9448
Email: info@irishpatients.ie
Website: www.irishpatients.ie

Money Advice and Budgeting Service (MABS)

Commercial House
Westend Commercial Village
Blanchardstown
Dublin 15
Tel: 8129350
Freefone 1890 283 438
Email: ndl@mabs.ie
Website: www.mabs.ie

Health insurers

Hibernian AVIVA Health

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

Quinn Healthcare (formerly BUPA)

Mill Island
Fermoy
Co Cork
Local: 1890 700 890
Fax: 025 42122
Email: info@quinn-healthcare.com
Website: www.quinn-healthcare.com

Voluntary Health Insurance (VHI)

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

National support groups**Bowel Cancer Support Group**

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

CanTeen Ireland

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

Lymphoma Support Ireland

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

Men Against Cancer (MAC)

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

Reach to Recovery

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

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

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

ARC Cancer Support Centre

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

Beacon Cancer Support Centre

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

Bray Cancer Support & Information Centre

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

Cancer Information & Support Centre

Mid-Western Regional Hospital
Dooradoyle
Co Limerick
Tel: 061 485163
Website: www.midwesterncancercentre.ie

Cancer Support Centre

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

CARE – South Tipperary Cancer Support Centre

14 Wellington Street
Clonmel
Co Tipperary
Tel: 052 82667
Email: caresupport@eircom.net
Website: www.cancercare.ie

Cork ARC Cancer Support House

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

The Cuisle Centre

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

Dóchas – Offaly Cancer Support

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

Dundalk Cancer Support Group

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

Éist – Carlow Cancer Support Group

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

Éist – East Inishowen Cancer Support Group

Moville
Co Donegal
Tel: 074 938 2874

The Gary Kelly Support Centre

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

Greystones Cancer Support

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

HOPE

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

Inis Aoi bhinn – Cancer Care West

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

Kerry Cancer Support Group

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

LARCC Retreat Centre

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

Listowel Cancer Support Group

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

Little Way Cancer Support Centre

4 Woods Way
College Road
Clane
Co Kildare
Tel: 045 902 996
Email: littlewayclane@eircom.net
Website: www.littlewaycancersupport.com

Little Way Cancer Support Centre

8 Stanhope Street
Athy
Co Kildare
Tel: 059 864 1701

Living Beyond Cancer

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

Mayo Cancer Support Association

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

Roscommon Cancer Support Group

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

Sligo Cancer Support Centre

2A Wine Street
Sligo
Tel: 071 9670 399
Email: scsc@eircom.net
Website: www.sligocancersupport.ie

'Solas' – Donegal Cancer Support Centre

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

South East Cancer Foundation

7 Sealy Close
Earlscourt
Waterford
Tel: 051 876 629
Fax: 051 876 718
Email: infosecf@eircom.net

Suimhneas Cancer Support

Pastoral Centre
Church Road
Nenagh
Co Tipperary
Tel: 067 37403

Tallaght Cancer Support Group

Tel: 087 217 6486

The Tuam Cancer Care Centre

30 Temple Jarlath Court
High Street
Tuam
Co Galway
Tel: 093 28522
Email: tcgg@eircom.net
Website: www.tuamcancercare.ie

West Clare Cancer Support Group

Tel: 065 905 6327 / 065 905 1517
Email: hlnKennedy@hotmail.com

Wicklow Cancer Support

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

**Useful contacts outside
Republic of Ireland****Action Cancer**

Action Cancer House
1 Marlborough Park
Belfast BT9 6XS
Tel: 028 9080 3344
Fax: 028 9080 3356
Email: info@actioncancer.org
Website: www.actioncancer.org

American Cancer Society

1599 Clifton Road NE
Atlanta, GA 30329-4251
Website: www.cancer.org

Cancerbackup/Macmillan Cancer Support (UK)

89 Albert Embankment
London SE1 7UQ
Tel: 0044 207 840 7840
Website: www.cancerbackup.org.uk

Cancer Research UK

Website: www.cancerhelp.org.uk

EUROPAC

EUROPAC Study Co-ordinator
Division of Surgery and Oncology
University of Liverpool
5th Floor UCD Building
Royal Liverpool University Hospital
Daulby Street
Liverpool L69 3GA, UK
Tel: 0044 (0) 151 706 4168
Email: europac@liverpool.ac.uk
Website: www.europac-org.eu

Macmillan Support & Information Centre

Belfast City Hospital Trust
79–83 Lisburn Road
Belfast BT9 7AB
Tel: 028 9069 9202
Fax: 028 9069 9203
Email: cancer.info@bch.n-i.nhs.uk
Website: www.actioncancer.org

Mayo Clinic (US)

Website: www.mayoclinic.com

Memorial Sloan-Kettering Cancer Center (US)

Website: www.mskcc.org

National Cancer Institute (US)

Website: www.nci.nih.gov

Pancreatica

Website: www.pancreatica.org

Pancreatic Cancer Action Network

Website: www.pancan.org

Pancreatic Cancer Research Fund

PO Box 47432
London N21 1XP, UK
Tel: 0044 (0)20 8360 1119
Email: m0003@pcrf.org.uk
Website: www.pcrf.org.uk

Pancreatic Cancer UK

Website: www.pancreaticcancer.org.uk

Royal Marsden Hospital Foundation NHS Trust

Fulham Road
London SW3 6JJ
Tel: +44 20 7808 2811
Website: www.royalmarsden.nhs.uk

The Ulster Cancer Foundation

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

University of Pennsylvania Cancer Center

Website: www.oncolink.com

Helpful books

Free booklets from the Irish Cancer Society:

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *Radiation Therapy: A Patient Pathway (DVD)*
- *Understanding Cancer and Complementary Therapies*
- *Coping with Fatigue*
- *Diet and Cancer*
- *Understanding the Emotional Effects of Cancer*
- *Lost for Words: How to Talk to Someone with Cancer*
- *Who Can Ever Understand? Taking About Your Cancer*
- *Talking to Children about Cancer: A Guide for Parents*
- *A Time to Care: Caring for Someone Seriously Ill at Home*



Cancer at Your Fingertips

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

Challenging Cancer: Fighting Back, Taking Control, Finding Options

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

The Chemotherapy and Radiation Therapy Survival Guide: Information, Suggestions, and Support to Help You Get through Treatment

Judith McKay, Nancee Hirano & Myles E Lampenfeld
New Harbinger, 1998
ISBN 1-57224-070-9

The Bristol Approach to Living with Cancer

Helen Cooke
Robinson, 2003
ISBN 1-84119-680-0

The Key Model – A New Strategy for Cancer Recovery

Dr Sean Collins & Rhoda Draper
Ardagh Clinic, 2004
ISBN 0-95214-445-X

The Secret C: Straight Talking About Cancer [explaining cancer to children]

Julie A Stokes
Winston's Wish, 2000
ISBN 0-95391-230-2

Taking Control of Cancer

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

What You Really Need to Know about Cancer

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

Why Mum? A Small Child with a Big Problem

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

Helpful DVD

Understanding Radiation Therapy: A Patient Pathway

Call 1800 200 800 for a copy.
Website: www.cancer.ie

Questions to ask your doctor

Here is a list of questions that you may want 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 will I know if I have pancreatic cancer?
- What tests do I need?
- How long will it take to get the test results?
- What type of pancreatic cancer do I have?
- What stage is my cancer at? Has it spread beyond my pancreas?
- What treatment will I need?
- Will surgery cure my cancer? Can the cancer be resected?
- Are there other treatment options? Why is this one best for me?
- Will I be transferred to a centre that specialises in treating pancreatic cancer?
- What is my prognosis?
- Would I be suitable for a clinical trial?
- How long will my treatment take?
- Do I have to stay in hospital for my treatment?
- What side-effects or after-effects will I get?
- Is there anything I can do to help myself during treatment?
- Should I stop smoking or drinking?
- Should I change my diet?
- Will I be able to have children?
- Can my symptoms be controlled?
- What does palliative care mean?
- How often will I need check-ups?
- Can my family be screened for pancreatic cancer?

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Would you like more information?

We hope this booklet has been of help to you. If you feel you would like more information or someone to talk to, please phone our National Cancer Helpline 1800 200 700.

Would you like to be a patient reviewer?

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

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, education and research. 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.

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

