

Understanding

Cancer of the Pancreas

Caring for people with cancer

Understanding

Cancer of the Pancreas

This booklet has been written to help you understand more 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:
Medical social worker	Tel:
Dietitian	Tel:
Emergency number	Tel:
Treatments	Review dates

If you like, you can also add:

Your name _____

Address _____

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

PANCREATIC CANCER ADVISERS

Prof Kevin Conlon, Consultant General Surgeon
Mr Paul F Ridgway, Senior Lecturer in Surgery/Consultant Surgeon
Mr Justin Geoghegan, Consultant Surgeon
Dr Ray McDermott, Consultant Medical Oncologist
Dr Jerome Coffey, Consultant Radiation Oncologist
Marie Egan, Pancreatico-Biliary Nurse Specialist
Sinéad Duggan, Senior Clinical Nutritionist
Maebh Doran, Upper GI/Hepatobiliary and Pancreas Oncology Coordinator
Emer Burton, Clinical Nurse Specialist
Anne McGuire, Clinical Nurse Specialist
Oonagh Griffin, Senior Dietitian

CONTRIBUTOR

Anne-Marie McGrath, Cancer Nurseline Nurse

EDITOR

Tara Droog

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

- *A Strategy for Cancer Control in Ireland*, National Cancer Forum, 2006.
- *Cancer in Ireland: 1994–2004: A Summary Report*, National Cancer Registry Ireland & Northern Ireland Cancer Registry, 2009.
- 'Treatment of Pancreatic Adenocarcinoma: A European Perspective', DJ Gouma, ORC Busch, TM van Gulik, *Surgical Oncology Clinics of North America* 17, 2008.
- 'Guidelines for the Management of Patients with Pancreatic Cancer Periampullary and Ampullary Carcinomas', Pancreatic Section of the British Society of Gastroenterology, Pancreatic Society of Great Britain and Ireland, Association of Upper Gastrointestinal Surgeons of Great Britain and Ireland, Royal College of Pathologists, Special Interest Group for Gastro-Intestinal Radiology, *Gut* 54, 2005.
- *Cancer Nursing: Principles and Practice*, CH Yarbro, MH Frogge, M Goodman & SL Groenwald, Jones and Bartlett, 2000.
- *The Chemotherapy Source Book*, M Perry, Lippincott Williams and Wilkins, 1997.

Published in Ireland by the Irish Cancer Society.

© Irish Cancer Society, 2010, revised 2016

Next revision: 2018

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

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

ISBN 0-95323-690-1

Contents

4 Introduction

About pancreatic cancer

- 5 What is cancer?
- 6 What is the pancreas?
- 7 What is cancer of the pancreas?
- 7 What increases your risk of getting pancreatic cancer?
- 10 What are the symptoms of pancreatic cancer?
- 11 How is pancreatic cancer diagnosed?
- 15 What are the types of pancreatic cancer?
- 15 What are the stages of pancreatic cancer?

Treatment and side-effects

- 17 How is pancreatic cancer treated?
- 22 Surgery
- 29 Chemotherapy
- 34 Radiotherapy
- 36 What follow-up do I need?
- 37 Research – what is a clinical trial?
- 38 Cancer and complementary therapies

Controlling symptoms

- 41 Supportive care
- 48 Palliative care
- 48 Who can help me at home?
- 49 Who else can help?
- 50 Advice for carers

Coping and emotions

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

Support resources

- 65 Health cover
- 69 Irish Cancer Society services
- 71 Useful organisations / Helpful books
- 78 What does that word mean?
- 81 Questions to ask your doctor
- 82 Your own questions

Introduction

This booklet has been written to help you understand about cancer of the pancreas. It is divided into 5 parts:

- **About pancreatic cancer** gives an introduction to cancer of the pancreas, including symptoms and diagnosis.
- **Treatment and side-effects** looks at the different treatments used and possible side-effects.
- **Controlling symptoms** gives details of the supportive care that you can get if your pancreatic cancer is advanced.
- **Coping and emotions** discusses your feelings and the emotional effects of having cancer of the pancreas.
- **Support resources** gives information on further sources of help and support. This includes helpful organisations, books, support groups and websites. You will also find an easy-to-read explanation of words and terms used throughout this booklet.

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

>>> Reading this booklet

Remember 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 want to know more, read another section. If you do not understand something that has been written, discuss it with your doctor or nurse. You can also call our Cancer Nurseline on Freephone 1800 200 700. You can also visit a Daffodil Centre. See page 69 for more information about Daffodil Centres.

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



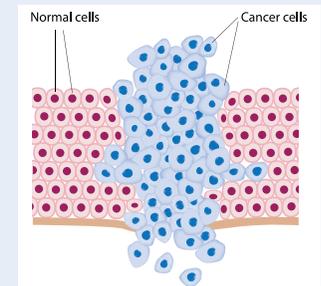
Cancer Nurseline Freephone 1800 200 700

About pancreatic cancer

>>> What is cancer?

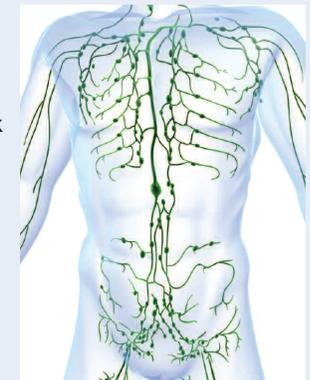
Cancer is a word used to describe a group of diseases, not just one. There are more than 200 different types of cancer. Each is named after the organ or type of cell in which the cancer first grows. For example, prostate cancer, breast cancer or leukaemia. All cancers are a disease of the body's cells,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

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



What is the lymphatic system?

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



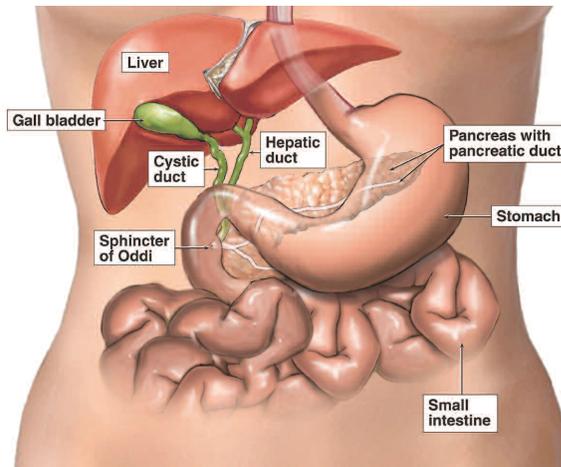


To sum up

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

What 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 leaf and has three main parts: the head, the body and the tail. The head is the broad rounded part of your pancreas. It is connected to the last part of the stomach (the pylorus) and the first part of the small bowel (the duodenum). The body lies in the middle and the tail is the thin end below your left ribcage. Important structures and several blood vessels surround the pancreas.



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.

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 increases your risk of getting pancreatic cancer?

The exact cause of pancreatic cancer is unknown. It is not a common cancer and affects about 400 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:

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

Age: The risk of getting pancreatic cancer increases with age and most people diagnosed are over 60 years of age

Smoking: Smoking is associated with almost a third of all pancreatic cancer cases. The chemicals in cigarettes, cigars and chewing tobacco increase your risk of getting cancer.

Obesity: If you are overweight or obese, you have a higher risk of getting pancreatic cancer. Your risk is also higher if you are not physically active.

Diet: Recent research suggests that diets high in sugar, animal fat or red meat can increase your risk of getting pancreatic cancer. A lack of fresh fruit and vegetables in your diet may also increase the risk.

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 rule out 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 11 for more about these tests. You may be offered genetic counselling if you have a strong family history of pancreatic disease or cancer. If you are a smoker, you will be advised to quit.

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 37 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
- Painless jaundice – yellow, itchy skin; dark urine; pale stools
- Indigestion that does not respond to treatment
- Feeling full very quickly
- Change in bowel habit – pale, smelly, floaty stools
- Sickness or nausea
- Feeling very tired
- A new diagnosis of diabetes without weight gain
- A new diagnosis of irritable bowel syndrome over the age of 50

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.

If the symptoms listed above are occurring on most days and are getting worse, you should get them checked out by your doctor. Remember that these symptoms can be caused by conditions other than cancer. For example, jaundice 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 do a physical exam, discuss your symptoms and ask you about your family medical history. They will also check your urine and blood. After that, you are likely to be referred to a hospital specialist for more tests.

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

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.

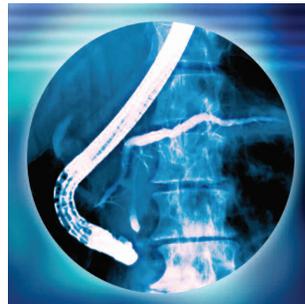
CT scan (CAT scan): This special X-ray gives a detailed picture of the tissues inside your body. The scan is painless. It is the most important test in the diagnosis of pancreatic cancer. For a CT scan of your abdomen, you may be asked to fast before the test. You may be given a special drink which helps 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.

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.

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 ultrasound



An ERCP

Endoscopic ultrasound (EUS): An EUS 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.

MRCP scan: 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.

MRA scan: 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 laparoscopy

A small sample of tissue (biopsy) may be taken and examined in the lab. This is to confirm a diagnosis of pancreatic cancer. 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.

Biopsy: 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.



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 our Cancer Nurseline on 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 our Cancer Nurseline on 1800 200 700 to speak to one of our cancer nurses.

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.

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

- **Stage 1:** This means the cancer is at a very early stage. The tumour is approximately 2cm in size or less and found within the pancreas. There is no sign that it is in the lymph nodes or that it has spread.
- **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.

Cancer Nurseline Freephone 1800 200 700

Treatment and side-effects

How is pancreatic cancer treated?

Because pancreatic cancer is a rare cancer, all surgery is carried out in specialist pancreatic cancer centres. The staff at these centres have great experience in managing patients with pancreatic cancer who need surgery. As a result, you may be transferred to another hospital from the one where you receive your diagnosis. If this happens, your doctor will explain why. Your doctor will still work closely with the surgeon in the specialist centre.

In Ireland surgery for pancreatic cancer is carried out at St Vincents University Hospital, Dublin and Cork University Hospital.

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

There are many ways to treat pancreatic cancer. Once all the tests 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 to remove pancreatic cancer: 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 22 for more details.

Chemotherapy: Chemotherapy is sometimes given to patients with pancreatic cancer. It can be given before or after surgery or on its own. Chemotherapy before surgery is called neoadjuvant chemotherapy. In pancreatic cancer this may be given for 3 months and then a scan is done. This scan will help your doctors to decide whether the chemotherapy has been able to shrink the tumour and if surgery is possible. Newer drugs called targeted therapies are also being used for pancreatic cancer. These drugs only target the cancer cells. They work by blocking the signals that tell cancer cells to grow and divide.

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 can be used to shrink the tumour before surgery can be done.

Surgery to relieve symptoms (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. See page 26 for more details.

Using stents to relieve symptoms: 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. Having a stent put in does not need an operation as such. For more information see page 26.

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 48 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 unusual for it to be diagnosed at an early 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:

Hepatobiliary surgeon	A surgeon who specialises in surgery to the pancreas, liver, gall bladder and bile ducts.
Gastroenterologist	A doctor who specialises in diseases of the digestive system.
Endocrinologist	A doctor who specialises in diseases of the endocrine system. Also specialises in other conditions 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.

Clinical nurse specialist/ oncology liaison nurse	A specially trained nurse who works in a special cancer care unit. They can help give you and your family information and support from diagnosis and throughout treatment. They may help to organise care for you after you leave the hospital.
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. They can help you and your family cope with the emotional distress. In the community, they are known as the 'homecare team'. A specialist palliative care service is available in most general hospitals.
Radiation therapist	A specialist 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 free counselling service. For details, call our Cancer Nurseline on Freephone 1800 200 700 or visit a Daffodil Centre.

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.

Multidisciplinary team meeting: A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of cancer. They will meet to discuss your test results and decide your treatment plan.

Treatment options: Your doctor and nurse will explain your treatment options. 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. Do bring a relative or friend with you when you are discussing your treatment with your doctor.

Second opinion: It is important that you agree with your doctors' decision on what is the best treatment plan for you. If you are unhappy, you are free to get a second medical opinion. This may take some time, so it is best to do it as quickly as possible.

Giving consent

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

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

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



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 shrink the tumour.
- 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.

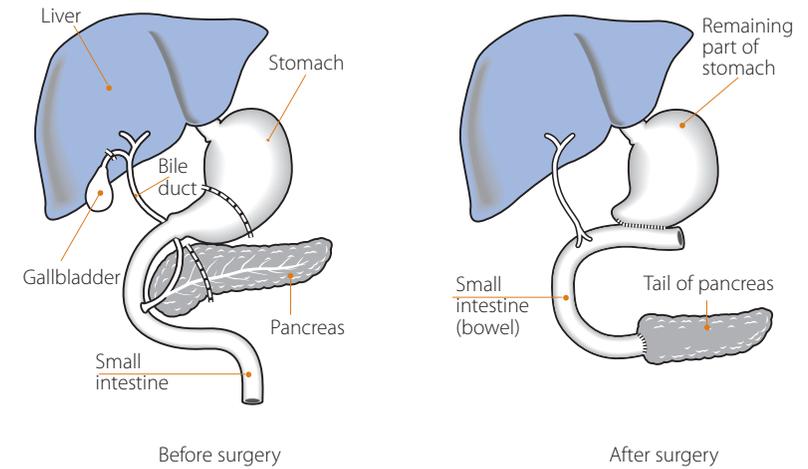
Surgery

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. See page 17 for more information.

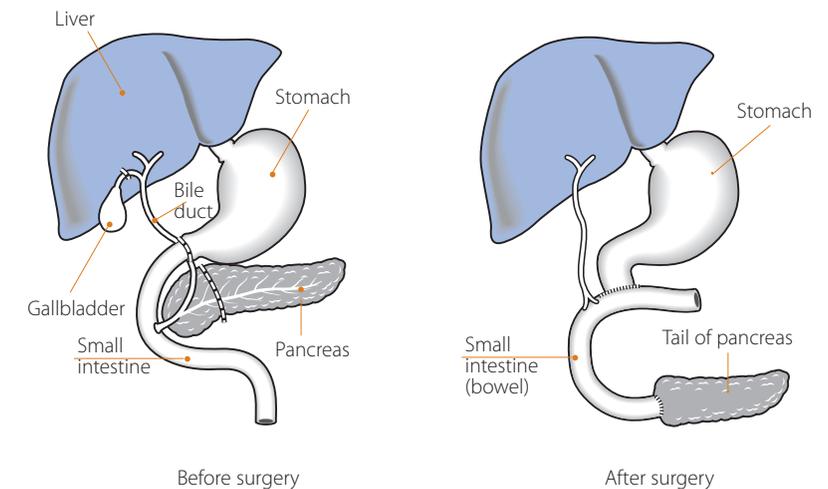
There are about three different types of surgery, depending on where the cancer is found:

- **Whipple's Procedure (pancreaticoduodenectomy):** The cancer has not spread beyond the pancreas and does not involve major blood vessels. The surgeon will remove the head of the pancreas, the lower end of the stomach, part of your small bowel, some of the bile duct, your gallbladder and surrounding lymph nodes.



After their removal, the remaining pancreas, bile duct and stomach are joined up to the small intestines. This allows the pancreatic enzymes, bile and stomach contents to flow into the small intestine for normal digestion.

- **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.
- **Distal pancreatectomy:** This is done for cancer in the body and tail of the pancreas. The lower end of the pancreas is removed as well as your spleen.
- **Spleen-preserving distal pancreatectomy:** This is when the lower end of the pancreas is removed but the spleen is left intact.

Before surgery

Before surgery, you will attend the pre-operative assessment clinic. The purpose of this clinic is to make sure that you are ready for surgery. You will also be told what to expect before, during and after your surgery. You will also meet a member of the anaesthetic team.

Your doctor and nurse will give you advice on any preparations before surgery. For example, your bowels may need to be empty and you will not be allowed to eat or drink for a few hours before surgery. If you need extra nutrition for a few days beforehand, your dietitian will advise you. You may be asked to stop any anticoagulants (blood-thinning drugs) such as aspirin and warfarin. There are 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 up your nose and down into your stomach will remove fluid from the stomach and stop you feeling sick. 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. You may have a small needle in your back for an epidural (pain relief medication). Or you may have a patient controlled analgesia pump. This is with a small pump where you can press a button to give yourself some extra pain relief. If you need to press the button very often, let your medical team know as they may want to increase the dose in it. It is important to tell your nurse if you are in pain.

Wound site: You will have one or more tubes coming out of your stomach near your wound to drain fluid away. 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 pancreatic 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 Procedure, 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: After major surgery to this area the bowel stops working for a while so you will be unable to eat and drink for a few days. As a result, you will get fluids through a drip. Once your bowel starts to work, you will have to take it slowly starting with sips of fluids. 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. This will get easier once all your drips and drains are gone. Gradually you will start to feel better.

Going home

Your hospital stay is usually around 10-14 days. It is possible to have complications after your surgery which may delay your discharge. You will be advised not to drive for 4-6 weeks after your surgery. Your physiotherapist will also advise you to avoid heavy lifting and to gradually build up your level of activity. 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.

Pathology report

During your surgery samples of tissue will be taken. The samples will be tested by a doctor called a pathologist to give more information about the cancer. The pathology report will show how effective treatment has been and help your doctors to decide if you need further treatment. Your doctor will discuss the results of these tests with you before you go home or at a follow-up appointment.

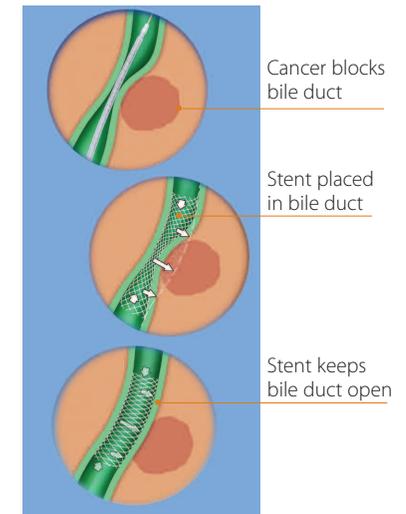
Bypass surgery

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.

Stents

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 12). 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.



A stent to keep the bile duct open

Your doctor and nurse will give you more information about stents or bypass surgery if you need it.

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 HSE Quit Team 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 Quit Team can also put you in touch with the smoking cessation officer in your area. For more information, call the Quitline 1800 201 203. You can also visit the special HSE website: www.quit.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. If you are finding it hard to eat well and you are losing weight, you may be told to eat high-energy foods. 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 drugs can be given as a tablet but they are usually given into the vein. Chemotherapy into the vein is called intravenous chemotherapy. Intravenous chemotherapy can be given:

- Into a vein on your arm or hand
- Through a tube that goes into a vein under your collarbone (a central line)
- Through a tube that goes into a large vein in the front of your arm above your elbow (PICC line)

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®)
- Folfirinix
- Erlotinib (Tarceva®)
- Paclitaxel (Abraxane®)

The drugs listed above may be used on their own or in combination. 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 fewer side-effects. They are also known as targeted therapies.

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 37 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 prone to infections. This happens because most chemotherapy drugs affect your bone marrow which makes the white blood cells that fight infection. If you do not have enough white blood cells, even minor infections such as a cold or sore throat could make you quite ill.

During treatment cycles you will have blood tests to make sure that you have enough white blood cells. If your white cell count is low, your doctor may ask you to watch out for signs of infection. These signs could include feeling shivery and unwell or running a high temperature of 38°C (100.4°F) or higher. If you have a high temperature you will need to go to hospital and have a blood test taken. Sometimes antibiotics are needed to treat the infection.

You will be more at risk of picking up infections while on treatment. Try to avoid close contact, such as hugging or kissing, with people who have colds or flu or other infections such as chickenpox, shingles

or measles. Let your doctor know if you are in contact with these or any other infections. During the day wash your hands often, especially before you eat and after going to the bathroom. Infection can be a serious complication of chemotherapy and needs to be treated as soon as possible. Talk to your doctor or nurse, who will give you more information.

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. Try to keep your teeth, gums and mouth very clean, as this will reduce the risk of getting a mouth infection. Clean your teeth after every meal using a soft toothbrush. If you have dentures remove them if your gums are sore. There are special mouthwashes that you can use too. Your nurse will show you how to use them properly.

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

Bruising: Blood cells called platelets may be reduced by the chemotherapy. If there are not enough platelets in your blood (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 or notice tiny red spots under your skin that look like a rash. He or she will tell you what to do.

Nausea and vomiting: Not everyone feels sick (nausea) or gets sick (vomiting) with chemotherapy. It all depends on the drugs being given. But if you do, it can happen during or after treatment and may last for several hours. Your doctor or nurse will give you medication to stop you feeling sick, often before you receive your chemotherapy treatment. This may be given as an injection or tablet. Always take the medication you are given, even if you don't feel sick, as it can stop the sickness from happening in the first place. If the medication isn't helping, tell your doctor or nurse so that they can try a different treatment.

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, 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. 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.

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 47 for more about fatigue. You can also call our Cancer Nurseline on 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. 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 other than those listed from pages 30 to 33 and it concerns you, tell your doctor or nurse straight away. They will give you advice. For more information on chemotherapy, contact our Cancer Nurseline on 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 our Cancer Nurseline on 1800 200 700 for a free copy of the booklet *Understanding Radiotherapy*. You can also visit a Daffodil Centre or download it from www.cancer.ie



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 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.

Cancer Nurseline Freephone 1800 200 700



Research – what is a clinical trial?



Research on pancreatic cancer goes on all the time. By using new drugs or new combinations of drugs and treatments that are already in use, doctors can find new and better ways of treating cancer. If a drug or treatment looks as if it might be useful in treating cancer, it is given to patients in research studies called clinical trials. These aim to find a safe dose, see what side-effects may occur and see which cancers can be treated. Before a drug or treatment is used on patients it goes through many stages to make sure it is safe to use.

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

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

Taking part in clinical trials

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

Your doctor may refer you to another hospital if he or she feels a clinical trial there may help you. Before a drug or treatment is used on patients, it goes through many phases of research to make sure it is safe to use. You will be carefully monitored during and after the study.

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

For more information, call our Cancer Nurseline on 1800 200 700, visit a Daffodil Centre or see our website: www.cancer.ie

Cancer and complementary therapies

Complementary treatments for cancer are treatments that can be given alongside standard (conventional) medical treatment. For example, yoga or massage. Some people find them very helpful during their illness. 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.

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. Alternative therapies have not been scientifically proven. Some alternative therapies may even harm your health. For example, some diet therapies restrict the types of food you can eat. This can mean you don't get the calories or nutrients that you need. Always talk to your doctor if you are considering an alternative to conventional treatment.



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



Before you decide to change your treatment or add any methods of your own, be sure to talk to your doctor or nurse. Some methods can be safely used along with standard medical treatment. But others can interfere with standard treatment or cause serious side-effects. For that reason, it is important to talk openly with your GP or cancer specialist if you are thinking of having treatment with either a complementary or alternative practitioner. Don't be afraid that your doctor will be offended by your wish for other treatments. In fact, he or she may be able to recommend therapies that could be safe and useful for you.

Be cautious in selecting a practitioner. Don't be misled by promises of cures. At present in Ireland, this area is not fully regulated. 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 our Cancer Nurseline on 1800 200 700.



Controlling symptoms

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
- Eating problems
- Vomiting
- Jaundice
- Weight loss
- 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. See page 48 for more information on palliative care.

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

Pain

Pancreatic cancer can cause pain but it can usually be well controlled. 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. For example, 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 used to treat different types of pain and different levels of pain. 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 our Cancer Nurseline on 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 26 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 our Cancer Nurseline on 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 our Cancer Nurseline on 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 fraiche
- 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
- 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. Dietitians are experts in the nutritional needs of people who have pancreatic cancer. They can discuss ways to increase calories so that you can feel stronger and improve your quality of life. Your dietitian may also advise you to take digestive enzymes.

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.

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

Cancer Nurseline Freephone 1800 200 700



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.

A note for family and friends – eating problems and weight loss

Eating normally can be difficult for some patients with pancreatic cancer. This can be because of symptoms such as a poor appetite, pain, diarrhoea, nausea and taste changes. The resulting weight loss and loss of strength can cause family and friends to be worried and concerned.

Family members and friends may often try to help by preparing favourite meals and snacks. This can make the patient with pancreatic cancer feel under pressure to eat. Don't feel upset if they eat very little of your carefully prepared meal. It can help to understand why people with pancreatic cancer may find it difficult to eat.

For more information on caring for someone with eating difficulties, see our booklet *Diet and Cancer*. For a free copy, call the Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie

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 such as milk or milkshakes and softer food like ice-cream, custard, milk puddings and yoghurt.

More information: Talk to your doctor or nurse or call our Cancer Nurseline on 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 our Cancer Nurseline on 1800 200 700 for a free copy. You can also visit a Daffodil Centre or download it from www.cancer.ie



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.
- 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. For example, gentle exercise.
- Avoid stimulants before bedtime, such as alcohol, coffee, tea, coke or chocolate.

Palliative care

Palliative care aims to improve the quality of life of patients and their families when the cancer advances. As well as providing relief from pain, nausea and other symptoms, palliative care offers support and comfort to patients and their families. It involves caring for their physical, emotional and spiritual needs in the best way possible.

Palliative care can be given in a hospice or hospital or your own home. You can also attend a hospice for managing your symptoms. These days hospices are places that specialise in symptom control and you can spend a day or two there receiving treatment. Do talk to your doctor or nurse for more advice.

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 our Cancer Nurseline on 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.

Cancer nurse specialists: The major cancer treatment hospitals have pancreatic nurse specialists. These specially trained nurses can support you and your family from the time of diagnosis and throughout treatment. The nurses work along with other members of your medical team to meet your needs. They can also introduce you to the clinical nurse specialist in palliative care.

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

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

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

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

Irish Cancer Society nurses: Our cancer nurses will be happy to talk about any concerns you or your family may have, at any stage of your illness. This can range from treatment information to practical advice about financial matters. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence. They can also give you information about any of the services outlined above or support services in your area, including counselling. You can also email the nurses at cancernurseline@irishcancer.ie

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 a 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.

Email: cancernurseline@irishcancer.ie

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 or long after you have finished treatment..

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. A helpful booklet that discusses this in detail is *Understanding the Emotional Effects of Cancer* and is available from the Irish Cancer Society. Call our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre 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 well 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. 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 our Cancer Nurseline on 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre 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 our Cancer Nurseline 1800 200 700 or visit a Daffodil Centre. You can also download it from www.cancer.ie

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. 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 our Cancer Nurseline on 1800 200 700 or visit a Daffodil Centre 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 a public hospital. There is a €75 a night charge up to a limit of €750 in 1 year. These charges do not apply to medical card holders. Higher rates apply for semi-private or private care.

Outpatient cover

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

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

Medical card

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

You will have to pay a prescription charge of €2.50 per item up to a limit of €25 per family per month.

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

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

GP visit card

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

Drugs Payment Scheme

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

Private healthcare cover

Private health insurance is used to pay for private care in hospital or from various specialists in hospitals or in their practices. In Ireland, this is available through the VHI, Laya Healthcare, AVIVA Health, GloHealth,

and other schemes. They provide cover for day care/ inpatient treatment and hospital outpatient treatment. Before attending hospital, it is best to check the level of cover provided by your insurance company, both for inpatient and outpatient services.

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

Benefits and allowances

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

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



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

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

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

See page 70 for information on the Travel2Care fund and the Volunteer Driving Service provided by the Irish Cancer Society. Some local communities may also provide volunteer transport services.

Further information

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

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

For social welfare queries, contact:

Dept of Social Protection – Information Service

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

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

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

Information is also available from your local Citizens Information Centre. A list of these centres is available from: **Citizens Information**
Tel: 0761 07 4000 **Email:** information@citizensinformation.ie
Website: www.citizensinformation.ie



If you have financial worries...

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

There is help available if you find it hard to cope with all these expenses. Contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also in certain cases give some assistance towards travel costs and other expenses because of your illness. See page 70 for more details. You can also call the Cancer Nurseline



on 1800 200 700 or visit a Daffodil Centre and the cancer nurse will suggest ways to help you manage.

If you feel you are getting into debt or are in debt, there is help available. Contact the Money Advice and Budgeting Service on the MABS Helpline on 0761 07 2000. This service can help you work through any financial issues you have. They can assess your situation, work out your budget, help you deal with your debts and manage your payments. The service is free and confidential. See page 71 for contact details.

Irish Cancer Society services

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

- Cancer Nurseline Freephone 1800 200 700
- Daffodil Centres
- Survivor Support
- Support in your area
- Patient travel and financial support
- Night nursing
- Publications and website information

- Our **Cancer Nurseline Freephone 1800 200 700**. Call our Cancer Nurseline and speak to one of our cancer nurses for confidential advice, support and information. The Cancer Nurseline is open Monday to Thursday 9am–6pm and Friday 9am–5pm. You can also email us on cancernurseline@irishcancer.ie or visit our Online Community at www.cancer.ie
- Our **Daffodil Centres**. Visit our Daffodil Centres, located in thirteen hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide confidential advice, support and information to anyone concerned about or affected by cancer.
- Our **Survivor Support**. Speak to someone who has been through a cancer diagnosis. Our trained volunteers are available to provide emotional and practical support to anyone going through or finished with their treatment.

- **Support in your area.** We work with cancer support groups and centres across the country to ensure cancer patients have access to confidential support including counselling.
- **Patient travel and financial support services.** We provide practical and financial support for patients in need, travelling to and from their cancer appointments. There are two services available through the Society:
 - **Travel2Care** is a limited fund, made available by the NCCP, for patients who are having difficulty getting to and from their treatments while attending one of the national centres of excellence or their approved satellite centres.
 - **Irish Cancer Society Volunteer Driving Service** is for patients undergoing chemotherapy treatments who are having difficulty getting to and from their local appointments in our partner hospitals.

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

- **Irish Cancer Society Night Nursing.** We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is the only service of its kind in the Republic, providing palliative nursing care at night to cancer patients.
- **Our publications and website information.** We provide information on a range of topics including cancer types, treatments and side-effects, coping with cancer, children and cancer and financial concerns. Visit our website www.cancer.ie or call the Cancer Nurseline for a free copy of our publications.



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

Useful organisations

Irish Cancer Society

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

The Carers Association

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

Citizens Information

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

Get Ireland Active: Promoting Physical Activity in Ireland

Website: www.getirelandactive.ie

Health Promotion HSE

Website: www.healthpromotion.ie

All Ireland Co-operative Oncology Research Group

Website: www.icorg.ie

Irish Nutrition & Dietetic Institute

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

Irish Oncology and Haematology Social Workers Group

Website: <http://socialworkandcancer.com>

Money Advice and Budgeting Service (MABS)

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

Rotunda IVF

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

Health insurers

AVIVA Health

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

GloHealth

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

Laya Healthcare

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

Voluntary Health Insurance (VHI)

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

National support services**Survivor Support**

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

ARC Cancer Support Centres Dublin
[See page 73]**Brain Tumour Support Group**

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

Canteen Ireland

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

Cancer Support Sanctuary LARCC
[See page 73]**Connaught support services****Athenry Cancer Care**

Social Service Centre
New Line
Athenry
Co Galway
Tel: 091 845 228 / 087 412 8080
Email: athenrycancercare@gmail.com
Website: www.athenrycancercare.com

Ballinasloe Cancer Support Centre

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

Cara Iorrais Cancer Support Centre

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

Gort Cancer Support Group

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

Hand in Hand

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

Mayo Cancer Support Association

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

Roscommon Cancer Support Centre

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

Sligo Cancer Support Centre

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

Tuam Cancer Care Centre

Cricket Court
Dunmore Road
Tuam
Co Galway
Tel: 093 285 22
Email: support@tuamcancercare.ie
Website: www.tuamcancercare.ie

Leinster support services**ARC Cancer Support Centre**

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

ARC Cancer Support Centre

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

Arklow Cancer Support Group

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

Balbriggan Cancer Support Group

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

Cancer Support Sanctuary LARCC

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

Cara Cancer Support Centre

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

Cois Nore Cancer Support Centre

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

Cuisle Cancer Support Centre

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

Dóchas: Offaly Cancer Support Group

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

Dublin West Cancer Support Group

Generic Social Work Department
Oak Unit
Cherry Orchard Hospital
Ballyfermot
Dublin 10
Tel: 01 620 6273
Email: martina.mcGovern2@hse.ie/
noreen.obrien4@hse.ie

Éist Carlow Cancer Support Centre

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

Gary Kelly Cancer Support Centre

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

Greystones Cancer Support

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

Hope Cancer Support Centre

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

Midlands Myeloma Support Group

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

Purple House – Cancer Support

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

Tallaght Cancer Support Group

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

Wicklow Cancer Support Centre

Rear of Butler's Medical Hall
Abbey Street
Wicklow
Tel: 0404 326 96
Email: wicklowcancersupport@gmail.com

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

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

CARE Cancer Support Centre

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

Cork ARC Cancer Support House

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

Kerry Cancer Support Group

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

Recovery Haven

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

Solas Centre

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

Suaimhneas Cancer Support Centre

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

Suir Haven Cancer Support Centre

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

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

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

Crocus: Monaghan Cancer Support Centre

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

Cuan Cancer Social Support and Wellness Group

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

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

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

The Bella Rose Foundation

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

Cancer Care West

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

Cúnamh: Bons Secours Cancer Support Group

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

Dundalk Cancer Support Group

Philipstown
Hackballscross
Dundalk
Co Louth
Tel: 086 107 4257

East Galway & Midlands Cancer Support

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

The Forge Cancer Support Service

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

Killybegs Cancer Support Group

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

Newbridge Cancer Support Group

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

Rathdrum Cancer Support Group

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

Sláinte an Chláir: Clare Cancer Support

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

Solace: Donegal Cancer Support Centre

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

For other support services in your area, call 1800 200 700.

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

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

American Cancer Society (US)

Website: www.cancer.org

Cancer Focus Northern Ireland

40-44 Eglantine Avenue
Belfast BT9 6DX
Tel: 048 9066 3281
Email: hello@cancerfocusni.org
Website: www.cancerfocusni.org

Cancer Buddies Network

Website: www.cancerbuddiesnetwork.org

Cancer Research UK

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

Healthtalkonline (UK)

Website: www.healthtalk.org

Macmillan Cancer Support (UK)

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

Macmillan Support & Information Centre

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

National Cancer Institute (US)

Website: www.nci.nih.gov

Helpful books**Free booklets from the Irish Cancer Society:**

- *Understanding Chemotherapy*
- *Understanding Radiotherapy*
- *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 1859590365

Challenging Cancer: Fighting Back, Taking Control, Finding Options

Maurice Slevin & Nira Kfir
Class Publishing, 2002
ISBN 1859590683

The Bristol Approach to Living with Cancer

Helen Cooke
Robinson, 2003
ISBN 1841196800

The Key Model – A New Strategy for Cancer Recovery

Dr Sean Collins & Rhoda Draper
Ardagh Clinic, 2004
ISBN 095214445X

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

Julie A Stokes
Winston's Wish, 2000
ISBN 0953912302

Taking Control of Cancer

Beverley van der Molen
Class Publishing, 2003
ISBN 1859590918

Why Mum? A Small Child with a Big Problem

Catherine Thornton
Veritas, 2005
ISBN 1853908916

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. For example, chemotherapy or radiotherapy.
Anti-emetic	A tablet, injection or suppository given to stop you feeling sick or vomiting.
Benign	A tumour that is not able to spread.
Bile	Fluid that helps with digestion. It is produced by the liver and stored in the gallbladder.
Biopsy	When a small amount of tissue is taken from your body and examined under a microscope 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 including the stomach, intestines, liver and pancreas.

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 cells from where they first started to other parts of the body. Also known as secondary cancer.
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.

Steatorrhoea	'Fatty' stools which can be clay-coloured, oily in appearance, floating, difficult to flush and have an offensive smell. Steatorrhoea happens when you are not producing enough digestive enzymes.
Stent	A small hollow tube put into the bile duct to hold it open. This allows bile to drain into the small bowel as normal.
Total parenteral 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.



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?

Your own questions

1 _____

Answer _____

2 _____

Answer _____

3 _____

Answer _____

4 _____

Answer _____

5 _____

Answer _____



Notes

A large, light blue rounded rectangular area intended for taking notes.



Acknowledgements

We would like to extend a special word of thanks to the following for their invaluable contributions to this booklet:

Michael H Phillips, Illustrator
Alamy Images Ltd

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 Cancer Nurseline on 1800 200 700.

Would you like to be a patient reviewer?



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

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

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

Would you like to help us?

The Irish Cancer Society relies entirely on voluntary contributions from the public to fund its programmes of patient care, 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.

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

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

Irish Cancer Society

43/45 Northumberland Road, Dublin 4

T: 01 231 0500

E: info@irishcancer.ie

W: www.cancer.ie

Cancer Nurseline Freephone 1800 200 700

Open Monday to Thursday 9am to 6pm

Friday 9am to 5pm

Find us on Facebook

Follow us on Twitter: @IrishCancerSoc

