What is Pancreatic Cancer?

What it is and how it is diagnosed.

In this booklet, you'll find out more about pancreatic cancer and how it is diagnosed. It will also answer important questions about how the disease will affect your finances, relationships and lifestyle.

Understanding Pancreatic Cancer – Patient Information Booklets

Receiving a diagnosis of pancreatic cancer can be an upsetting, stressful and confusing time. We have listened to patients, relatives and carers to understand what information is useful. Our patient information booklets are easy to understand and beneficial to have at hand to answer any questions or concerns you may have.

All of these publications are produced under the Information Standard certified scheme and are reviewed by medical professionals and patients/carers who have been affected by pancreatic cancer.

To order further patient information, please visit: **panact.org/patient-booklets**

What is Pancreatic Cancer?

What it is and how it is diagnosed.

Surgery for Operable Pancreatic Cancer

Types of surgery, preparing for your surgery, eating after surgery and returning home.

Controlling the Symptoms of Pancreatic Cancer

Common symptoms, management and what to expect.

Chemotherapy Treatment for Pancreatic Cancer

Chemotherapy drugs, how they are given and managing side effects.

Diet and Nutrition for Pancreatic Cancer Patients

Dealing with malabsorption, advice for eating after surgery and while undergoing chemotherapy.

Supportive and End of Life Care for Pancreatic Cancer

Palliative care and life with advanced pancreatic cancer.

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Introduction

What is cancer?

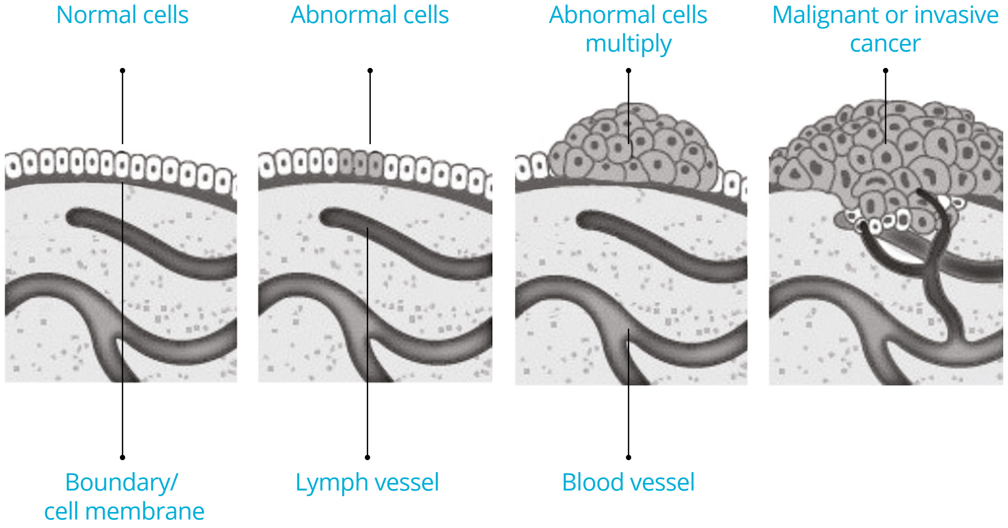
All cancers begin with changes in a cell or group of cells. The body is made up of many types of cell, which usually grow and divide in a controlled way to make more cells. These new cells are needed to keep the body healthy. When cells become old or damaged, they die and are replaced with new cells.

The way a cell grows, divides and dies is controlled by its genes (DNA). Sometimes DNA gets damaged or changed. If this damage affects genes that tell a cell when to grow, divide or die, cells do not die when they should, and new cells form when the body does not need them. The extra cells which are made, change the composition of the blood, or forms a lump, called a tumour, which is the beginning of cancer.

1 in 2 of us will **develop cancer** in our **lifetime**

Approximately **10,500** people are **newly diagnosed** with pancreatic cancer in the UK **each year**

How tumours develop



Benign tumours aren't cancerous. They can often be removed and, in most cases, do not come back. Cells in benign tumours do not spread to other parts of the body.

Malignant tumours are cancerous. Cells in these tumours can invade nearby tissues and spread to other parts of the body. Sometimes cells move away from the original (primary) cancer site and spread to other organs and bones where they can continue to grow and form another (secondary) tumour at a new site. This process is called metastasis. Secondary cancers keep the name of the original cancer location and are made up of the same type of cells. For example, pancreatic cancer that has spread to the liver is still called pancreatic cancer.

Cancer cells are dangerous because they will continue to grow and divide, even if they cause damage to the tissues around them.

Introduction

What is the pancreas?

The pancreas is an organ about 6 inches long and shaped like a thin pear lying on its side. The wider end of the pancreas is called the head, the middle section is called the body, and the narrow end is called the tail. The pancreas is found deep inside your body, behind the stomach and in front of the spine.

The pancreas has two main jobs in the body, it makes:

Enzymes

These help to digest (break down) foods.

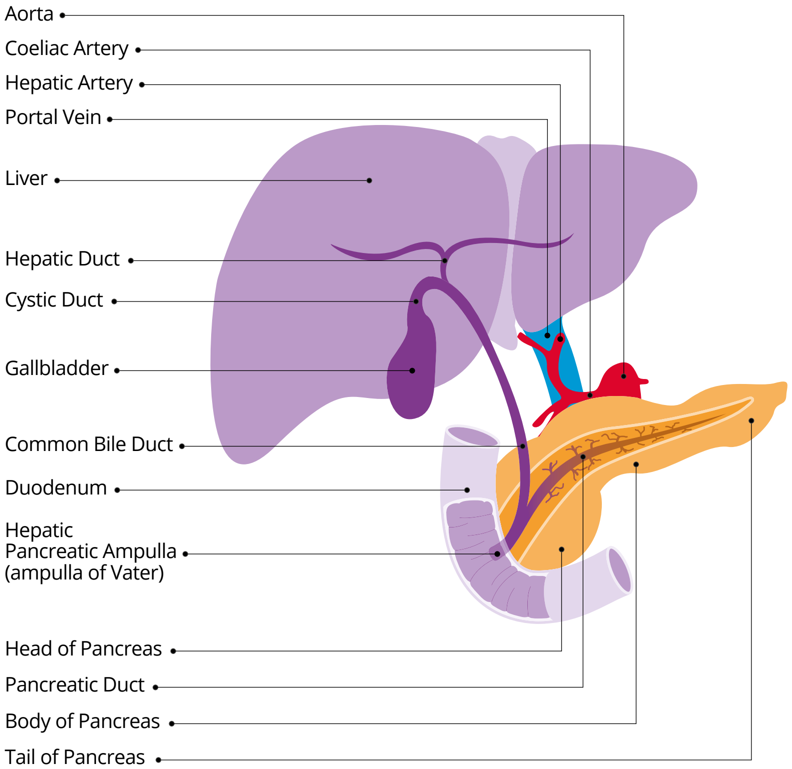
Hormones

Such as insulin and glucagon, which control blood sugar levels.

The pancreas helps the body use and store the energy it gets from food.

A tube called the pancreatic duct connects the pancreas to the first part of the small intestine, known as the duodenum. Digestive enzymes pass through this tube to help break down food. Another tube, called the common bile duct, passes through the head of the pancreas. This tube carries bile (a substance that helps to digest fats) from the liver and gall bladder to the small intestine. The bile duct may get blocked when a pancreatic tumour invades it. This causes jaundice (yellowing of the eyes and skin and dark urine).

The location of the pancreas



The pancreas contains two types of glands:

Exocrine glands

Create the enzymes which help digest (break down) foods.

Endocrine glands

Create the hormones such as insulin and glucagon, which control blood sugars.

Introduction

What is pancreatic cancer?

Pancreatic cancer occurs when a malignant tumour forms in the pancreas.

Worldwide there are around 496,000 new cases each year; in Europe that figure is more than 104,000. In the UK, approximately 10,500 people are newly diagnosed each year.

Pancreatic cancer affects men and women equally with incidence increasing from the age of 45. The average age at diagnosis is 72.

There are two main types of pancreatic cancer:

Exocrine tumours

These make up the vast majority of all pancreatic cancers (around 95%) and come from the cells that line the ducts in the pancreas which carry digestive juices into the intestine.

These are called pancreatic ductal adenocarcinomas.

Other exocrine tumours of the pancreas are rarer, and include adenosquamous carcinomas and undifferentiated carcinomas.

Endocrine tumours

These are also known as neuroendocrine tumours, (NETS) and are much less common. The neuroendocrine tumours we discuss here are found in the pancreas and are called pancreatic neuroendocrine tumours (pNETS).

These are tumours that develop in our endocrine glands that release hormones (which regulate some processes in our bodies), these are then circulated around the body.

Other rare tumours that can affect the pancreas include pancreatic lymphoma, a cancer that arises from the lymphatic tissue in the pancreas; various cystic tumours and pancreatic sarcomas, which develop in the tissue that holds cells in the pancreas together.

Tumours that arise from tissues close to the pancreas, such as the bile duct (cholangiocarcinoma), Ampulla of Vater (ampullary adenocarcinoma), or duodenum (duodenal adenocarcinoma), may cause similar symptoms to pancreatic cancer but have different treatments and outcomes.

Pancreatic endocrine tumours

In the pancreas, there are a group of cells, which are called the Islets of Langerhans, that produce hormones including insulin, glucagon and somatostatin which are involved in the control of sugar in the blood. PNETS are tumours found in these cells so are sometimes referred to as islet cell tumours.

There are two types:

1. Non-functional (non-secretory) PNETS. These tend to be cancerous, and **DO NOT** produce hormones.
2. Functional (secretory) PNETS. These tumours are less likely to be cancerous. These **DO** produce hormones such as insulin, glucagon to control blood sugar levels. Although they are less likely to be cancerous, they can produce symptoms due to the excessive production of hormones or the effects of the tumour displacing and pushing the surrounding tissue.

For more detailed information on the types of neuroendocrine pancreatic cancers, and their symptoms please visit **panact.org/PNETS**
This booklet, focuses on endocrine tumours, mainly pancreatic ductal adenocarcinomas.

80% of **pancreatic cancers occur** in the **head of the pancreas**
less commonly in the body (15%)
and tail (5%)

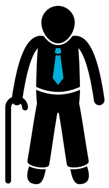
What are the risk factors?

The cause of pancreatic cancer is unknown. However, there are some risk factors which make developing pancreatic cancer more likely:

Tobacco Products

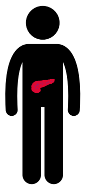
There is a direct relationship between the amount you smoke and the risk of pancreatic cancer.

Age



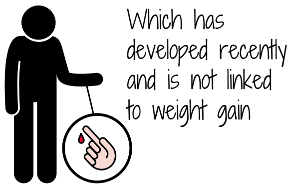
The likelihood of developing pancreatic cancer increases with age.

Chronic Pancreatitis



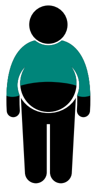
Long-term inflammation of the pancreas (pancreatitis) has been linked to pancreatic cancer.

Diabetes



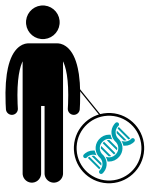
There have been a number of reports which suggest that those with type 2 diabetes have an increased risk of developing pancreatic cancer.

Obesity



Recent studies have shown that risk is higher in people who are obese (have a Body Mass Index more than 30).

Family History



If you have a first degree relative (parent, sibling or child) with pancreatic cancer this increases your risk. This is through faulty genes or inheriting certain syndromes.

There are other known risk factors however, there is less evidence around these. Please see our website for more information.

If you are worried about having pancreatic cancer the most important thing you can do is NOT smoke.

Does pancreatic cancer run in families?

Pancreatic cancer by itself (not part of a known syndrome) runs in some families. People with first degree relatives (mother, father, brother, sister) diagnosed with pancreatic cancer have an increased risk of being in that type of family.

This can be due to inheriting faulty genes that increase their risk of developing cancer. This can also be due to inheriting certain genetic syndromes.

Unfortunately, currently there is no genetic test for pancreatic cancer. In the majority of families, the genes that might cause pancreatic cancer are unknown. There is research being done by **EUROPAC** (European Registry of Hereditary Pancreatitis and Familial Pancreatic Cancer). One of the aims of EUROPAC is to identify gene changes that may increase risk in these families. Your specialist would suggest you to speak to them if he or she thinks there is a genetic predisposition in your family.

For more information on EUROPAC which is based in Liverpool, UK visit their website panact.org/EUROPAC

Be reassured that most cases of pancreatic cancer are 'sporadic' i.e. they do not run in families, but there are some rare medical syndromes which are known to increase the risk of developing pancreatic cancer.

For more information on hereditary pancreatic cancer please go to our website panact.org/hereditary

Hereditary pancreatitis and pancreatic cancer

Chronic pancreatitis affects between 6 and 9 in 100,000 people every year in the UK, however hereditary pancreatitis is quite rare. It is a rare genetic condition usually involving the development of several episodes of severe chronic pancreatitis which starts at an early age (usually between the ages of 5 and 26, but can occur at any time). Patients with recurring episodes of pancreatitis are recognised as having an increased chance of developing pancreatic cancer

Chronic pancreatitis is a long-term, irreversible inflammation of the pancreas, which causes severe pain in the centre of your tummy and can cause malabsorption.

Introduction

Symptoms of pancreatic cancer

As pancreatic cancer develops in the body, it may cause some of the following signs and symptoms. The symptoms and severity can vary for each person but it's important if you experience any of the following symptoms, which are persistent and not normal for you, that you visit your GP.

The most common type of pancreatic cancer is pancreatic ductal adenocarcinoma (PDAC). Below are the symptoms often seen with PDAC. For more information on symptoms with pancreatic neuroendocrine tumours (PNETs) please see our website.

The most commonly reported initial symptoms are often:

- **Pain in the back or tummy area** – the pain is often described as beginning in the stomach area and radiating around to the back. Pain is where a woman's bra strap would be and can radiate to the front.
- **Jaundice** – the most obvious sign is yellowing of the skin and whites of the eyes; it may also cause your urine to be dark yellow and itching of the skin.
- **Unexplained weight loss** – this can occur without any pain or apparent change in digestion.

Other signs and symptoms include:

- Indigestion - not responding to prescribed medication
- Pale and smelly stools - that don't flush easily
- Loss of appetite - not feeling like eating
- Nausea and vomiting - feeling and being sick
- New onset diabetes - which has developed recently and is not linked to weight gain
- Fatigue - feeling tired and exhausted all the time.

It is important to remember these symptoms can be caused by many different conditions, including irritable bowel syndrome or indigestion, and aren't usually the result of cancer.

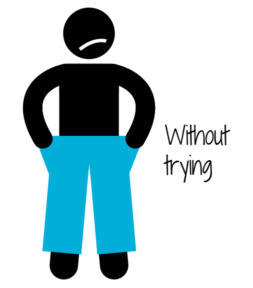
If you are experiencing jaundice seek urgent medical attention

Symptoms include...

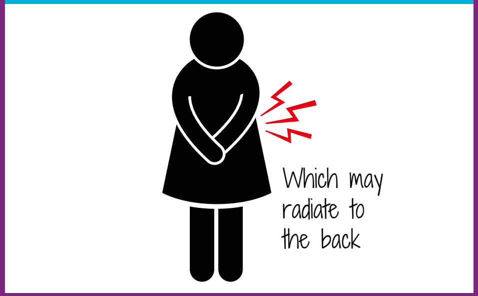
Mid-back pain

Changes in the way you poo

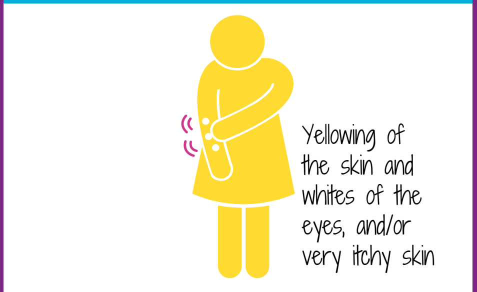
Unexplained weight loss



Upper abdominal pain or discomfort



Jaundice



Indigestion

If you persistently experience one or more of these symptoms which are not normal for you, **DO NOT IGNORE THEM,** contact your GP straight away.

Diagnosis and tests

First-line investigations

How is pancreatic cancer diagnosed?

Patients who present themselves with one or more of the signs and symptoms that suggest pancreatic cancer (page 12) need a quick investigation. This is often by an ultrasound scan followed by a CT scan and early referral to a specialist unit for other investigations.

These investigations and tests will help your specialist team diagnose, treat and monitor your condition. These tests along with other relevant investigations are referred to as staging investigations. The results of these tests will provide information about the abnormal area in your pancreas and your general health. Your specialist team will also want to get to know you and your family so that they can make the most appropriate treatment choice for you.

There are two aspects to staging investigations. Some are designed to find out as much as possible about the tumour itself, and some are designed to assess your general fitness. There are many treatment options and your doctors will be trying to work out which is best for you, taking into account all of the information.

These decisions are usually taken at a multi-disciplinary team (MDT) meeting.
See page 16 for more information on MDT meetings.

First-line investigations

If your doctor suspects that you have pancreatic cancer, you will have a number of tests to confirm the diagnosis. Some of these tests show if the cancer has spread to other parts of the body.

You will not have all the tests mentioned in this booklet.

Diagnosis and tests

First-line investigations

Blood tests

Cancer is not diagnosed by blood tests alone. Your blood may be tested for a cancer marker. Markers are chemical substances that can show up in the blood of patients with some types of cancer.

There are two markers that some pancreatic cancers may produce, called CEA and CA 19-9. Serum CA 19-9 is more commonly used and is considered to be elevated when its value is greater than 37 U/ml.

What does the CA 19-9 test measure?

The CA 19-9 is a simple blood test that measures the level of antigens (substances that cause the immune system to make a specific immune response) in the blood serum of a person with pancreatic cancer. CA 19-9 antigens are the substances released by pancreatic tumour cells. The normal range of CA 19-9 in the blood of a healthy individual is 0-37 U/ml. CA 19-9 associated antigen levels are elevated in the blood of many patients with pancreatic cancer.

Not every patient with Pancreatic Cancer will have elevated CA 19-9.

There are also some non-cancerous conditions that can cause a high level of CA 19-9 which is why it is not particularly useful as a diagnostic test for pancreatic cancer.

Ultrasound test

An abdominal ultrasound uses sound waves to create a picture of your pancreas and the area surrounding it, including your liver. This is normally done in the x-ray department of the hospital. This is the same procedure that is done with mothers during pregnancy when doing check-ups.

The procedure is completely painless. You will be taken into a scanning room and be asked to lie on the couch next to the ultrasound machine. A clear gel will be spread onto the skin of your stomach.

A small device called a transducer will be moved across your abdomen. The transducer creates sound waves that echo when they meet an organ or tumour. The computer will turn these echoes into pictures, which the radiographer or doctor will interpret and the results will be sent to either your GP or your specialist.

CT scan

CT stands for **computed tomography**. It is really a more detailed and specialist type of x-ray. The CT unit is linked to a sophisticated computer that builds up lots of very detailed images from inside your body. Having a CT scan is completely painless.

The scanner is shaped like a doughnut. It is about three feet wide and open at both ends. All you need to do is lie still on a table, which slides into the scanner. If necessary, your head and neck will be supported.
The scan usually lasts from 15 to 45 minutes, but it depends on the area to be examined.

If you need a CT scan, your local scanning department will offer you more detailed written information. When you go for your scan the radiographers will do their best to help you relax.

Diagnosis and tests

First-line investigations

What will happen?

Remember, you will not be enclosed in any way and most people do not have a problem with having a CT scan.

Preparation for a CT scan can vary from patient to patient. The x-ray department, your doctor or nurse will tell you what you need to do before you go for your scan.

You might be asked to drink and/or have an injection of dye. This allows the doctor to see the area being scanned more clearly.

If you are allergic to iodine, fish or dyes, you will need to tell the person doing the CT scan in advance, as you may not be able to have the dye, drink or injection.

You will need to let your doctor or nurse know if you:

- Have any allergies
- Have asthma
- Have kidney problems
- Are taking any medication
- Are pregnant
- Are afraid of needles
- Have had any problems before with any type of x-ray or radiology examination are taking medication for diabetes.

When will I get the result?

It can take some time before a full report is available to your consultant. Make sure you arrange an appointment to get the result. Sometimes, more information might be required or for some reason the scan may not be as clear as it should be. If this is the case, you will be asked to return for a repeat scan.

Diagnosis and tests

Second-line investigations

Endoscopy (ERCP)

An endoscope is a long, thin tube with a light and a camera at the end. It is passed down your throat and into your digestive system. Endoscopy can show blockages or swelling in the pancreatic ducts and allows the doctor to judge whether these problems are caused by cancer or not.

During the procedure, doctors can also take samples of tissue or fluid to help them find out if you have cancer. This is called a biopsy.

A dye may be injected into the pancreatic and bile ducts via the endoscope, so that these organs can be viewed as x-ray pictures, known as cholangiograms. This procedure is known as endoscopic retrograde cholangiopancreatography (ERCP).

Diagnosis and tests

Second-line investigations

Endoscopic ultrasound (EUS)

Endoscopic ultrasound (EUS) is a type of endoscopy where the doctor uses a thin flexible camera with a small ultrasound probe at the tip. During the test, the doctor will look at the lining of your pancreas, as well as examining the lymph nodes. Everything will be magnified on a television screen and images will also appear on the ultrasound machine.

If necessary, your doctor will take samples of cells from the surrounding areas, by means of a fine-needle aspiration (FNA), and send them to the laboratory for examination.

You cannot eat or drink for several hours before an endoscopy. You will have a sedative and a local anaesthetic to make you feel as comfortable as possible. Because of the sedative you should not drive or operate heavy machinery for 24 hours after your endoscopy.

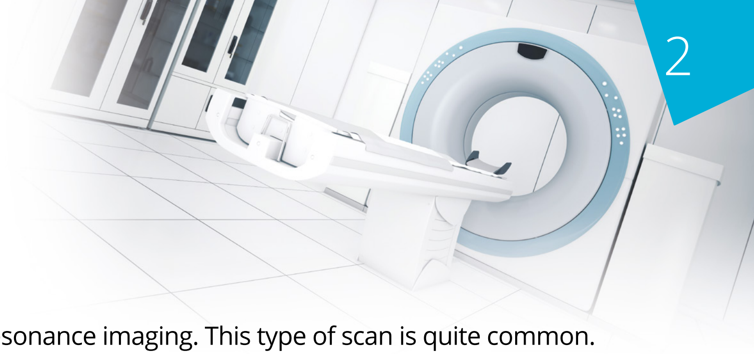
How long will it take?

The test takes between 20-45 minutes.

When will I get the results?

If you have had biopsies taken it may take 7 to 10 days before the results are available. Before you leave the hospital after your endoscopy, make sure you have an appointment to go back and see your doctor for the results.

If, after the procedure you develop a high temperature, have difficulty swallowing or have increasing tummy or chest pain, contact your doctor immediately.



MRI scan

MRI stands for magnetic resonance imaging. This type of scan is quite common. It produces detailed pictures of the body. Instead of x-rays it uses a large magnet and radio waves that are fed into a computer. The computer then builds up cross-sectional images of your body. If you need an MRI scan, more written information will be available from your local scanning department.

Safety

There is no special preparation for an MRI. However, because of the powerful magnet used to produce the scans, safety guidelines must be followed. You may have to fill in a questionnaire before the scan can be carried out.

It may not be possible to have an MRI scan if you have:

- A heart pacemaker
- Some types of surgical clips inside your head
- Metal fragments in your eyes or elsewhere
- Neuron-stimulator implants.

Please tell your doctor or nurse if you:

- Have any allergies
- Have asthma
- Have diabetes
- Have kidney problems
- Are taking any medication
- Are pregnant
- Have had any surgery in the past 12 weeks
- Are in any doubt about your suitability for an MRI scan
- Have had any problems before with any type of x-ray or radiology examination.

If you are allergic to iodine, fish or dyes, you need to tell the person doing the MRI scan in advance, as you may not be able to have the dye, drink or injection.

For the scan:

- Wear something loose without metal zips or buttons
- Remove all metal objects, including rings, before scanning
- Remember to check that you do not have credit cards in your pockets as the magnetic strip is affected by the scan.

If necessary, you will have an injection of dye into a vein in your arm. This can help improve the images. You will be asked to lie on a scan table in a type of tunnel. The table contains the magnet and the part of your body to be scanned lies directly over its centre. The table moves into position inside the tunnel and although you will not feel anything, there will be quite a lot of noise. All you need to do is try to relax and keep still while the pictures are being taken.

Because of the noise, you will be given earplugs and headphones may be available so you can listen to music or an audiobook. An MRI scan usually takes about 20-30 minutes, but it may be much shorter or can take up to an hour. The radiographer stays outside the room but you can talk with them through a microphone. The radiographers are very experienced and will do all they can to help you relax.

You may be able to bring a friend or relative with you when you go to the clinic. They can wait in the waiting room while you have your scan. Please check with the radiology department first in case the clinic is very busy.

When will I get the results?

At the end of the scan there could be up to 100 images for the radiologist to look at. Once these have been carefully studied, a report will be sent to your consultant. Make sure you have an appointment to get the result.

Positron Emission Tomography (PET)

A PET scan will produce a three-dimensional, colour image of your body, which will show how body tissues are working and also what they look like. It can be used to help diagnose cancers and it can help doctors tell the difference between scar tissue or an active cancer in the body.

A PET scan for pancreatic cancer can show:

- Whether there is a tumour present in the pancreas
- Help identify what stage the cancer is at
- Show whether the cancer has spread to other parts of the body
- Help your specialists decide on the best treatment for you
- Show how well current treatment is working
- Identify the difference between scar tissue and tissue that is cancerous.

What is a PET scan and how does it work?

PET scans are becoming more widely used in the NHS but they are still very expensive and only a few specialist hospitals in the UK have one.

Diagnosis and tests

Second-line investigations

Many hospitals will have their PET scanner in the Nuclear Medicine Department, which will have special facilities to contain the radiation. PET scanners have a flat bed with a large, circular scanner at one end.

You may be asked to fast for about 4 to 6 hours prior to your scan then a radiographer will give you an injection of a very small amount of a harmless radioactive substance (radiotracer) into a vein. You will need to wait for about 1 hour while the radiotracer spreads through your body. You will then be asked to lie down on the flat bed of the scanner unit, which will move through the circular scanner at the end.

The radiographer will control the scan from outside the room and they will be able to see and talk to you. You will need to stay as still as possible while the scan is taking place.

> The amount of radiation is very small (no more than you have during a normal x-ray) and it only stays in your body for a few hours.

The radiotracer releases gamma waves (a form of radiation) that a camera in the PET scan can detect. When the dye and glucose are injected into the body, it travels to places where glucose is used for energy. Cancer tumours use glucose in a different way to normal tissue, and the PET scan shows these differences and can tell doctors whether cancer is present.

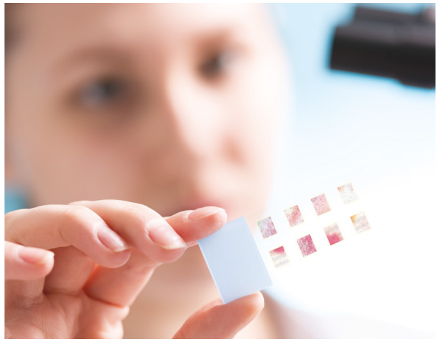
The radiographer will control the scan from outside the room and they will be able to see and talk to you. You will need to stay as still as possible while the scan is taking place.

The amount of radiation is very small (no more than you have during a normal x-ray) and it stays in your body for only a few hours.

Sometimes a CT scan can show that there may be cancer left after treatments such as chemotherapy. A PET scan can confirm whether or not it is active cancer or just scar tissue left over as a result of treatments.

There are usually no side effects from this type of scan. It can take up to an hour to complete and you will need to lie still throughout the procedure.

Biopsy for Pancreatic Cancer



During a biopsy, a sample of tissue from the tumour is removed and looked at under a microscope to see if there are cancer cells. There are several types of biopsies that might be done. In the past, a biopsy was often done as part of surgery. Now, fine needle aspiration biopsy with the help of an endoscope is sometimes used.

Most common methods of obtaining a biopsy for pancreatic cancer are (in no particular order):

Endoscopic retrograde cholangiopancreatography (ERCP)

A flexible tube with a camera and other tools on its end (endoscope) is advanced from the mouth to the small intestine, near the pancreas. ERCP can collect images from the area, as well as take a small biopsy with a brush.

Endoscopic ultrasound

Similar to ERCP, an endoscope is advanced near the pancreas. An ultrasound probe on the endoscope locates the mass, and a needle on the endoscope plucks some tissue from the mass.

Laparoscopy

A surgical procedure that uses several small incisions. Using laparoscopy, a surgeon can collect tissue for biopsy, as well as see inside the abdomen to determine if the pancreatic cancer has spread.

Percutaneous needle biopsy

Under imaging guidance, a radiologist inserts a needle into the mass, capturing some tissue. This procedure is also called a fine-needle aspiration (FNA).

For more information on the above procedures, please see our website: panact.org

Multi-Disciplinary Team (MDT) meeting

Typically, before cancer patients undergo treatment, they are reviewed by a multi-disciplinary team (MDT) to decide on the best course of treatment.

The MDT is made up of healthcare professionals who all have specialities relevant to the site of the cancer.

Pancreatic cancer MDTs include a range of expertise needed to effectively manage and treat every aspect of pancreatic cancer. The team includes:

- Surgeons to decide and carry out the best course of surgery (if appropriate);
- Oncologists to plan and deliver chemotherapy and radiotherapy treatments;
- Radiologists capable of providing accurate imaging for tumour staging, as well as carrying out therapies to treat tumours;
- Clinical nurse specialists to communicate outcomes and options from the MDT meetings to patients, and provide information, support, and care throughout their treatment.

Most pancreatic cancer patients will have their case discussed at a multi-disciplinary team (MDT) meeting where decisions regarding their care will be made by a collection of specialists in surgery, radiology, oncology, pathology and a specialist nurse.

Don't be afraid to ask someone in your specialist team if something is not clear or you would like more information.

Staging and prognosis

Staging

Staging shows how advanced the cancer is (whether it has spread). The tests on the preceding pages not only diagnose the cancer, but help doctors determine the stage of the cancer and the best treatment for you.

Stage	Tumour
I	The cancer is confined to the pancreas and has not spread anywhere else. This is known as early-stage disease
2	A tumour confined to the pancreas and local lymph nodes (small bean like glands near the pancreas) or tissues around the pancreas like the bile duct
3	The tumour has started to involve large blood vessels near the pancreas, this makes it inoperable. In some cases, the tumour may be able to be shrunk away from the blood vessels using chemotherapy and/or chemoradiotherapy which may make it operable.
4	The tumour has spread to other organs such as the liver or lungs. This is known as metastatic disease. These tumours are non-operable as surgery would not improve the outcome.

Prognosis

Prognosis means the expected outcome of a disease. You will need to discuss your prognosis and treatment options with your specialists. However, it is not possible for any doctor to predict exactly what will happen. **The sooner pancreatic cancer is diagnosed, the better the prognosis. This is because the cancer may not have spread beyond the pancreas and treatment can be started earlier.**

Treatments for Pancreatic Cancer

Most treatments are varied and are dependent on the stage of your disease and your fitness level. Sometimes how fit and healthy you are can influence whether you will be considered for a potentially curative treatment, or treatments to control your symptoms. This is because the treatments can be hard to go through and can cause negative side effects to your body. If you are healthy and fit, you are more likely to cope with the treatments. Your specialist will tell you how your fitness will impact on your treatment considerations. See page 30 on how to maintain a fit and healthy lifestyle.

Coping with your diagnosis

Coping with your diagnosis

For many people, a cancer diagnosis can be a life changing event. It is natural to experience many different thoughts and feelings. Some people feel upset, shocked or anxious, while others feel angry, guilty or alone. There is no right way for you to feel. These feelings might last a long time, or may quickly pass. The important thing is to find a way that helps you cope.

Often talking to someone can help, whether this be someone close to you, your doctor or local support groups. Local support groups can be helpful as you are talking with people who understand your situation and are going through something similar. You are not alone in this, soon it is thought 1 in 2 people will have cancer in their lifetime.

If you are having continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you might be experiencing depression.

Depression is not a sign of failure or an inability to cope. Depression can be common with cancer diagnoses, and can often be treated successfully. There are both medical and non-medical approaches to managing depression. Your doctor or psychiatrist will be able to help. Although it may seem hard, help is there for you.

If you are having some of these thoughts or feelings you can call the Samaritans' 24-hour confidential helpline: 116 123.

For more information on coping with cancer we can recommend the Macmillan website, where there is a lot of helpful information.
macmillan.org.uk/information-and-support/coping

Relationships with others

Cancer can affect your relationships with family, friends and colleagues. Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example by being overly positive, playing down fears, or keeping a distance. It can be helpful to be open with partners, friends, and family about how you are feeling. Even though talking about this may be difficult, it helps to know how each other are feeling to understand how best to cope and support each other with what is happening.

Practical considerations

There are practical considerations you may want to consider;

Work

Cancer can affect your work and you may need some time off work due to treatments or symptoms (such as fatigue). If you feel your work will be affected, talk to your manager or HR (human resources) officer as early as possible. In the UK you are covered by legalisation that protects your rights at work. If you live in England, Scotland or Wales, the Equality Act 2010, and for Northern Ireland, the Disability Discrimination Act 1995 (DDA) (as amended) protects you, even if you are self-employed or a carer. It may be helpful to discuss with your doctor whether your treatments will affect your ability to work. For more information see:
macmillan.org.uk/information-and-support/organising

Finances and financial support

Having cancer may have an impact on your financial situation, especially if you are unable to work. It could be helpful to speak to a hospital or community social worker, or contact Citizens Advice, who can advise you about your financial situation, advise on what benefits may be available and suggest the next steps. Macmillan Cancer Support also provide financial advice. For more information see:
macmillan.org.uk/information-and-support/organising/your-finances
Or call them on: 0808 808 00 00.

Practical considerations

How to maintain a fit and healthy lifestyle

The fitter and healthier you are, the more likely it is that you will be able to cope with and recover from the treatments you are given. You can have an influence.

- If you smoke, consider quitting
- Keep active. Light exercise may help reduce fatigue and increase your appetite, it is also good for your mood. Taking short walks can be helpful
- A major problem with cancer can be weight loss, or inability to maintain weight. See our recipe book for meal ideas that help you maintain weight, you can go to our website and order one, or call us on **0303 040 1770.**

For more information and sources of support please see our website:
panact.org/support

Your medical team and second opinions

Your medical team

Within the specialist pancreatic units in the UK, the first treatment you receive is usually decided based on your test results and will be relatively consistent from unit to unit. There may be slightly different opinions regarding suitability for certain treatments as every patient is an individual, and there are always areas where there is debate about the best treatment option.

The decisions regarding treatment in specialist centres are no longer made by individual consultants but are decided by a committee including specialists in surgery, radiology, pathology and oncology and are based on all the evidence from the tests that have been carried out. This is known as a Multi-Disciplinary Team (MDT).

Treatment decisions

What treatment you have, is your decision. The medical experts are there to advise you with their knowledge and what they think may be the best treatment option for you. However, you are the individual who knows your body, values, preference and your social circumstance. These are also important factors for your treatment decisions.

This is a difficult time, particularly after a new diagnosis. You are expected to take in and understand a lot of important information from a wide range of specialists. You may feel very anxious or stressed which may make it difficult to retain and process the information you receive. Having a friend or family member with you at appointments may be helpful as well as asking for written information to refer back to.

Your medical team and second opinions

Second opinions

All decisions regarding treatments are made by a multi-disciplinary team (MDT) who are specialists in surgery, pathology, oncology and radiology. They use national treatment guidelines to decide the most suitable treatment for you. Even so, you may want to seek another medical opinion about your diagnosis or treatment.

You may have doubts about your diagnosis, may not understand the information you are given, or are not happy with the treatment that has been recommended, or you may just want to talk to another doctor or specialist about your diagnosis or treatment.

All patients in the UK have a right to a second opinion and this may form a valuable part of your decision-making process. Some people feel uncomfortable asking their doctor for a second opinion, but specialists are used to patients doing this. You can ask your GP to refer you to another consultant or specialist, either on the NHS or privately. Or you can ask your current consultant or specialist to refer you for a second opinion.

As the specialists from a region are likely to have been involved with the initial decision, obtaining a second opinion will normally require travel to a different regional specialist centre. It may also be a good idea for a family member or friend to come with you to support you and help process the complex information. It is worth thinking about what you would like to get out of the second opinion before the appointment and writing down questions you would like to ask.

For more information, call Pancreatic Cancer Action on **0303 040 1770** or visit panact.org

Further information

What are clinical trials

Clinical trials are where treatment alternatives are tested in volunteers. This could be a type of drug, surgery or maybe a combination of treatments. They are necessary, so we know how safe and effective this treatment option is before it is approved for use in patients. There are three stages (phases) a drug (or other treatments) pass through before it becomes available as an accepted treatment. Before a drug can be assessed in a trial, there will have been many years of development in research laboratories, the results of which have to suggest that there is a potential benefit to using the drug in patients.

How to take part in a clinical trial?

Treatment opinions can differ when new (and unproven) treatments are being tested as part of a clinical trial. Most regional pancreatic centres will be involved in research trials, but the clinical trials offered may be different from one centre to another. You should remember that a trial is being carried out because the benefit of the treatment is unknown (it may be better, the same, or sometimes not as good as the standard treatment). It may be worth asking your medical team if there is a pancreatic cancer clinical trial operating in your specialist unit that you may be eligible for.

If you go to our website, you can find out more information about clinical trials and available trials in your area. panact.org/clinicaltrials

Also talking to your doctor or nurse about more information will be helpful.

What to ask your doctor

You may find the following list helpful when thinking about the questions you want to ask your doctor about your illness and treatment. If you don’t understand any of the answers you are given, it is fine to ask for it to be explained again. Sometimes it is useful to bring your partner, another family member or a friend with you when you meet with your doctor to help you remember what has been said.

☐ **Have I got pancreatic cancer?**
☐ **What type of pancreatic cancer have I got?**
☐ **What tests do I need?**
☐ **What is the timescale for the MDT discussion?**

Other questions such as “Is it hereditary?” or “Is it caused by lifestyle?” may well be answered by information on our website. Visit panact.org

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Further information

Pancreatic Cancer Action

We are a national charity dedicated to saving lives through early diagnosis and improving the quality of life for those affected by pancreatic cancer. Please call or go to our website for more free information on pancreatic cancer.

Tel: 0303 040 1700
panact.org

Clinical trials information

For further information about clinical trial types, pros and cons and how to find and take part in a trial.

panact.org/clinicaltrials

EUROPAC (European Registry of Hereditary Pancreatitis and Familial Pancreatic Cancer)

This is a collaborative study based at the University of Liverpool with pancreatic specialists from around Europe. They are investigating hereditary pancreatic cancer diseases.

Tel: 0151 706 4168
Email: europac@liverpool.ac.uk
panact.org/EUROPAC

Macmillan Cancer Support

Resources and information designed to provide physical, financial and emotional support to cancer patients and their families

Tel: 0808 808 0000
macmillan.org.uk

Maggie's Centres

Maggie's centres provide free practical, emotional and social support to people with cancer and their family and friends. They are often built next to NHS cancer hospitals.

Tel: 0300 123 1801
maggiescentres.org

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Glossary

abdomen
The part of the body between the chest and hips, which includes the stomach, pancreas, liver, bowel, kidneys and bladder.

adenocarcinoma
This is cancer of the exocrine cells that line the pancreatic ducts. The majority of pancreatic cancers are of this type.

adenosquamous carcinoma
A very rare aggressive form of pancreatic cancer.

ampullary adenocarcinoma
Cancer that develops in the ampulla of vater (where pancreatic ducts and bile ducts merge).

Ampulla of Vater
The widened portion of the duct through which the bile and pancreatic juices enter the intestine.

anaesthetic
A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

artery
A blood vessel which delivers oxygen rich blood from the heart to the body.

benign
Not cancerous or malignant. Benign lumps don't usually spread to other parts of the body.

bile
A fluid made in the liver and stored in the gall bladder that helps with the digestion of fats.

bile duct
The passage leading from the liver and gall bladder to the duodenum. Bile travels through the bile duct.

cells
Cells are the basic building blocks of all living things. The human body is composed of trillions of cells. They provide structure for the body, take in nutrients from food, convert those nutrients into energy, and carry out specialised functions. Cells also contain the body's hereditary material and can make copies of themselves.

cholangiogram
X-ray images of the bile duct.

cystic tumours
Tumours that cause fluid filled sacs in the pancreas. Most are benign.

Glossary

diabetes
A chronic disease in which sugars from food are not properly converted into energy in the body because the pancreas does not produce enough of the necessary hormone (insulin). Diabetes may be a risk factor for pancreatic cancer.

diagnosis
The identification and naming of a person's disease.

DNA
DNA is the complex chemical that carries genetic information. DNA is contained in chromosomes, which are found in the nucleus of most cells.

duodenum
The first section of the small bowel (small intestine).

endoscopic retrograde cholangiopancreatography
A procedure used to examine the pancreatic and bile ducts. The doctor injects dye into the organs and creates x-ray pictures of the organs.

endoscopy
A type of examination or diagnostic test. A thin, flexible tube with a camera on the tip – called an endoscope – is used to examine the inside of the body.

enzymes
Proteins that are essential for the normal functioning and performance of the body. Enzymes aid digestion.

gall bladder
A pear-shaped organ on the underside of the liver that stores bile. Bile is transferred from the gall bladder to the duodenum via the bile duct.

gland
Specialised organs or groups of cells that make various fluids that are used in the body or excreted.

glucagon
Is a hormone that is naturally made in the pancreas and works to raise blood sugar.

insulin
A chemical messenger (hormone) secreted by the pancreas to regulate the amount of sugar (glucose) in the blood. If the body does not produce enough insulin, diabetes will develop.

jaundice
A condition caused by increased amounts of bile in the blood. This can cause the skin and whites of the eyes to turn yellow, your urine to darken, tiredness, loss of appetite and itchy skin.

liver
A large organ in the top right side of the abdomen. The liver plays an important role in the breakdown and build-up, digestion, detoxification and removal of substances from the body.

lymph nodes
Small, bean-shaped structures that form part of the lymphatic system and help fight infections. Also called lymph glands.

malabsorption
This is when your intestine is not digesting or absorbing nutrients properly from food.

malignant
Cancer. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

metastasis
A cancer that has spread from another part of the body. Also known as secondary cancer.

neuroendocrine pancreatic cancer
Neuroendocrine tumours (NETs) start in the cells of the neuroendocrine system. The neuroendocrine system is a network of endocrine glands and cells throughout the body.

pancreas
An organ in the digestive system. The pancreas produces insulin and enzymes that help to digest food.

pancreatic lymphoma
Is very rare. Pancreatic lymphoma, or primary pancreatic lymphoma (PPL) is a cancer of the lymphatic system of the body that originates as a pancreatic mass.

pancreatic sarcomas
Tumours that form in the connective tissue that holds together the pancreatic cells. This is very rare.

pancreatitis
Inflammation of the pancreas.

prognosis
How you are expected to do after a disease is diagnosed.

radiotherapy
The use of radiation, usually x-rays, to kill cancer cells or injure them so they cannot grow and multiply.

tissues
A collection of cells that make up a part of the body that then make up a part of the organ.

tumour
A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

ultrasound
A non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and position of a tumour.

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Acknowledgements

We would like to thank the following for their contribution to the development of this booklet:

Mr Ross Carter MD FRCS, Consultant HPB Surgeon,
Glasgow Royal Infirmary & President of the Pancreatic Society of Great Britain & Ireland 2012 for content and review.

Mr Neville Menezes MS FRCS, Consultant HPB Surgeon,
Royal Surrey County Hospital for content and review.

The Pancreatic Cancer Action lay review panel.

For sources and references used in the compilation of this booklet, please contact us at the address overleaf.

Pancreatic Cancer Action

This booklet has been funded through the generosity of supporters of Pancreatic Cancer Action, a UK charity founded by a pancreatic cancer survivor, Ali Stunt, who was diagnosed with pancreatic ductal adenocarcinoma in 2007. With a focus on early diagnosis, it is Pancreatic Cancer Action's mission to improve survival rates by raising awareness of pancreatic cancer and its symptoms among the public, medical education, improved information and by funding research specifically to improve early diagnosis of the disease.

If you would like to support us or find out more, please contact us at:
enquiries@panact.org or visit panact.org

If you are unsure of anything at any time please consult your own doctor, dietitian or Cancer Nurse Specialist (CNS)

If you would like to help us by either holding an awareness event or by fundraising, please **email enquiries@panact.org** or call **0303 040 1770**. For more information or to donate directly please visit **panact.org**

☎ 0303 040 1770

✉ enquiries@panact.org

⌂ panact.org

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Saving lives through early diagnosis

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