

Controlling the Symptoms of Pancreatic Cancer



Common symptoms, management and what to expect.



Understanding pancreatic cancer booklet 3

In this booklet, you'll find out more about inoperable pancreatic cancer, the treatments available to control the symptoms and what to expect. 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



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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.

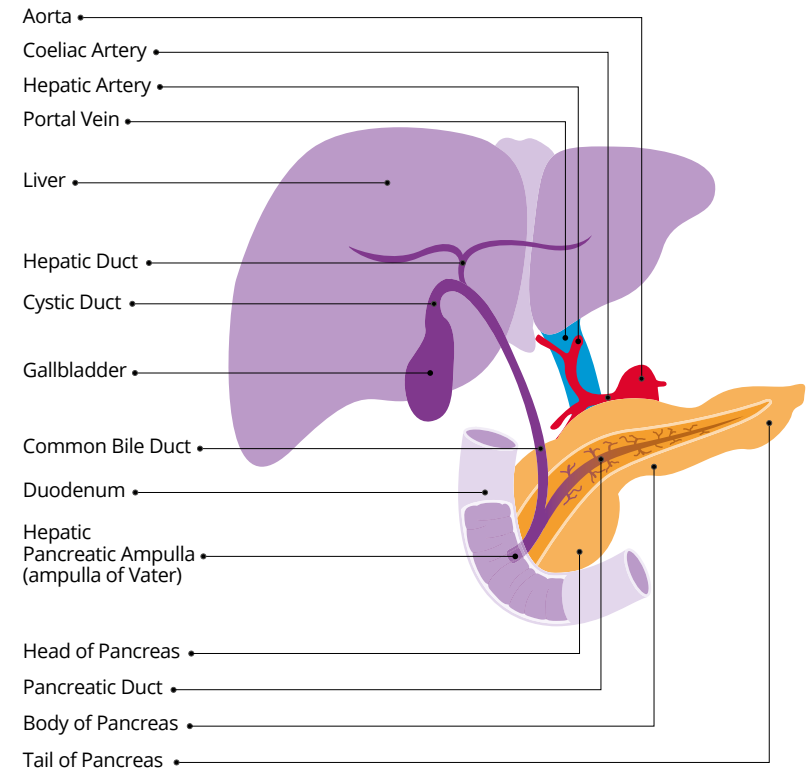
Hormones

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.

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 the cells in the pancreas together. Metastases (tumours that have originated in another part of the body and developed one or more secondary tumours elsewhere) can affect the pancreas as well.

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 have similar symptoms to pancreatic cancer but are not the subject of this booklet.

You will have undergone various tests such as **ultrasound** scans, CT scans and possibly had an **endoscopy** to determine that you have pancreatic cancer. These tests are important as they will inform the doctors about the size and position of the tumour and whether it's possible to have it surgically removed (resected).



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

What is the aim of pancreatic cancer treatment?

Treatment for pancreatic cancer will depend on the tumour type, where it is and at what stage it is diagnosed. Stages of pancreatic cancer are described in the table opposite.

Treatment varies depending on whether your cancer is operable or not. If your tumour is operable, Pancreatic Cancer Action produces a separate booklet that you may find helpful - **“Surgery for Operable Pancreatic Cancer.”**

Often, pancreatic cancer is detected when the tumour is no longer operable. Treatments will aim to prevent the tumour growing further and the focus will be on quality of life and making sure that you are as involved in treatment decisions as possible.



This booklet focuses on pancreatic adenocarcinomas, (the most common type of pancreatic cancer).

Different tumour types such as pancreatic neuroendocrine tumours (pNETs) are treated differently, with surgery or multiple other therapies depending on the spread of the cancer. Sometimes in these cases, metastatic tumours will be operated on.

You should always discuss your treatment options with your medical team.



Stage	Tumour
1	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.

Who will be involved in my treatment and care?

It is possible that you will have already encountered the phrase “multi-disciplinary team”. (MDT) This is a group of health care professionals who are involved in diagnosing and treating your condition. There may be several different people and professionals involved in your care and this is likely to change as your condition changes.

There will be oncologists (cancer doctors) and specialist nurses in the MDT. There may be physiotherapists and occupational therapists who can assist in helping you maintain independence. There may also be dietitians who can give you advice on nutrition.

You might also hear about specialist doctors and nurses from the **palliative care** team. Some people worry that palliative care only involves hospice visits and means that they do not have long to live. In fact, palliative care teams can help you in any location to keep you as independent and symptom free as possible. They are there to help you and your loved ones with all aspects of your diagnosis including your physical, emotional and social needs.

You may also encounter social workers and other professionals based in and out of the hospital to help you cope with your diagnosis and maintain your quality of life. You can approach any of these professionals for help and advice.



Common pancreatic cancer symptoms

When you are first diagnosed with pancreatic cancer it can be frightening, upsetting and bewildering. The symptoms you may have been having prior to diagnosis might seem relatively mild compared to what you would expect from a serious illness.

This section aims to inform you of some of the more common symptoms and how they might progress. It can help prepare you for what to expect.

Managing your symptoms is important to make sure that you can enjoy the best possible quality of life. How symptoms are managed varies from person to person. You should inform your medical team of any new symptoms or changes in existing ones to ensure that you get the support you need.

People's fears around pancreatic cancer commonly centre around managing their symptoms and their pain. You may not experience many symptoms discussed in this booklet, or you may experience a mixture of different symptoms at different times. The important thing is to ensure that you speak to a carer or health care professional about any symptoms as they arise. Good **symptom management** can ensure that you have the highest quality of life possible.

Pain

People often complain of pain in the **abdomen** (tummy) that can radiate around to the back. Some people also get back pain, around where a bra strap would be or around their shoulder blade.

Managing your pain is important and can be done in a number of ways personalised to you. You should feel confident to inform your doctor or specialist nurse if you are in pain or if your pain relief is not working well enough.

Regular pain assessments from your medical team should ensure that your pain is managed effectively. Your doctor may ask questions about the position and intensity of your pain and if any treatments make it better or worse. Pain relief should be based on your individual needs and the type and dose of medication can be adjusted to keep you as free from pain as possible.

Symptoms and disease progression

Pain relief is best taken on time and regularly, rather than as and when you need it. This avoids spells of uncontrolled pain. Sometimes 'just in case medicines' may be useful if you experience pain out of hours and need something to top up your regular medications.

Pain relief can be given through several routes. Orally (tablets or liquid medicine), via a patch on the skin or via injection.

Coeliac Plexus Nerve Block

You may be offered a **coeliac plexus** nerve block to stop you from feeling pain for some time. This involves injecting a substance such as a local **anaesthetic** or **anti-inflammatory** into the space around the group of nerves called the coeliac plexus, which send pain signals to the brain. A needle is inserted into the space around your spine with x-ray guidance or **endoscopy** and the medication delivered. There are some potential complications to having this treatment that your doctor will discuss with you. It is often used to treat people who do not respond well to other methods of pain relief.



Syringe Drivers

Syringe drivers are sometimes used to provide medications if you cannot swallow well or are vomiting. Syringe drivers deliver a continuous infusion of medication to you, and therefore the medication does not come in peaks and troughs like it would with some of the other methods.

The syringe driver works by placing a small needle into the skin and delivering the medication through a battery powered pump. The box for a syringe driver is small and can be carried around or tucked beside you when you are resting. The syringe driver allows for management of multiple symptoms such as pain, nausea and vomiting and can be given in any setting not just in hospital.

Choice of pain treatment

How your pain is treated will depend on the cause. Sometimes it may be because of a blockage caused by the tumour. You may need a bypass or the insertion of a **stent** to unblock things or divert around the tumour which could relieve your pain. This can be diagnosed with a scan and procedures to treat are detailed in the following pages.

Pain relief can come with side effects such as constipation and your medical team will advise you on this and how to treat or minimise them. Other ways of controlling pain yourself, without the use of medication include breathing exercises, distraction techniques and massage.

Symptoms and disease progression

Nausea and vomiting

There are many reasons why you might feel or be sick at different times throughout your illness. Sometimes the disease itself causes these symptoms due to the space it is taking up inside your body or because it is preventing you being able to digest nutrients in the normal way (**malabsorption**). Some treatments and medications may cause nausea and vomiting such as chemotherapy. Sometimes constipation or the body not moving things through the intestine as it should (intestinal dysmotility) is the cause. Nausea and vomiting can be caused by the tumour due to an **obstruction** (blockage). A CT scan may reveal the blockage and you may have a stent fitted in the area affected. Whatever the reason, there are ways of relieving nausea and vomiting.

If you have malabsorption you may notice that you have lost weight and your stools are pale, large and very smelly. Pancreatic **enzyme replacement therapy** will allow you to digest your food better and prevent the sickness. **Dietitians** can give you advice about your intake and you can ask to be referred by your medical team.

You can have oral, liquid, injected or syringe driver medication for nausea and vomiting. You may need to try a number of different medications and doses before you find what works for you. Other tips include eating foods or sipping drinks with ginger or mint flavours.

Constipation

Being constipated, or unable to open your bowels, is common for people with pancreatic cancer. It may be due to the disease itself or it may be because of a treatment you are receiving. Constipation can be uncomfortable and can also cause bladder symptoms such as incontinence or retention (holding) of urine.

If you are constipated, medications can be given to help get your bowels moving again. This ranges from medicines you drink to suppositories (inserted in the rectum) or a liquid **enema**. You can take regular medication to keep things moving and prevent constipation but remember to let your doctor know if you develop loose stools (diarrhoea).

Increasing the amount of fluid you drink will help to soften stools. Moving around as much as possible helps to keep your bowels moving too. Though this can be difficult if you are feeling unwell.

Fatigue

Fatigue is not just tiredness. It is a level of tiredness where you feel as though you cannot do things that you normally do. Fatigue can feel disabling and reduce your quality of life. It can be due to the cancer itself or the side effect of a treatment or may be due to depression. Getting as active as you can, even when it feels like the last thing you want to do, will boost your energy levels. Moving around a little may give you more energy and help to stimulate your appetite. It is important to tell your doctor about fatigue. There may be a treatable cause such as **anaemia**. If your fatigue is due to depression you should recognise that this is not an inevitable part of your disease and to see your GP to discuss treatment.



Symptoms and disease progression

Diabetes

Not everyone who has pancreatic cancer also has diabetes but there is a link between the two diseases. A tumour in your pancreas may damage it and affect its ability to produce **insulin**, the **hormone** that controls blood sugar levels in the body. If you are diabetic, then managing this alongside your diagnosis can be difficult. Speaking to your GP, diabetic nurse and cancer nurse specialist may be useful as well as getting dietitian input. You may need to take medication for your diabetes if you didn't before. Monitoring your blood sugars and keeping them stable may affect the kind of treatments you can have and how you cope with them.

Weight loss

Weight loss in pancreatic cancer patients varies from slight to extreme. Weight loss can be caused by pain, treatments such as chemotherapy, fatigue, loss of appetite, the effects of the tumour or the emotional difficulty of dealing with the disease. Losing a lot of weight can affect how you feel about yourself and your quality of life. There are ways to treat weight loss and stop it from becoming serious. Your medical team can assess your risk of becoming malnourished due to weight loss. **Oral nutritional supplements** can be helpful when you don't really feel like eating. They may be recommended by your dietitian or prescribed by your doctor. They come in many forms to suit your taste.

- **Nutritional drinks - juices, milkshakes and high energy shots**
- **Powders - to add to milk and cream. Powdered protein soups**
- **Nourishing puddings - useful for people struggling to swallow**

Dealing with weight loss can be difficult and can make meal times stressful. You may also feel as though there is extra pressure from friends and family to eat. Pancreatic Cancer Action publishes a patient information booklet on diet and nutrition for pancreatic cancer which it may be helpful to refer to. We also publish a free recipe book with advice on how to make your meals as appetising and nourishing as possible when you don't really feel like eating and drinking. Available to order on our website:

panact.org

Jaundice

Jaundice, develops when the bile duct becomes blocked and yellow pigment builds up (**bilirubin**). This can be very itchy and can be irritating. It can also make skin feel hot and uncomfortable. This itching is called pruritis. Jaundice can also cause nausea and vomiting as well as digestive problems and tiredness.

There are many ways of treating jaundice and your medical team will help you decide which is the right one for you. One option is to be fitted with a stent to remove the blockage and keep the bile duct open. Another option is a surgical procedure called a pancreatic biliary bypass. The surgeon will bypass the blockage and allow bile to flow from your stomach to the small intestine which should solve the jaundice. Surgical procedures for jaundice are discussed in more detail in the following pages.

The symptoms of jaundice can be eased using medications if these surgical approaches are not appropriate to help drain your bile duct. **Antihistamines** and skin care are also important to relieve the itching. Keeping skin cool and using moisturising creams to stop it drying out can help relieve the symptoms.

Ascites

Ascites is a build up of fluid in the **peritoneum**. These are the layers that line the inside of your abdomen (tummy). This may happen in pancreatic cancer patients if your **liver** function becomes poor or due to the effects of the tumour or fluid (exudate) it produces. Ascites can cause pain or shortness of breath as your abdomen swells. It can be drained in hospital using a tube that can be either temporary, and removed once the fluid has drained, or permanent.



Symptoms and disease progression

Blood clots

Cancer can increase your chances of getting a blood clot. Some treatments also increase the risk such as chemotherapy. You may be offered medication to prevent blood clots and thin the blood. Clots can occur anywhere in the body. It is likely that the affected area will cause you pain. You can also reduce the chances of a blood clot by taking regular short walks, drinking lots of water and doing chair or bed exercises (marching, shoulder rolls etc). A physiotherapist may be able to advise on some exercise to suit you depending on your activity levels.

Depression

Depression is a feeling of very low mood. You may feel as though you don't have any energy, have a loss of appetite and poor sleep. Depression can reduce your quality of life and make your other symptoms feel worse.

The link between pancreatic cancer and depression is complicated. Some researchers think that depression may be a symptom of pancreatic cancer. It is not completely clear if this is the case, but it is certainly true that a diagnosis of pancreatic cancer can lead to **anxiety** and depression. Rates of depression are high in pancreatic cancer patients. No one is completely sure why, it may be a mix of factors caused by the tumour and because of the diagnosis itself.

Depression doesn't always occur when you have a cancer diagnosis. It is not a sign of failure or an inability to cope. Depression can often be treated successfully. There are both medical and non-medical approaches to managing depression. Your doctor will be able to help, and different therapies and treatments are available to suit you. Although it may seem hard, cancer and depression can feel very lonely, but help is available.

If you are having some of these negative thoughts or feelings, you can call the Samaritans' 24-hour, free, 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](https://www.macmillan.org.uk/information-and-support/coping)



Chemotherapy for symptom control

If you are having **chemotherapy** for pancreatic cancer, either after surgery, with radiotherapy or as a stand-alone treatment there are a number of side effects.

Chemotherapy treatment is the use of cell killing (**cytotoxic**) medication to destroy the cancer **cells** in your body. You may be offered one or more types of chemotherapy together. Pancreatic Cancer Action produces a free booklet "chemotherapy and how it is given" that will give you more information about how chemotherapy is given and what it involves.

Because chemotherapy kills some healthy cells in your body there are a number of side effects which can be difficult to manage. Chemotherapy makes the levels of blood cells in your body drop about a week after treatment starts and for up to three or four weeks after your treatment. When the cell levels in your blood drop there are a number of possible side effects

1. Infections

The white blood cells in your body are part of your **immune system** and are normally active in fighting off infection. When the number of these in your bloodstream is low (**neutropenia**) you are more likely to get an infection. Symptoms include fever (temperature above 37.5 degrees), low body temperature, shivers, rapid breathing or heart rate. Depending on where the infection is you may have other symptoms such as a cough or pain/ difficulty passing urine. Infections during and after chemotherapy need to be treated urgently and you should inform your doctor straight away or you may have been given an emergency contact for out of hours. Make sure you do not delay seeking help, this is a medical emergency.

2. Anaemia

A drop in the number of red blood cells in your blood means that your body cannot transport oxygen as effectively around your body. This may leave you feeling tired and breathless. In some cases, you may need a **blood transfusion** to help you feel better.

3. Bleeding

A drop in the level of **platelets** means that your blood cannot clot as easily. This means that if you cut yourself or bruise it will be worse than usual. Try a soft toothbrush and electric razor to avoid this. If your platelet levels drop too low you may need to have a platelet infusion, which is like a blood transfusion but with all the other cells (red and white) removed.

Other side effects may include:

- Sore mouth and changes in how things taste or smell - drink plenty of fluids, use mouth wash and suck strong sweets. Try to avoid strong smells, for example the smell of cooking if someone is preparing a meal for you.
- Nausea and vomiting - please see section on managing nausea and vomiting (page 14), there are many ways to manage this.
- Diarrhoea and constipation - See section on constipation (page 15). Tell your doctor if you are having diarrhoea or are constipated. Try to drink plenty of fluids.
- Hair loss - whether you lose your hair depends on the type of chemotherapy you are having. If it is likely, your medical team will direct you to a specialist nurse. You can use shampoos without harsh chemicals to help avoid this.
- Fertility - chemotherapy can affect your ability to have a child, in women by bringing on early menopause and changing your menstrual cycle, for men it can damage your sperm count. It is also advised to not get pregnant during chemotherapy as it can damage the developing baby.
- Skin - some people get sore, red and peeling palms and soles of their feet (palmoplantar syndrome). Other people report darkened fingernails and other changes to their nails which eventually grow out when the treatment stops. Try to keep your skin moisturised using creams without harsh chemicals.
- Fatigue - please see page 15 for advice on managing fatigue.
- Pins and needles - some types of chemotherapy can damage the nerves that control your muscles (**peripheral neuropathy**). This can give you tingling and pins and needles symptoms. This can also cause numb or burning feelings in your hands and feet. Peripheral neuropathy can be managed by massage, wearing layers such as thick socks, applying creams for comfort and checking your skin regularly to ensure that you have no cuts or scrapes.

You should inform your medical team if you experience any of these symptoms.

Radiotherapy for symptom control

Radiotherapy is not used as often as chemotherapy or surgery to treat pancreatic cancer. You may have radiotherapy alongside chemotherapy or on its own. It works by using high energy rays to destroy cancer cells, whilst leaving your healthy cells as unharmed as possible.

Radiotherapy can help control the growth of the cancer and treat pain. It works by shrinking the size of the tumour, so if it is pressing on structures in your body and causing pain, this can be relieved. If you have radiotherapy for symptom relief like this, it is known as **palliative radiotherapy**.

Some people can have **stereotactic radiotherapy**, where rays are fired at the tumour from a number of angles inside a radiotherapy machine.

Radiotherapy takes place in a radiotherapy department in a hospital. You may have a treatment daily Monday to Friday with a break over the weekend. Each treatment may take between ten and thirty minutes. Like any treatment, radiotherapy comes with its own side effects. These include skin infections, fatigue, loss of appetite, diarrhoea, nausea and vomiting.



Surgery input for symptom control

Surgery for pancreatic cancer symptoms

Sometimes your tumour may block your bile duct, this is what causes jaundice. The bile duct is close to the pancreas and carries bile from the liver to the duodenum (the first part of the small intestine). Bile helps with digestion and when the bile duct becomes blocked you develop jaundice.

The tumour may also block the duodenum, so food cannot flow out of the stomach. This may make you feel constantly full, cause nausea and vomiting and for you to lose weight.

You may be offered a surgical procedure to remove a blockage like these in the form of a stent or a bypass. If you are offered surgery, it is important that you read any information you are given before the operation and that you attend your pre-operative assessments. If you have **diabetes** or **glaucoma** you will need to inform the medical staff once you are aware of your appointment. If you take any medication that acts as a blood thinner i.e. warfarin, you will need to inform medical staff as they will advise on when to stop taking them in the days prior to your procedure.

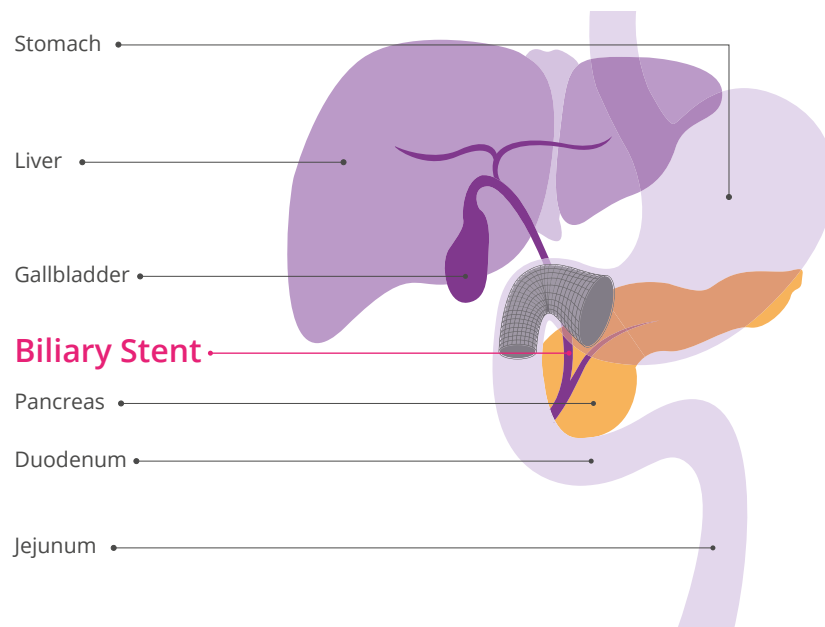


Surgery input for symptom control

Stent insertion

A **stent** is a plastic or metal tube that is used to unblock the bile duct. This will relieve your symptoms of jaundice and if you are having chemotherapy will allow this to go on uninterrupted. Metal stents are used more often than plastic stents and are less likely to become blocked. There are a few ways of inserting the stent and your doctors will advise you on which method is best for you.

Where a biliary stent will be inserted



ERCP - Endoscopic Retrograde Cholangio-Pancreatography

This test allows your doctor to look at an image of your pancreas and bile duct via an x-ray. ERCP takes place in the x-ray department in hospitals. The results of this can allow doctors to visualise where your blockage is and treat it appropriately.

You will have a needle inserted in the back of your hand so that you can be **sedated**. You will then lie on your left side with your left arm behind your back. Your pulse and oxygen levels will be monitored using a probe on your finger, you may be given oxygen if you need it.

Doctors will pass a flexible camera (an endoscope) down your throat and into your stomach. The tube will pass into the first part of your intestine (duodenum) where the bile duct is. The doctor will pass a narrow plastic tube called a catheter down the endoscope and into this opening.

A dye will then be injected through the catheter to visualise your bile ducts and pancreas through the x ray. The dye is completely harmless and will pass out of your body naturally. If the doctor can see a narrowing or blockage to the bile duct a stent can be inserted. If there is anything else unusual on the x-ray, then a **biopsy** can be taken where a cell sample (**brushing**) is removed from the ducts to be examined under a microscope.



5 Surgery input for symptom control

Preparation

If you need an ERCP you will need to attend a pre-admission clinic so you can receive information about the procedure and have any blood tests required. If you have diabetes or glaucoma you will need to inform the medical staff once you are aware of your appointment. If you take any medication that acts as a blood thinner i.e. warfarin you will need to inform medical staff as you will need to stop taking them in the days prior to your procedure.

You will be advised about eating and drinking before your ERCP, often people cannot eat or drink (nil by mouth) for around six hours prior to the procedure. You may also be given an antibiotic to prevent infection.

How long does the test take?

An ERCP takes around 30-90 minutes

How will I feel after the test?

You will go back to the ward and a nurse will check your pulse and your blood pressure regularly until you are fully awake. You may feel sleepy for a couple of hours because of the sedation.

After you have been back on the ward for a few hours, if you have abdominal pain, some blood will be taken to check if there has been any irritation to your pancreas (**pancreatitis**) after your ERCP. If you develop pancreatitis, you will need to stay in hospital until it settles.

If you are allowed home on the same day as the test, then you will need someone to look after you for the next 24 hours. It takes this long for the sedative to leave your system and during this time you must not drive, operate heavy machinery, make any important decisions or drink any alcohol.

Percutaneous Transhepatic Cholangiogram (PTC)

This is like an ERCP in that a dye is used to see any obstruction on an x-ray. Instead of inserting a tube with an endoscope, a needle is inserted through the skin between your ribs and a very thin wire passed through the liver and through the blockage in the bile duct. A stent is then fed along this wire.

You will be given advice about eating and drinking before your procedure, but it is likely that you won't be able to eat or drink anything for six hours beforehand. You may be given a local or **general anaesthetic** so that you don't feel any pain as the needle is passed through the skin. If you have a **local anaesthetic**, you may also be given sedation to ensure that you feel no discomfort as the needle is positioned correctly. You will be given antibiotics before and after your PTC to prevent infection.

How will I feel afterwards?

After your procedure you will need to lie flat in bed for around six hours. You will need to stay in hospital for a few days. You may have had a temporary drain to help bile flow again after your procedure which will be removed before you are discharged home.

How will I know if the stent is working or blocked?

For both ERCP and PTC you should feel your jaundice symptoms start to improve after a few days and after two to three weeks your symptoms should have gone. You will have blood tests to ensure that the bilirubin (yellow pigment) causing the jaundice is gone. Once your levels are back to normal you will be able to start chemotherapy or radiotherapy.

If you think your stent is blocked it is important that you contact your GP, hospital doctor or specialist nurse immediately. Make sure you have their phone numbers to hand. Signs of a blockage include jaundice, right upper stomach pain, feeling hot and cold with episodes of severe shivering (rigours), dark urine or pale bowel movements.

Surgery input for symptom control

Gastro-jejunostomy

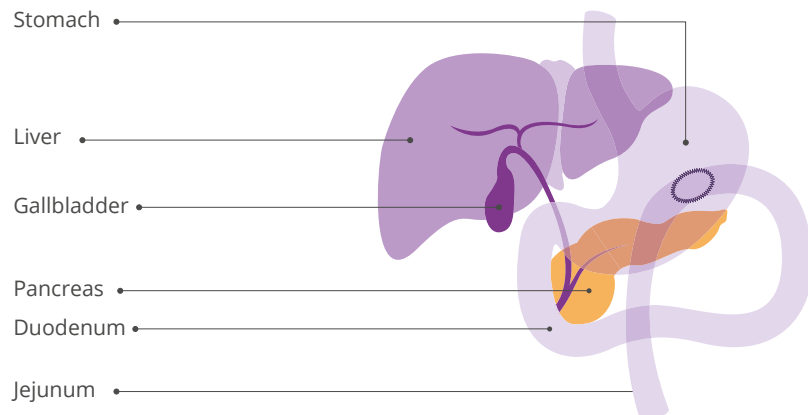
At some stage, many pancreatic cancer patients find that their tumour begins to compress or restrict the duodenum (the first part of the small intestine, immediately after the stomach). This often occurs gradually and begins to cause discomfort after eating and nausea. Fluids may be easier to take than solids. The stomach gradually stretches so that you feel like vomiting slightly less and weight loss occurs as food cannot reach the small intestine for nutrients to be absorbed.

Gastro-jejunostomy bypasses the duodenum so the effects of the tumour no longer affect your digestion. You will have a general anaesthetic and your surgeon may use key-hole surgery (laparoscopy) or make a small cut in your tummy called a mini-laparotomy. The duodenum will be passed by connecting another section of the small intestine (jejunum) directly to the stomach.

How I will feel afterwards

You will be taken back to the ward or to a high dependency unit and will normally be discharged home after around 48 hours. Recovery is usually fairly quick, and you should be able to start drinking fluids on the same day and slowly introducing foods so that you are eating and drinking normally again when you go home.

Gastro-jejunostomy



Duodenal stent insertion

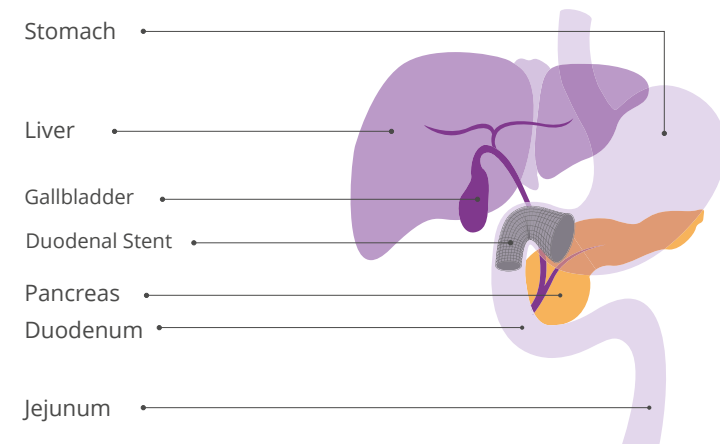
An alternative to a stomach bypass operation is to insert a stent to hold the duodenum open in the same way stents are used to open the bile duct. Inserting a stent aims to allow food and fluid to pass through the stomach and reduce the uncomfortable feeling, nausea and vomiting. The procedure takes place in an x-ray department or endoscopy suite like an ERCP and takes around 30 minutes.

Your medical team will advise you when to stop eating and drinking before the stent is inserted. You will be given sedation through a needle and once you are sleepy the doctor will pass the endoscope down your throat to your duodenum. A wire is then passed which guides the stent into the right place.

How will I feel afterwards?

You will be taken back to the ward once the sedation has begun to wear off and once you are eating and drinking without any problems you will be able to go home. This is often on the same day or after an overnight stay. It may be difficult to return to solid foods after the stent insertion. Some people have problems with solid foods getting stuck. Your dietitian should be able to advise you on soft foods and nutritional fluids. Pancreatic Cancer Action also produce a booklet "eating after a duodenal stent" to help you chose and plan meals.

Diagram showing insertion of a duodenal stent



Surgery input for symptom control

Bypass surgery

Bypass surgery may be offered to you rather than a stent depending on the blockage and your symptoms. Bypass surgery may also take place if during surgery to remove a tumour it is found that the tumour had spread beyond the pancreas and removing only part of the tumour is not beneficial. Bypass surgery will not remove all the tumour and it is used for symptom relief not a cure.

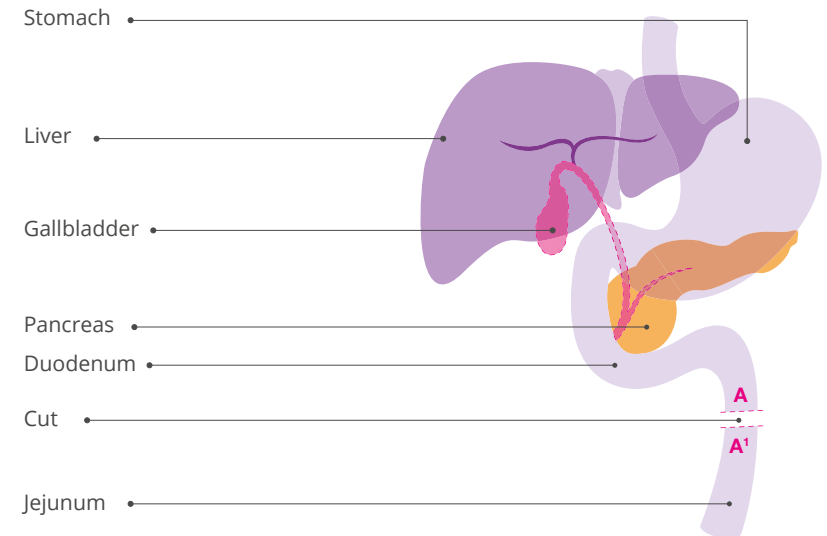
The aim of the surgery is to allow you to recover as quickly as possible (so that more appropriate treatment may be started) and at the same time make sure the liver and stomach continue to work properly. The surgeon will join the bile duct directly to part of the small intestine called the jejunum. This allows the bile to flow from the liver into the small intestine and in time the jaundice should fade. At the same time your surgeon will connect a piece of small intestine to the stomach, to bypass the duodenum. This will allow your stomach to empty properly and should prevent blockage of the duodenum at a later stage.

How will I feel afterwards?

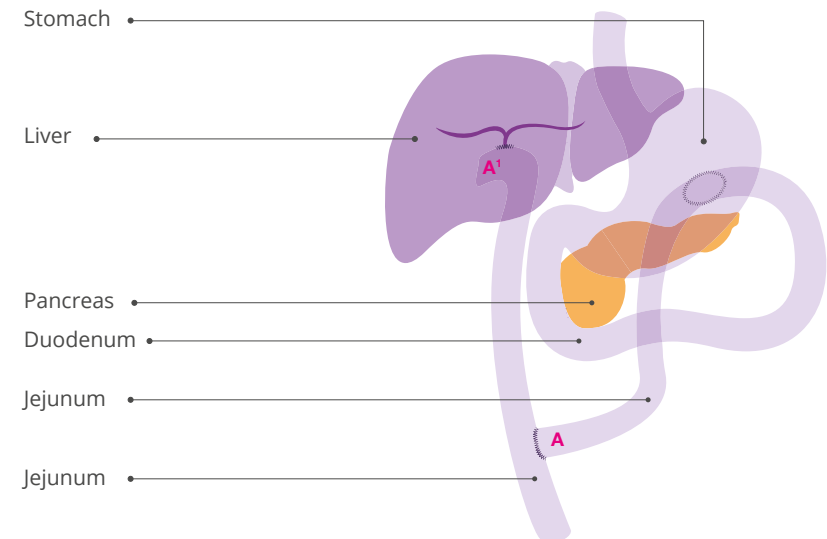
You may be cared for in a High Dependency Unit (HDU) before going back to the ward. You might be able to start drinking fluids the evening after your operation and gradually start eating solid food. You should be able to go home once you're eating and drinking has improved, and your jaundice is getting better.



Double bypass Surgery before



Double bypass Surgery after



If you are experiencing new or recurrent symptoms or have any concerns regarding your symptom management, it is useful to know who you can contact to help. You may be given contact information for someone in your multidisciplinary team (the people looking after you) or a key worker to speak to as a first point of contact. This is often a clinical nurse specialist who can offer help and advice. You can also speak to your GP or district nursing team about symptom management or any of your concerns.

Out of hours you should be given a name and contact number for someone to call. If you are having chemotherapy you will have been given an emergency telephone number if you have signs of an infection such as a raised temperature.

In the case of an emergency and you can't get in contact with your medical team, you should go to accident and emergency or call 999 for an ambulance to ensure that you are treated promptly.

What is advanced Pancreatic Cancer?

If your cancer cannot be operated on, you may have been told that your disease is advanced and cannot be cured. This means that it will likely to lead to your death and you will be offered palliative care and treatments.

It is important to realise that this does not necessarily mean that you are dying immediately. It means instead that treatment will focus on your quality of life and managing your symptoms.

Often, because the symptoms of pancreatic cancer can be quite vague, the disease is difficult to diagnose. Therefore, your tumour may have spread to nearby organs and blood vessels (locally advanced) or to distant organs (metastatic) and it is not possible to operate and remove the disease.

Most of the symptoms that occur throughout the course of your disease can be managed and it is important that you report any new or changing symptoms to your doctor to make sure this happens quickly. It is likely that your diagnosis has come as a shock and your physical and emotional wellbeing are important to your medical team.

Deciding what treatments work for you

Discuss with your medical team which treatments are right for you. Depending on the stage of your cancer and where the tumour is, more or less aggressive treatment may be recommended.

It is important that you feel as though you fully understand all of the treatments explained to you and what your options are. Ask your doctor to explain your **prognosis** and what the treatment is for. Some treatments are used for different reasons depending on the stage of your disease. For example, if you are offered chemotherapy it is important to make sure that you know whether this is being offered to cure the disease or to improve your quality of life. You should expect to be told about any side effects of treatments that you might receive beforehand.

You should also talk to a member of your medical team about what your priorities for treatment are. Many people talk about quality of life, extending life and symptom management. Matching treatments to your priorities are likely to make sure that your wishes are fulfilled.

Once you know your wishes, you can make a list or **advance care plan** (living will) with your medical team to make sure that everyone who treats you or comes into contact with you knows choices you have made. This may be especially helpful if you become ill and cannot communicate these needs yourself any longer. If your tumour is inoperable then input from the palliative care team may help you decide which treatments are best for you and how your decisions can meet your priorities.



Palliative care

Involving palliative care early on in your disease process can be helpful in managing your symptoms. Palliative care does not mean that you are actively dying, you can still receive anticancer treatments whilst being under this team. Palliative care nurses can help decide what treatments are right for you, relieve symptoms and manage the progression of your disease. They can help to explain treatments and the benefits or burdens involved in them. Palliative care professionals can support you wherever you are, at home, a care home, hospital or hospice.

End of life care

Managing your symptoms effectively is just as important towards the end of your life, as after diagnosis.

End of life care and decisions about it can be daunting and not something that you want to think about. However, thinking about this early can ensure that your wishes are met when the time comes and will allow you and your loved ones to have some piece of mind.

Pancreatic Cancer Action produces a booklet to help guide you through end of life decisions and advance care planning. Age UK and the **Malnutrition** Task Force have come together to produce a booklet "lets talk about death and dying" which may also help you start these conversations with your loved ones.

Emotional support

A cancer diagnosis can be a life changing event both for yourself and your loved ones. It is natural to experience many different thoughts and feelings. People react very differently to this news. You may feel as though you wish to withdraw and pull away from people to spend some time reflecting. On the other hand, you may wish to have friends and family around you as much as possible. There is no right, or wrong answer and you may move between these two opposites or sit somewhere in the middle.



You are likely to have a mix of feelings after your diagnosis from shock and denial to anger, fear and guilt. These are all perfectly normal feelings and you need to take the time to come to terms with your diagnosis. You may feel as though you are alone in your experience, but your friends and family are likely to be feeling the same way.

They may not spend as much time with you as you expected or be there for you in the way you had hoped.

Often this is because people do not know how to react and do not want to be in the way, or maybe it's because they don't know what to say. The important thing is to talk to them and discuss your feelings; this is the best way to help them to understand.

Emotional support is available. Remember to take one day at a time and seek a coping method that suits you. Your medical team, friends and family can all be sources of emotional support. Some people prefer to talk to someone they know less well like a counsellor or attend a local support group. Macmillan Cancer Support provides a supportive telephone service as does Cancer Research UK. Marie Curie also provides telephone support and a directory of cancer specific services that can assist you. Pancreatic Cancer Action publishes information on palliative care for patients and carers in the form of free booklets.

Sex and relationships with pancreatic cancer

A diagnosis of pancreatic cancer can affect your sex life and relationships. Sexuality and being able to express it is important and affects your wellbeing. Everyone experiences cancer and treatments differently and sexual attitudes and behaviour vary from person to person. There is no right or wrong way to manage the effects pancreatic cancer may have on your sexuality. There are multiple possible reasons you may experience sex and relationship issues, detailed below.

The effects of surgery, chemo and radiotherapy as well as the disease itself can cause symptoms that may affect your ability or desire to give and receive sexual pleasure. Some of these side effects may continue for months or years. Some treatments also affect fertility, your doctor or cancer specialist nurse should discuss this with you.

Body image may be affected by weight loss or scars. Pancreatic cancer can cause multiple changes to your body and how you feel about it. Body confidence and overall well being are often affected by cancer and treatments.

Emotions involved with pancreatic cancer such as fear, anger and sadness can lead to a loss of interest in sex. Love and the closeness associated with sex can improve these feelings and distract you from these feelings.

There is no right or wrong way to manage sex and relationships with pancreatic cancer. Sexuality is not fixed and finding new ways to enjoy intimacy can bring you and your partner closer together. These include touching, massaging, holding hands and just being close to each other. The most important thing is to ensure that you are communicating with your partner and finding a way to be together that works for both of you.

Some people need help and support in their relationship. Problems often improve with time and communication but it can be useful to speak to a counsellor either alone or in a couple. Many people go through sex and relationship problems during their lives, with or without cancer, it's just not often discussed openly.

Second opinions

Your Multi-disciplinary team (MDT) will be made up of professionals from across a range of disciplines and they will have discussed your case carefully, with each professional having an input into what they believe is the right treatment decisions for you. However, you can request advice from a second MDT and sometimes people find that this can be helpful to confirm a diagnosis or treatment plan or offer something new. You can ask your medical team for a second opinion, they are quite used to this and will be able to refer you another doctor or medical team. Often, this may be a little out of your way or out of area to ensure that the second opinion does not contain professionals from the first MDT. If you have a concern about any aspect of your care you can speak to your hospital's Patient Advice and Liaison Service (PALs) who can advise or assist with complaints. Seeking a second opinion from your consultant does not mean an automatic switch in your care. Any tests carried out will need to be sent to them and a new consultant needs to be agreed and arranged. If you are seeking a second opinion from a GP it is mostly possible to book an appointment with another GP at your surgery. Otherwise, you can register with another local surgery.

Clinical trials

At the time of your diagnosis, your doctor may have discussed [clinical trials](#) with you. These are experimental and used to assess a new intervention or treatment for your cancer. Clinical trials take place across the country and are carried out on specific stages of the tumour and/or in different patient groups. You may be eligible for a trial at diagnosis or may become eligible throughout your treatment process. You do not need to wait for your doctor to mention clinical trials, you can ask about them at appointments and check Cancer Research UK or Clinical Trials Gateway for listings of pancreatic cancer trials near you. Your medical team will need to refer you to a trial and there are often criteria for inclusion that you may or may not meet. If you have any questions about clinical trials or a specific study in particular it is best to take the information you have to your doctor and discuss it with them.

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. If 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 legislation 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.

Support for loved ones

Many people worry about the impact of their illness on their loved ones. Talking about this can be difficult as your friends and family may not want to upset you by explaining how they are feeling. Pancreatic Cancer Action produces a carer's booklet to help guide your loved ones through the course of your cancer. Carers UK and Carers Trust are two carers organisations across the UK who can offer information and support to carers. Macmillan Cancer Support offers information on support groups and Pancreatic Cancer UK hosts an online chat forum for patients and carers. People find their own ways of coping but sometimes talking to someone out of the situation like a counsellor can 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, you can ask for it to be explained again. Sometimes it is useful to bring your partner, another family member or friend with you when you meet with your doctor to help remember what has been said:

- What type of pancreatic cancer do I have?
- What treatments do you advise and why?
- What are the risks and possible side effects of each treatment?
- Will I have to stay in hospital, or will I be treated as an outpatient?
- How long will the treatment take?
- Will I have pain from the cancer or any of the treatments?
What will be done about this?
- Will the treatment affect me physically or sexually?
- Will I need to change my diet after treatment?
- Are there any other treatment choices for me? If not, why not?
- What will happen if I don't have treatment?
- Are there any clinical trials that I should know about?
- How often will I have check-ups and what will they involve?

Other questions may be answered by information in our patient information booklets or on our website. Visit panact.org

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

Cancer Research UK

Cancer Research UK provides information, online and telephone support for patients and carers.

Helpline: 0808 800 4040

cancerresearchuk.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

Further information

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.

maggiescentres.org

Marie Curie

Marie Curie provide information and support to anyone affected by terminal illness.

Helpline: 0800 090 2309

mariecurie.org.uk



abdomen

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

adenocarcinoma

This is cancer of the exocrine (enzyme producing) cells that line the pancreatic ducts. The majority of pancreatic cancers are of this type.

adenosquamous carcinoma

A very rare and aggressive form of pancreatic cancer. Two types of cells are affected, gland like cells and squamous cells (thin, flat cells that line some organs including the pancreas).

advance care plan

A document containing your wishes and advice on what treatment you would like to help inform those caring for you.

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 combination of drugs stop a person feeling pain during a medical procedure. Local anaesthetic numbs part of the body; a general anaesthetic relaxes the muscles and causes the person to lose consciousness for a period of time.

anaemia

A condition caused by too few red blood cells or low haemoglobin in each red blood cell.

antihistamines

A type of medication to treat allergies or symptoms associated with allergies such as itchy skin.

anti-inflammatory

A medication to reduce inflammation or swelling as a result of an infection or damage to the body

anxiety

A feeling of unease, such as worry or fear. This can be either mild or severe. Someone with anxiety find this feeling difficult to control and the feeling is constant.

artery

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

ascites

Abnormal build up of fluid in the abdomen under the perineum. Causes swelling of the abdomen which can make breathing feel difficult.

bile

A fluid made in the liver and stored in the gallbladder that helps with the digestion of fats.

bile duct

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

biliary stent

A treatment for jaundice caused by a blocked bile duct. A plastic or metal tube called a stent is out into the bile duct to open it up and allow bile to drain through it.

bilirubin

A yellow pigment formed in the liver by the breakdown of haemoglobin from red blood cells and excreted in bile.

biopsy

Removal of sample of tissue from the body for tests or examination. Helps to determine if a mass or tumour is cancerous, can tell which kind of pancreatic cancer you have.

blood transfusion

When blood or blood products are put into the bloodstream through a vein. Often the blood used is from a blood donor.

brushing

During an ERCP, a brush at the end of the endoscope can scrape away cells to take a tumour biopsy.

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 materials and can make copies of themselves.

chemotherapy

The use of cytotoxic (cell killing) drugs to treat cancer by killing cancer cells or slowing their growth.

clinical trials

Medical studies to test a new treatment or intervention on people. May involve screening, prevention, diagnosis or treatment.

Coeliac plexus

A bundle of nerves in the upper back

cystic tumours

Tumours that cause fluid filled sacs in the pancreas, most are benign.

cytotoxic

A substance that kills cells, including cancer cells. The cells are stopped from dividing and growing and can help to shrink tumours.

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 or develop as a result of it.

diagnosis

The identification and naming of a person's disease.

double bypass surgery

Re-routes the flow of bile around a tumour and allows food to flow from the stomach to the intestines around a blockage.

duodenum

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

duodenal stent

A tube that holds the sides of the duodenum open to relieve a blockage.

endoscopic retrograde cholangiopancreatography (ERCP)

A procedure used to examine the pancreatic and bile ducts.

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.

enema

Medication injected into the rectum to relieve constipation

enzymes

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

enzyme replacement therapy

Replacement or supplementation of digestive enzymes to allow you to digest food properly after damage to or removal of the pancreas.

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.

gastro-jejunostomy

A way to bypass the duodenum by connecting the jejunum to the stomach.

general anaesthetic

A set of medications given to make sure that you are asleep and feel no pain during operations or medical procedures

gland

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

glaucoma

Damage to the optic nerve caused by raised pressure of the fluid inside the eye. Treatment with drops can help prevent sight loss.

glucagon

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

hormone

A chemical messenger produced by cells to start, regulate or stop processes in the body.

immune system

The network of cells, organs and substances that help the body fight infections and disease.

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 levels of bile (specifically bilirubin) in the blood. This causes the skin and whites of the eyes to turn yellow, tiredness, loss of appetite and itchy skin.

jejunum

The middle portion of the small intestine.

laparoscopy

A procedure in which a laparoscope is inserted into the abdomen to examine the organs and carry out a biopsy or surgery.

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.

local anaesthetic

Medication given to numb a small area of the body so that you can have a medical procedure without feeling anything.

malabsorption

A condition in which there is a difficulty digesting or absorbing nutrients from food.

malignant

Malignant cancer cells can spread (metastasis) and can eventually cause death if they are not or cannot be treated.

malnutrition

Occurs when insufficient nutrients (too few or too many) are taken to meet the bodies requirements.

neuroendocrine pancreatic cancer

Neuroendocrine tumours start in the cells of the neuroendocrine system; a network of endocrine glands and cells throughout the body.

neutropenia

A decrease in the number of neutrophils in the blood. These cells are part of the immune system and normally fight infection.

obstruction

A blockage, often caused by a tumour in pancreatic cancer, in some parts of the body such as the bile duct.

oral nutritional supplements (ONS)

Macro and micronutrients that are taken orally for people who are unable to meet their nutritional needs. Include powders, liquids and puddings.

palliative care

Care that focuses on symptom management without curing a disease.

palliative radiotherapy

Radiotherapy to shrink or slow down the growth of a cancer to control symptoms rather than as a cure.

pancreas

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

pancreatic lymphoma

Very rare form of pancreatic cancer. 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.

peripheral neuropathy

Diseases of the peripheral nerves which are any nerves that are not part of the brain or spinal cord.

peritoneum

A membrane or layer of cells that covers the abdominal wall.

platelets

Cells found in the blood that help with blood coagulation (clotting).

prognosis

How you are expected to be after a disease is diagnosed.

radiotherapy

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

sedation

Drugs given to create calm or deep sleep.

stent

A metal or plastic tube that is inserted into a vessel to keep it open and prevent closure.

stereotactic radiotherapy

Builds a three-dimensional model of the tumour to create precise radiotherapy across it.

symptom management

Aims to prevent or treat the symptoms of a disease as well as side effects caused by other treatments. A key part of palliative care.

tissue

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

tumour

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

ultrasound

A non-invasive scan that uses sound waves 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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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



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Saving lives through early diagnosis

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