Surgery for Operable Pancreatic Cancer

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

pancreatic cancer action

Understanding pancreatic cancer booklet 2

In this booklet, you'll find out more about pancreatic cancer, types of surgery, postoperative treatments and recovery. 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.

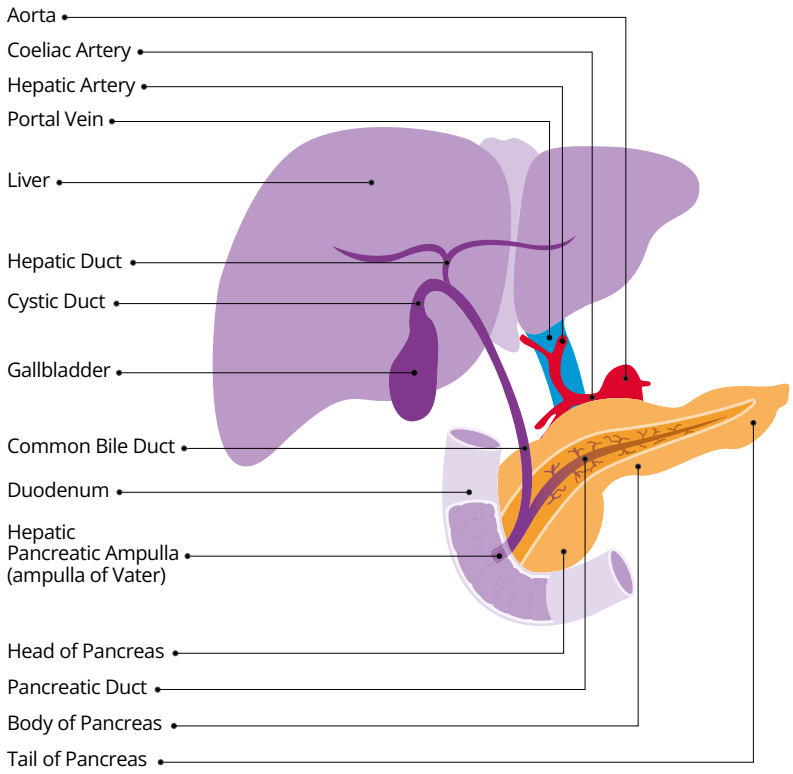
Hormones

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.

Introduction

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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.

When is surgery possible?

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 is possible to have it removed (resected).

In order to have the tumour resected doctors need to know:

- How big the tumour is (smaller tumours are easier to take out)
- Where the tumour is and that it doesn't involve any major blood vessels
- That there is no cancer in the surrounding tissues
- That the cancer has not spread to other parts of your body (such as your liver or lungs)
- That you are fit enough to undergo a major operation

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

Introduction

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Early stage pancreatic cancer can be treated with the following operations:

- Whipple's procedure
- Total Pancreatectomy
- Distal Pancreatectomy

The above surgical procedures are explained in this booklet.

All of the surgery listed above for pancreatic cancer is complex and comes with risks. When surgeons remove the tumour, they will be able to examine it and see if it has spread to structures such as lymph nodes near the pancreas. Your medical team can then discuss how successful operating is likely to have been and when you will start chemotherapy.

Surgery for pancreatic cancer is a big decision that is not always easy to make. It involves a major operation and treatments with a lot of side effects. Your medical team will assess you to ensure that surgery is right for you and you will get the maximum benefit from your treatments. A member of the medical team in charge of your care should explain the benefits, risks and burdens of surgery alongside treatment options and your prognosis afterwards. Make sure that you ask any questions you have about your surgery or what will happen afterwards.

Surgery will normally have a short-term effect on your quality of life due to the long recovery period. Most people recover their fitness in three to six months. Even if your surgery does not completely cure your disease long-term, it may reduce your symptoms and give you a better and longer life. This booklet describes the surgeries you may be offered and recovery afterwards.

I have been told I am borderline resectable – what does this mean?

In some cases the tumour may be very close to major blood vessels and it may be difficult for surgeons to determine whether it is appropriate to take the cancer out just by looking at scans. Further investigations may be carried out to assess whether an operation is possible.

In other cases, the doctors may prescribe a course of chemotherapy (drugs that kill cancer cells) or chemo-radiotherapy (targeted radiation to kill the cancer cells, along with low-dose chemotherapy) before surgery to try to shrink the cancer and make it operable. This is known as neo-adjuvant treatment and is normally provided as part of a clinical trial.

On our website we have stories of individuals who had operable pancreatic cancer, please see our website for more information:
panact.org/operablecancerstories

Types Of Surgery

Laparoscopy

Laparoscopic surgery is an investigation which allows your doctor to look directly into your abdomen using a special camera instrument called a laparoscope. Your doctor can also take biopsies and 'washings' of peritoneal fluids for detailed examination during this test.

Not all patients need a laparoscopy.

In some cases, just before your operation, your surgeon may prefer to do a laparoscopy to confirm there is no spread of the tumour beyond the pancreas to your liver or peritoneal cavity. Your peritoneum is the space between the inside of your abdominal wall and the organs which lie in it. If that is the case, the surgeon will take biopsies (samples) from these areas and may cancel the operation.

Do I need to do anything beforehand?

You will have a general anaesthetic and therefore will not be able to eat or drink before your laparoscopy. Depending on where you live advice about how long this is for may vary. European guidelines suggest no solids 6 hours before and no fluids 2 hours beforehand.

What happens?

Once in the theatre, and when you are asleep after your general anaesthetic, the doctor will make a small cut below your belly button. He/she will then insert a small telescope and inject gas into your abdomen. The gas creates a space inside your abdomen so that your doctor can thoroughly examine your internal organs.

It may be necessary to make 1 or 2 more small cuts in your tummy, so he/she can insert more instruments that are necessary to do the examination.

Once the procedure is finished, the gas is removed and the doctor will close the wounds and apply dressings.

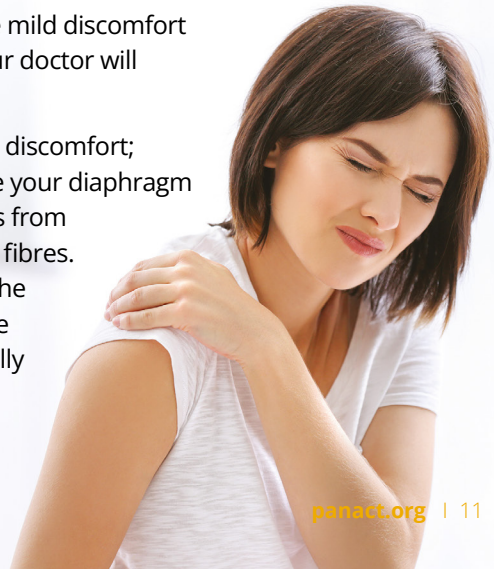
If you have a laparoscopy before major surgery, your doctors will either go ahead with the full operation to remove the pancreatic tumour straight away or you will go to the recovery area so that your doctors can discuss your future treatment options with you when you have woken up.

How will I feel after the test?

Immediately after your laparoscopy you will go to the recovery area for a few hours until the anaesthetic has worn off. If you are allowed home on the same day, you will need someone to stay with you overnight to look after you.

For the next few days you may feel some mild discomfort and you may take painkillers for this. Your doctor will advise you on what is best.

You may have some occasional shoulder discomfort; this is quite normal as the gas can irritate your diaphragm (the big muscle that separates your lungs from your abdomen) by stretching the muscle fibres. The nerves to the diaphragm also go to the shoulder which is why you may feel some discomfort here. Any shoulder pain usually settles within 1 to 2 days.



Types Of Surgery

The Whipple's procedure

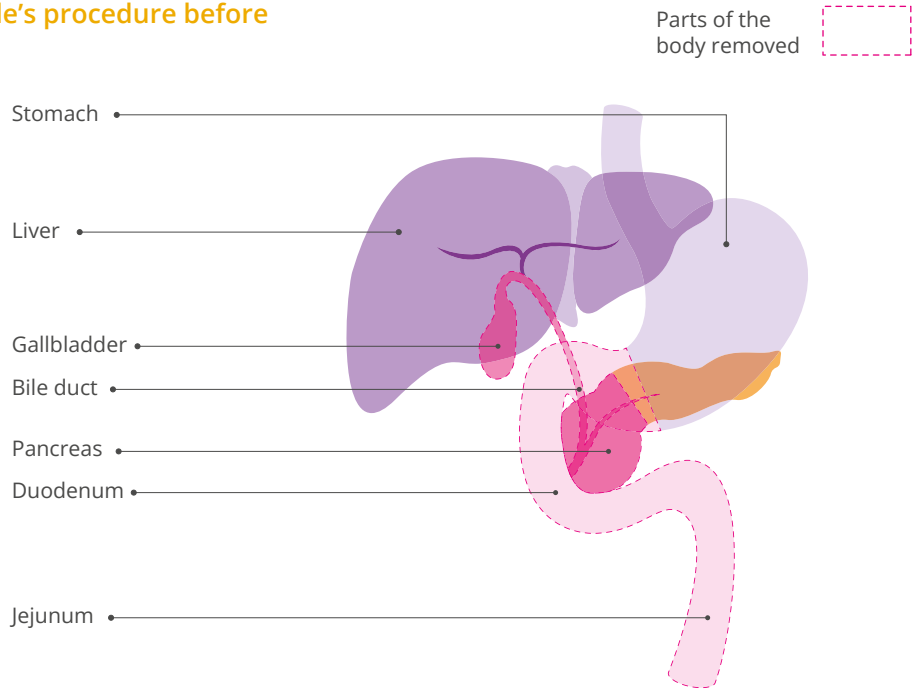
The Whipple's procedure (or pancreaticoduodenectomy, PD) is the most common type of surgery to remove pancreatic tumours. The procedure involves removal of the "head" (wide part) of the pancreas next to the first part of the small intestine (duodenum). It is usually only carried out if the cancer has not spread beyond the head of the pancreas and the patient is in good enough health to withstand a major operation.

The operation normally lasts for 4 to 7 hours and the surgeons will aim to completely remove the cancer to give you the best chance of a cure.

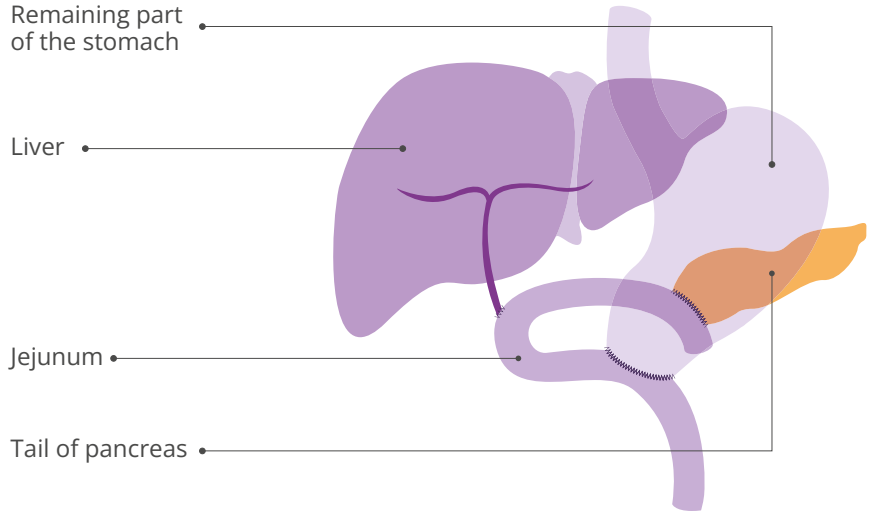
The diagram (below) shows the stomach, liver, pancreas, gall bladder, small intestine and pancreas of a patient with a tumour in the head of the pancreas. The dotted lines show the area to be resected (cut out).

The head of the pancreas, a portion of the bile duct, the gallbladder and the duodenum (the first part of the small intestine) are removed along with part of the stomach. The rest of the pancreas, the bile duct and the stomach are reattached to the small intestine. This allows pancreatic enzymes, bile and food to flow into the gut, so that digestion can proceed normally. Nearby lymph nodes may also be removed.

Whipple's procedure before



Whipple's procedure after



Types Of Surgery

Pylorus Preserving Pancreatoduodectomy (PPPD)

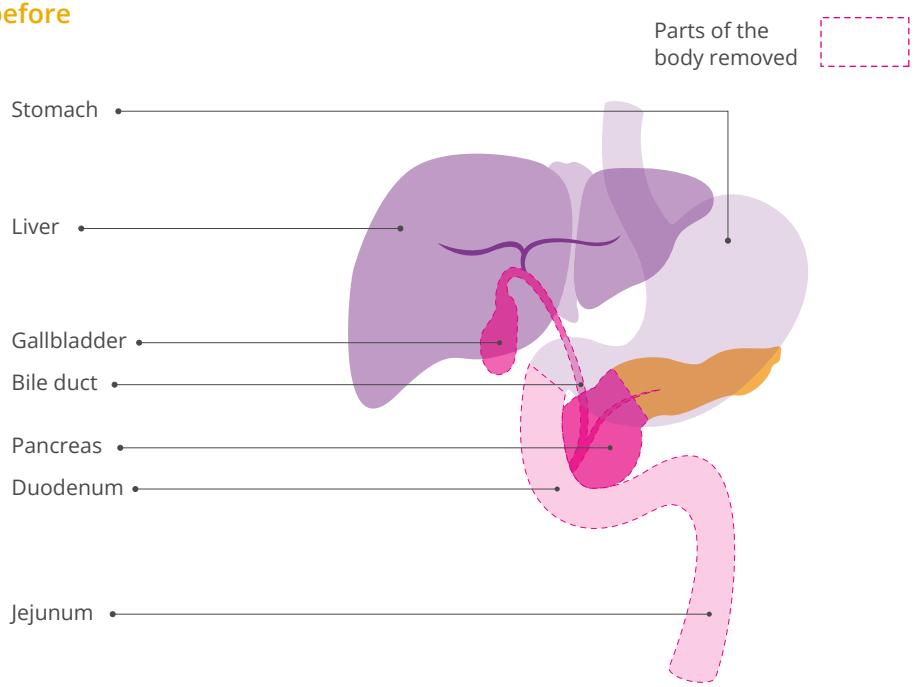
The Pylorus Preserving Pancreatoduodenectomy (PPPD) is a modified Whipple's procedure. In this case, only part of the duodenum is removed and the pylorus (the part of the stomach that connects to the duodenum) is kept. The remains of the pancreas are then attached to the stomach or the intestine. Some doctors think this helps with food digestion after the operation.

There is no evidence however, that one of these operations works better then the other.

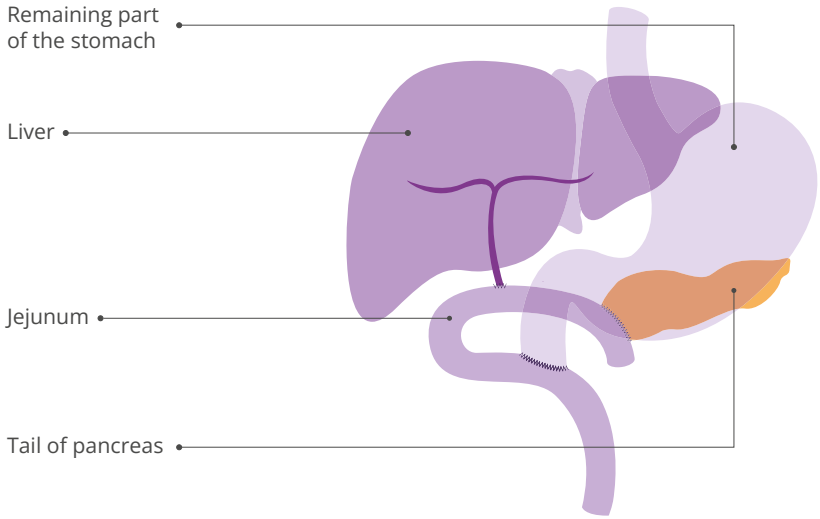
It is often a technical decision, ask your surgeon if you have any questions about your operation.

Both the Whipple's and PPPD operations are major operations with risks of complications. You will need a general anaesthetic to keep you asleep during surgery and you're likely to need to be in hospital for at least a week or so depending on how well you recover.

PPPD before



PPPD after



Types Of Surgery

Distal Pancreatectomy

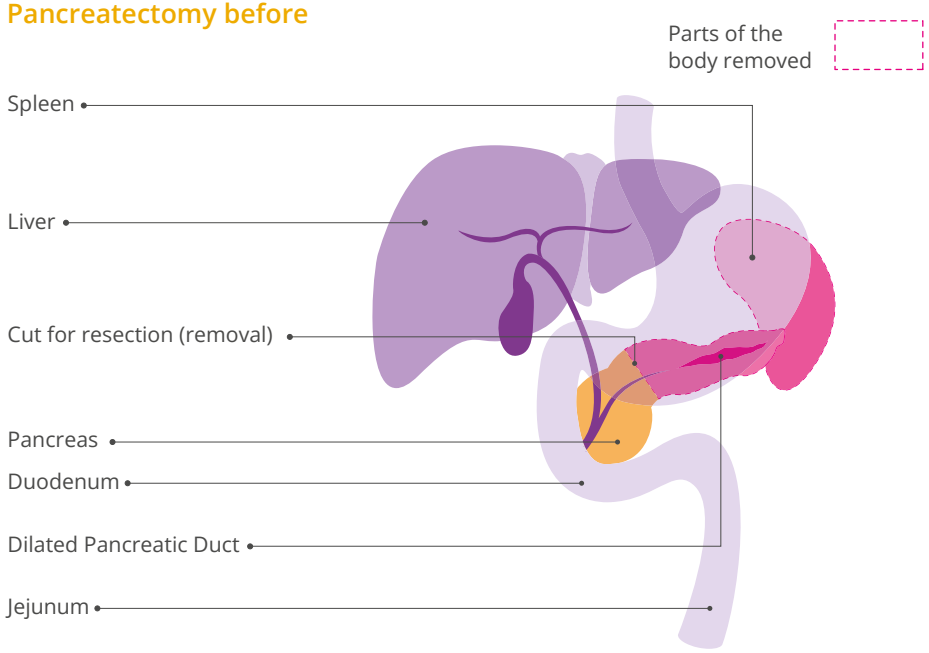
A Distal Pancreatectomy is usually performed when a patient has a tumour in the body or tail (thin end) of the pancreas.

This procedure involves having the tail and body of your pancreas removed, leaving the head of the pancreas intact. The surgeon will normally remove your spleen at the same time because it is located next to the tail of the pancreas.

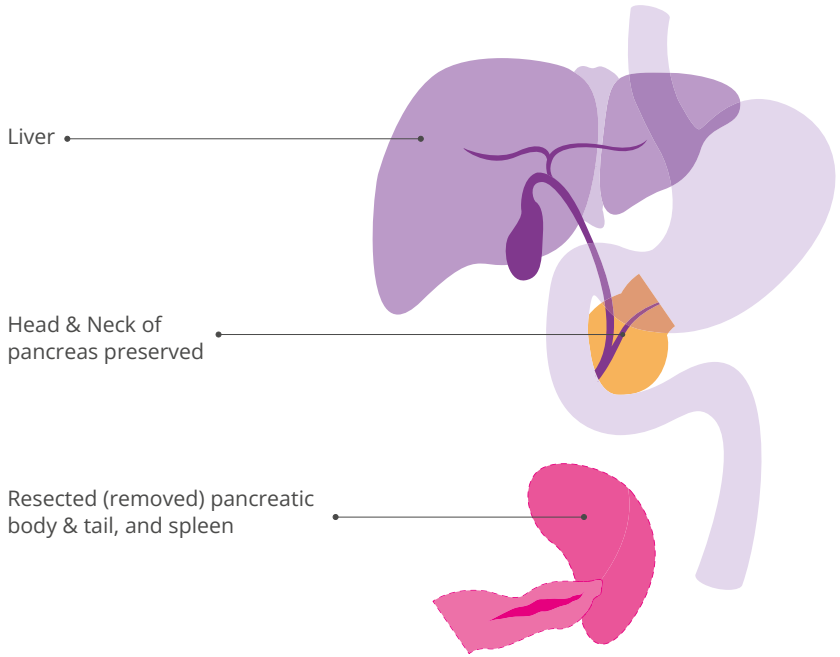
Even though a distal pancreatectomy is less complicated than the Whipple's procedure, it is still major surgery. The spleen is an important part of your immune system, and if it is removed, you may be on antibiotics and 5 yearly vaccinations for the rest of your life to prevent infections.

Some specialists may opt to perform Distal Pancreatectomies via a laparoscopic procedure (see page 6). This is not common, it only happens in a few specialist centres and generally only when the tumour is small. As it is keyhole surgery, recovery time for patients is usually faster than for open surgery.

Distal Pancreatectomy before



Distal Pancreatectomy after



Types Of Surgery

Total Pancreatectomy

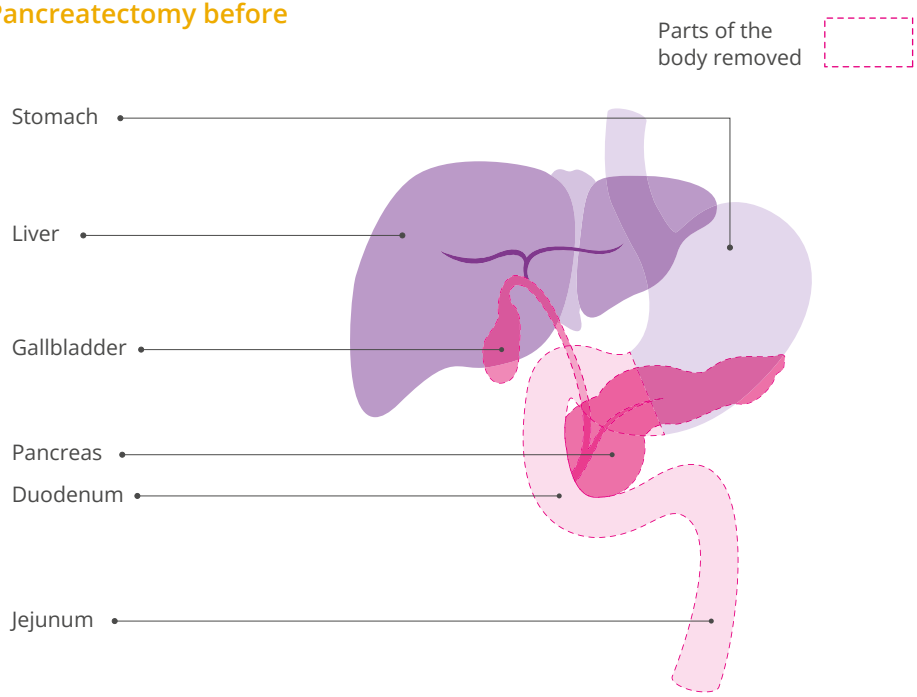
A Total Pancreatectomy involves the removal of the whole pancreas as well as the duodenum, part of the stomach, the gallbladder, part of your bile duct, the spleen, and many of the surrounding lymph nodes. This is very major surgery. This operation is not often carried out as it has not been found to be any more effective for survival than either the Whipple's procedure or Pylorus Preserving Pancreatoduodectomy (PPPD) which is a modified Whipple's procedure.

There are some conditions for which it is used;

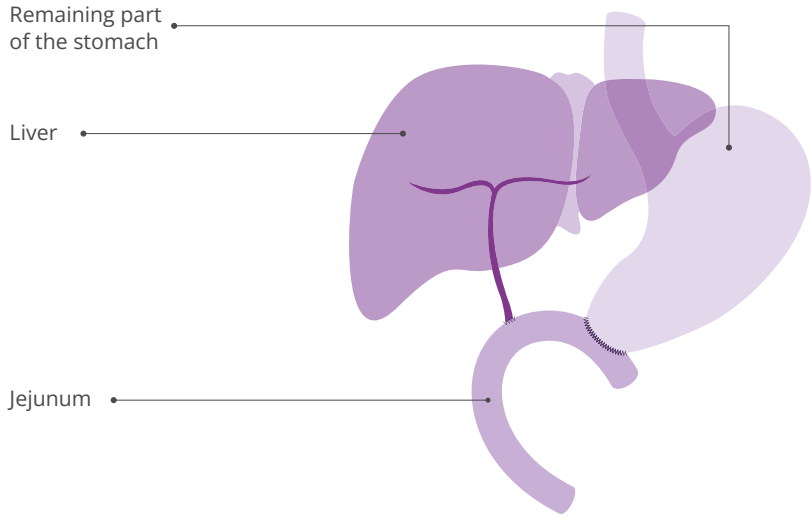
1. When tumours are found in more than one location in the pancreas
2. When the tumour extends along the pancreatic duct
3. Sometimes when there is a rare or specific type of pancreatic tumour. This includes pre-cancerous IPMNs (intraductal papillary mucinous neoplasms). An IPMN is when abnormal growth of cells in ducts within the pancreas. As the abnormal cells grow they secrete a thick fluid called mucin leading to the formation of a cyst. Some IPMNs have a higher risk of developing into cancer e.g. those arising from the main pancreatic duct (main-duct IPMN). However most IPMN's are a type called branch IPMN's which are often benign and able to be observed rather than actively treated.
4. When it is extremely risky or impossible to join the pancreas either to the intestine or stomach.

See our website, or Pancreatic cysts and cystic tumours booklet for more information.

Total Pancreatectomy before



Total Pancreatectomy after



Types Of Surgery

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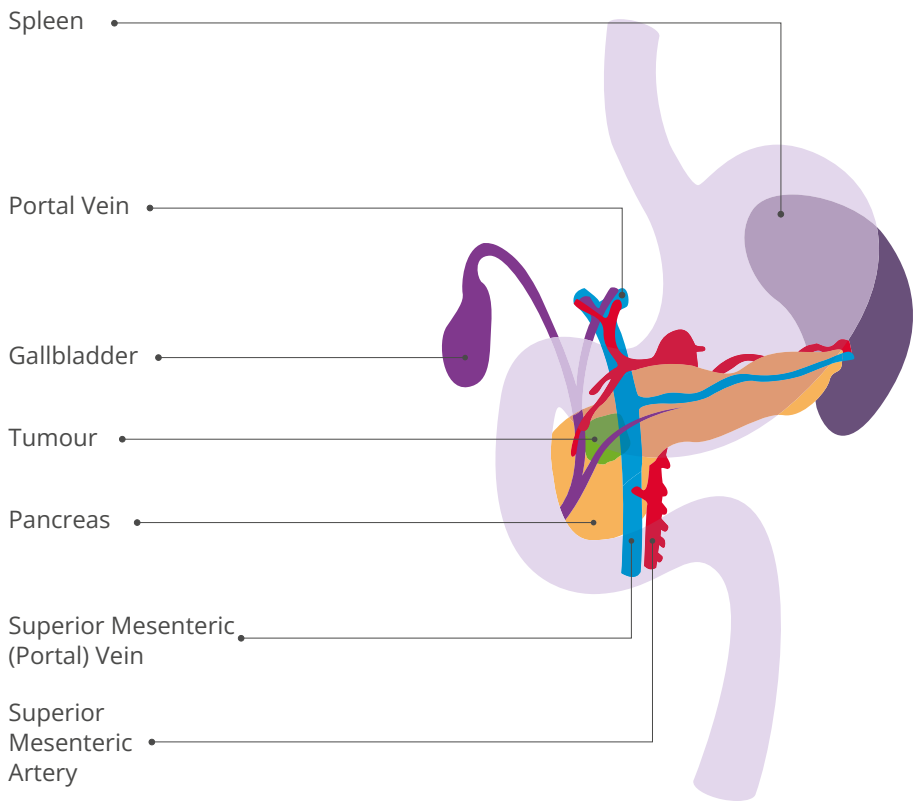
Vein resection for pancreatic cancer surgery

Getting a margin of clearance around a tumour when resecting it is important for prognosis and ensuring that the whole cancer is removed. Sometimes the only factor preventing a clear resection margin is how close the tumour is to the major veins near the head of the pancreas (such as the superior mesenteric vein or portal vein).

If it is thought that the surgery to remove a section of vein will make a difference to the resection margin, then surgery is considered where sections of the vein involved are removed then joined together again using a graft from another part of the body.

Portal vein resection is performed when the vein is involved and the surgeon believes they can remove all of the cancer. The vein can be reconstructed with stitches or using a graft. If however, an artery is involved rather than a vein, surgery will only be considered in exceptional cases after chemotherapy. Your medical team will be able to explain what is right for you.

Location of the pancreas in relation to the major blood vessels



Preparing For Pancreatic Surgery

Smoking

If you smoke it is very important to stop before any major operation. Smoking increases the risk of breathing difficulties when you are given an anaesthetic; it can slow your recovery and increases the risk of infection after your operation.

Exercise

Exercise can improve your fitness for surgery and helps strengthen your muscles. If you exercise regularly and you feel up to it, continue with your routine. If you are not used to exercise, gentle walking or swimming are good ways to start to improve your fitness. Always consult your doctor before taking up any strenuous exercise. You will not be able to do any heavy lifting for around six weeks after surgery.

Diet

It is important to ensure you eat well before major surgery especially if you have been losing weight. Try to eat little and often; eating lots of small portions of foods which are high in sugar, fat and protein will provide lots of energy and help boost your strength before surgery. You may want to ask a specialist dietitian about what is best for you. If you are diabetic then do not make any changes to your diet without consulting your doctor or diabetic nurse.

Digestive enzymes

You may be prescribed digestive enzymes to help you to digest your food before and after your operation. The pancreas normally produces enzymes to help break down your food. When all or part of the pancreas has been removed, you may need to take digestive enzyme supplements. Your specialist will tell you how and when to take these.

Prepare at home

Regardless of how long you stay in hospital, you may need help with relatively simple activities of daily living when you get home (shopping, cleaning, family life, etc.). It may be helpful to make sure this is in place before you go into hospital. If you have young children you will need to ensure you have help to look after them as well.

If you live alone you may need support from community nurses or carers for a few weeks until you are able to manage again. Your ward nurses can help to arrange this.

If you are working

If you are currently working, you will need to prepare by arranging cover not just for the time in hospital but also for a period of convalescence which can be a few months in some circumstances.

If you are having adjuvant treatment (treatment alongside or following your surgery) for example chemotherapy, this may also impact your ability to work and you may need to prepare for extended time off depending on how well you are feeling.

Approximately **29%** of **pancreatic cancer cases** are **caused by smoking** cigarettes

Preparing For Pancreatic Surgery

Pre-assessment for surgery

You may be asked to attend a pre-assessment clinic 1 to 2 weeks before your surgery. At this clinic your general health and fitness will be determined. A nurse will take your medical history, examine you and take some tests.

Some of the tests you are likely to have before surgery:

- Blood and urine tests
- Blood pressure test
- Chest x-ray
- Electrocardiogram (ECG) to check your heart rhythm. This is routine for patients undergoing surgery

Other tests that you may have, include:

- Exercise tolerance test (tests how your heart copes with exercise)
- Lung function test (tells the doctors how well your lungs are working)
- Faecal (stool) elastase test (tells doctors how well your pancreas is functioning)
- Glucose tolerance test (tests for diabetes)

Diabetic patients

If you have diabetes and you measure your blood sugars, it is helpful to bring these measurements with you to the pre-assessment clinic.

For diabetic patients who need to take insulin, you will be given insulin before and after your operation and the dose will be adjusted depending on your blood sugar levels. This is known as sliding-scale insulin.

Your admission date

By the pre-assessment day you should have been given your admission date for surgery. At this point you will also be given information on eating and drinking just before the operation and what to do about the medicines you are already taking.

Going into hospital

What do I need to bring with me?

In the first couple of days you will be wearing a hospital gown but after this you will need night clothes then loose-fitting normal clothes once you are able to move independently.

It is recommended that you only take the essentials when you are first admitted, then get a friend or relative to bring in a second 'top-up' bag after a few days.

Some suggestions for what to pack for a stay in hospital:

Initial bag for first few days:

- Basic wash bag including toothbrush, toothpaste, hairbrush/comb, flannel, soap, shaver/razor, lip salve (lips can get dry after surgery)
- Loose-fitting slippers (your feet can swell after an operation) with grips on the bottom or thick socks with grips on bottom)
- Reading glasses
- Mobile phone and charger
- Books/magazines/pens
- Any medication that you normally take

Second top-up bag

- Extended wash bag to include shampoo, shower gel, deodorant, make-up
- Night clothes, dressing gown, loose-fitting day clothes
- Clean underwear
- Small hand towel
- Sanitary towels or tampons
- Fruit squashes and small snacks such as biscuits, chocolate, sweets, non-refrigerated desserts (jellies, rice puddings)
- Small amount of money for newspapers/snacks
- Address book and/or important phone numbers
- Antibacterial hand gel or wipes

Preparing For Pancreatic Surgery

The day of your operation

Your admission letter from the hospital will tell you the date and time of your operation and what time you need to arrive. You will usually see one of your medical team and the details of the procedure will be explained to you. You will then be asked to sign a consent form (unless you already did this at the pre-assessment clinic) giving your permission for surgery to go ahead. This form shows the doctors that you know what the procedure is for, and that you understand the risks involved.

If you are having a general anaesthetic you will have a visit from the anaesthetist who will talk about the anaesthetic they will give you to put you to sleep throughout the whole operation. It will be given to you via an injection or gas, which you breathe through a mask.

You will normally be asked to remove any dentures, piercings, jewellery or nail varnish before the operation.

You must tell your doctor or nurse if you are taking any medication to thin the blood or prevent clotting as these need to be stopped before surgery.

The core medical team:

- **Surgeon:** Performs your operation. Beforehand they will explain your operation and tell you about the potential risks and complications
- **Cancer Nurse Specialist:** A specialist nurse in this type of cancer and its treatments. They are available to offer advice and information about your surgery and are the main point of contact should you have any concerns
- **Anaesthetist:** Responsible for your anaesthetic which puts you to sleep for your operation. They also discuss the types of pain control available
- **Physiotherapist:** Helps you to get fitter and stronger. They will teach you deep breathing and coughing exercises which are important to help your lungs re-expand and help prevent chest infections. They will also encourage you to be mobile following your operation and to help you become as fit as possible before leaving the hospital
- Dietitian: Helps you manage your diet. You may see a dietitian before your surgery if you have been struggling with weight loss. Often patients will see a dietitian to manage eating following the operation.

An operation to remove a pancreatic tumour can take between 4 and 8 hours.

After your operation

After your operation you will usually wake up in the recovery room near to the operating theatre, where a nurse will care for you. You will then be taken to the High Dependency Unit (HDU) or occasionally the Intensive Care Unit (ITU) for 2 to 3 days so you can be monitored closely.

From there you will be taken to the specialist surgical ward. Patients usually stay in hospital for between 10 to 14 days.

Tubes and drains

When you wake up from your operation you will have some tubes and drains attached to you. These will have been placed while you were asleep under anaesthetic. The type and number you have will depend on what type of operation you had, but will often include:

- Tubes inserted into a vein in your arm and/or neck to provide you with fluids or medicines
- A drain is usually placed under your skin near the wound site to drain off fluid
- A catheter (fine tube) will be placed into your bladder to collect your urine into a bag. This means you don't have to worry about getting out of bed to go to the toilet and the nurses can monitor how much urine you are producing
- An epidural catheter system (an injection into the back) will often be used to give pain relief immediately following the operation
- A feeding tube, either going through your nose or directly into your tummy

Your tubes and drains will be removed as soon as your medical team feels they are no longer needed.

Preparing For Pancreatic Surgery

Possible risks and complications

Your doctors will discuss the risks of you having surgery when you give your consent to go ahead with the operation. Surgery is complex and always comes with risks. Approximately one in ten people will have serious complications following pancreatic cancer surgery. There is always a small risk of death, this should be discussed with you and any questions you have answered.

Please note: Not all patients will have the following complications

Anastomotic leak

By far the most important complication following a Whipple's procedure or other pancreatic surgery, is when one of the anastomoses (the joins between either the bowel and the liver and pancreas) do not heal properly, allowing the contents to leak out. If a leak does occur then you may need to stay in the hospital longer than planned. These leaks usually dry up. Very rarely drains may need to be placed in the tummy and in exceptional circumstances, a second operation may be needed. You might have an x-ray to ensure the drain is put in the right place. Sometimes leaks heal on their own, but this takes time. Leaks from the pancreas can be serious as the pancreas releases digestive enzymes which can damage nearby tissue.

Delayed emptying of the stomach

Sometimes your stomach may take longer to adapt to the changes after surgery and your food may not be able to pass through efficiently. You may need to stick to a liquid-only diet for a while. Alternatively, you may need to be fed through a nasogastric tube (a feeding tube in the nose) until this resolves.

Bleeding

Any operation carries a risk of bleeding after surgery. A radiological procedure to block the bleeding vessel without operating (embolisation) may be needed. In exceptional circumstances an operation may be needed to control the bleeding.

Chest infections

It is possible you could develop a chest infection following an operation, especially if you are a smoker. To minimise your risk, a physiotherapist will visit you after your operation to help you to cough and breathe properly.

Chyle leak

Some patients may leak a milky liquid called chyle into their abdominal drain after surgery. Chyle is a bodily fluid that can build up in the tummy following injury or surgery. This is treated by reducing the amount of food you eat for a period of time. Your dietitian or surgeon may feel that you should have artificial feeding during this period, such as a feeding tube, to support your nutrition intake.

Problems with food absorption

When you have had part of your pancreas removed, you may notice your stools (motions) have become pale, loose and greasy. You can correct this by taking pancreatic enzyme capsules which, when taken with food, will help you digest it. Your medical team will tell you how and when to take these and further information can be found in our booklet 'Diet and Nutrition for Pancreatic Cancer Patients'.
To order your copy call 0303 040 1770

After Pancreatic Surgery

Managing pain

The amount of pain experienced differs between individuals. Your medical team will work with you to ensure pain is kept to a minimum and it is essential you tell the nurses if you are feeling pain or if that pain gets worse.

Some of the ways pain can be managed in hospital are:

- Epidural catheter system (an injection into your back, usually immediately following surgery)
- Painkilling injections (every 3 to 4 hours)
- Painkiller suppositories - inserted into the rectum (back passage)
- Patient controlled analgesia (PCA) consists of a machine containing pain killer connected to a drip. You can receive a dose of pain killer by pressing a button when needed. The machine prevents too many doses being given
- Painkiller tablets.

Your doctors will explain which type of painkiller they will be giving you and how often you will receive it.

Washing

For the first day or so, you will need help with washing from the nursing staff. Once all the drains have been removed the nurses will help you to have a bath or shower.

Moving around

It is important to start moving around as soon as possible and you will be encouraged to get out of bed, sit in a chair, march on the spot and take short walks regularly. Some patients will be encouraged to sit upright on the evening of their operation and be out of bed the morning afterwards. This prevents stiffness, bed sores and constipation and helps keep your chest clear. You will be given a pair of surgical stockings to wear which help the blood flow in your legs and prevent clots forming.

The wound

Your wounds may be 'stitched' up using staples known as clips. They are usually removed about 10 days after surgery and this can be done by your GP if you have already been discharged. The dressings around your drains need to be changed regularly. If you notice any leaks or discharge from around the wound, let one of your medical team know.

Eating and drinking immediately after surgery

Eating and drinking after surgery will depend on how you are feeling and what your medical team recommends. Some people feel ready to start eating and drinking small amounts quite quickly. Other times you may need a bit more time and support.

Some (but not all) patients will be fitted with a feeding tube during their operation. This tube (known as a nasojejunal tube) will go through your nose and past the site of the operation. Sometimes it can take a while for the stomach to begin emptying normally after pancreatic surgery and this tube allows you to be kept well fed with special liquid food during this time. Your feeding tube will be removed once you are able to eat proper meals.

Going to the toilet

You will have a tube (catheter) fitted during the operation that goes into your bladder to drain out any urine. This will be taken out once you are able to get out of bed to use the toilet. It may take a few days before your bowels start working and when they do, you may have diarrhoea at first.

After Pancreatic Surgery

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Eating after surgery

When your doctors are happy for you to eat by by mouth, you will be given water to sip followed by the gradual introduction of a light diet then, after a few days, a normal diet.

When you are able to eat enough, your doctors may prescribe pancreatic enzymes to help you digest your food. Your dietitian will tell you how to take these.

What is a light diet?

Generally this is soft, moist and easily digested food.

Suggestions include:

Breakfast:

- Porridge, cornflakes or rice crispies
- White bread and butter or spread
- Smooth apple or orange juice

Main meals:

- Soup, white bread and butter or spread
- Mousse, custard or milky puddings (e.g., creamed rice)
- Bananas or fruit compotes

Snacks:

- Jelly, mousse or yoghurts
- Jelly beans/babies, wine gums, chocolate (no nuts or dried fruit)

Foods to avoid on a light diet:

- Spicy food
- High fat food
- Foods that contain lots of cheese (e.g. pizza, lasagne)
- High fibre food
- Food with bits and pips in

Fizzy drinks

Avoid fizzy drinks until you are on a normal diet. This is because fizzy drinks can make you bloated and reduce your appetite. Fizzy drinks can cause pain if drunk in the weeks immediately following surgery.

Nutritional supplements

Some people need additional high protein or high energy supplements to help them recover from the operation. You will be advised about these by your medical team. It is important to ask your medical team before taking any other supplements or herbal remedies as these may interfere with your treatments.

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Returning to a normal diet

It can take time to return to normal after some surgical procedures. It is advisable to try to eat little and often, with lots of small snacks and high energy drinks between meals.

You will need to ensure you are getting enough energy and protein from your food so try to avoid watery soups, too many fruit and vegetables in each meal and large drinks before or during meals.

Always check with your dietitian or medical team if you are unsure of what type of diet you should be on.

Suggested foods include:

Breakfast:

- Small bowl of porridge (add cream/jam/honey)
- Small glass of fruit juice

Snack:

- Small piece of cake
- Milky coffee

Lunch:

- Scrambled eggs made with full-fat milk and butter
- Creamy soup with croutons and toast and butter
- Thick & creamy yoghurt or mousse dessert

Snack:

- Biscuits
- Glass of milk

Dinner:

- Small portion of meat with potatoes, rice or pasta
- Small portion of vegetables
- Ice cream with sauce

Snack:

- Chocolate bar
- Cheese and biscuits

Drinks:

- Hot chocolate (milk based)
- Fruit juice
- Milky coffee

After Pancreatic Surgery

Returning home

When you go home will depend on how long you take to recover. It is normal to spend 10 to 14 days in hospital but some patients stay as little as a week and some stay in hospital for months. You should be given enhanced recovery information and advice from the ward when you are discharged. Following the advice will make sure that you recover in good time and are ready for your next treatment as soon as possible.

It can take some months before you get properly back to normal and in the early days you will need help to get washed and dressed, cook meals and to do shopping and housework.

You may need to accept some help from friends, family or neighbours during this time. If you live alone or there is no one around to help, you may wish to speak to your nursing team or social services about organisations to help you short term.

Getting back to normal

Wound advice

- All wounds go through natural stages of healing
- Scabs protect new tissue underneath so don't be tempted to pull them off
- If the wound becomes painful, starts to leak or becomes red and inflamed, seek advice promptly
- Tingling, itching and numbness around the wound is normal
- It is normal to feel a pulling or tugging around the wound

You should contact your medical team if you experience any bleeding, dizziness, a temperature above 38 degrees or worsening pain.

Rest

You will feel very tired after returning home. This is normal, so try to build in some rest time during the day. You may feel worried about going home and not being able to do the things that you could before. The best place to recover is at home, as you can build up your activity slowly.

Exercise

It is important to increase the amount of exercise you take every day. Start with short walks and gradually build up to longer distances. Avoid any heavy lifting, pushing or pulling for the first 6 to 8 weeks.

Driving

You should be able to safely drive about 6 weeks after you leave hospital. You need to be confident that you have the strength and concentration to drive and that you could do an emergency stop.

Returning to work

This depends on your job and how long it takes you to recover. It is reasonable to allow 3 to 6 months after hospital discharge; however, how long it takes you to recover varies between individuals. If you are having adjuvant treatment alongside surgery it may take longer to be able to return to work. Discuss this with your medical team who will be better able to advise you.

Diabetes

Some people develop diabetes following pancreatic surgery. You may be given tablets to manage your blood sugars but some patients will need insulin injections to replace the insulin that the pancreas normally produces.

You may be referred to a diabetes nurse specialist who will help you manage your diabetes and give help and advice about insulin injections and managing your diet.

If you are at home following surgery and have symptoms of diabetes, such as thirst, rapid weight loss and passing a lot of urine, contact your GP.

Further information about managing diabetes can be found in our booklet "Diet and Nutrition for Pancreatic Cancer Patients".

Pancreatic Enzyme Replacement

Why do I need enzyme replacement?

A blockage in the pancreatic duct, or removal of part of the pancreas, can cause a change in the flow and amount of pancreatic juice. Pancreatic juice contains enzymes that help the body to digest and absorb nutrients such as fat, carbohydrate and protein.

If your body cannot produce enough pancreatic juice, you will have difficulty getting nourishment from foods and eventually you will lose weight. Studies have shown that taking a pancreatic enzyme supplement can improve the absorption of nutrients from the digestive system, help nutrition and prevent weight loss.

Signs which indicate that taking enzyme supplements would be helpful are:

- Pale stools (bowel motions) that do not flush away easily. A greasy appearance on top of the water
- Loose bowel motions
- Abdominal pain and bloating after eating
- A lot of flatulence (wind)
- Good appetite and food intake but with continuing weight loss.

For more information on enzyme replacements please see Booklet 5 'Diet and nutrition for pancreatic cancer patients'

Chemotherapy After Surgery

Chemotherapy after surgery

After your surgery, you will be offered chemotherapy. This is to make sure that all of the cancer cells are destroyed and prevent the cancer from coming back. When treatment starts depends on how well you recover from the surgery and your medical team. Pancreatic Cancer Action produces a free booklet "Chemotherapy Treatment for Pancreatic Cancer" which explains what, where, how and why chemotherapy is given. It also explains side effects of treatment.

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 for you 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 may be helpful to discuss your feelings together, so you can understand how each other are feeling to know how to best cope and support each other with what is happening.

Practical Considerations

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.

They can assess your level of need, the needs of others in your household caring for you and your financial situation to see what help you are entitled to.

Or contact citizens advice who can advise you on financial support and benefits 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.

How to maintain a healthy lifestyle

- If you smoke, think about giving up.
- 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

Second Opinions And Clinical Trials

Second opinions

All decisions regarding treatments are made by a multidisciplinary team (MDT), (who are specialists in surgery, radiology, pathology, oncology and radiology) they use the national treatment guidelines to decide the most suitable treatment for you. Even so, you may want 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.

Treatment decisions

Your medical team can advise you on the appropriate treatment for you and give you information to aid your decisions. You need to feel involved in decisions regarding your care and be aware of what your options are. Your values, preferences and social circumstances are all important factors in deciding which treatment option works best for you and you do not have to accept a suggested treatment. You can always ask for a second opinion.

This is a difficult time, it is likely to be a time of great stress and anxiety, especially just after diagnosis. You are expected to understand and take in crucial information about complex care, by a wide range of specialists. When you are stressed and anxious it can decrease your attention and ability to retain and understand the information given to you. Having a family member or friend with you at consultation appointments can be helpful.

Seeking treatment abroad

Patients wanting to seek treatment abroad should be aware that in some healthcare systems the decision to operate can be sometimes influenced by financial return as much as whether the procedure will improve the outcomes for the patient.

In the UK, MDT decisions are evidenced-based. When doctors here decide not to operate they do so on the basis that the outcome for the patient will be the same if treated with therapies such as chemotherapy as they would be with surgery but without the risks involved with major surgery.

For more help on this topic, please contact us on **0303 040 1770**

Second Opinions And Clinical Trials

What are clinical trials

Clinical trials are where treatments or interventions are tested in volunteers. They are necessary so we know how safe and effective a drug 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, there is the latest clinical trials available.
Also talking to your doctor or nurse about more information will be helpful.
panact.org/clinicaltrials

Further Information

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 okay 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 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 other treatment choices for me? If not, why not?
- [ ] What will happen if I don't have any treatment?
- [ ] Are there any clinical trials I should know about?
- [ ] How often will I have check-ups and what will they involve?

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

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

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 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.

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.

CT scan
Computed tomography scan is a machine like a tunnel that produces x-rays to get a detailed 3D view of structures inside the body. Sometimes a dye may be drank or injected beforehand to highlight certain structures.

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

Glossary

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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.

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

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 causes the skin and the whites of the eyes to turn yellow, 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, 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.

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

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.

peritoneal
The tissue that lines the abdominal wall and covers most of the organs in the abdomen.

peritoneal fluids
A naturally produced fluid in the abdominal cavity, this covers most of the organs in the abdominal wall and pelvic cavity. This fluid is to lubricate the tissue in this area.

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.

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

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.

Whipple's procedure
An operation to remove part of the pancreas. Also known as a Whipple operation or resection.

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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**

0303 040 1770

enquiries@panact.org

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Suite 3.10 Covault, Fullarton Road,
Cambuslang, Glasgow, G32 8YL

pancreatic cancer action

Saving lives through early diagnosis

We are certified by the Information Standard so you can trust that our public health information is accurate, up-to-date, evidence-based and unbiased.

Correspondence address: Pancreatic Cancer Action, Suite 3.10 Covault, Fullarton Road, Cambuslang, Glasgow, G32 8YL. A Registered Charity in England & Wales (1137689) and Scotland (SC049777).
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