Pancreatic Cancer UK

Surgery to remove pancreatic cancer

This fact sheet is for people with pancreatic cancer who are having surgery (an operation) to remove the cancer. Families may also find it helpful. It explains the different types of surgery, how to prepare for your operation, what to expect, and recovering from surgery.

Every hospital will do things slightly differently. Speak to your doctor, surgeon or nurse (the clinical nurse specialist or CNS) if you have any questions about surgery.

You can also speak to our specialist nurses on our confidential Support Line. Call free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

This fact sheet is about surgery for pancreatic ductal adenocarcinoma (PDAC). This is the most common type of pancreatic cancer. It does not cover surgery for pancreatic neuroendocrine tumours. Neuroendocrine Cancer UK has information about this at: **www.neuroendocrinecancer.org.uk**

Contents

Key facts

- Surgery to remove pancreatic cancer can help people live longer.
- Surgery is only suitable for people who are fit enough to have the operation and if there is no sign the cancer has spread.
- There are different types of surgery. The type you have will depend on where the cancer is.
- Removing the pancreas may cause problems with digestion, weight loss and fatigue. You may also get diabetes. The cancer itself can also cause these symptoms. Your medical team can help manage these.
- You may be offered chemotherapy after surgery (see page 24). This is to reduce the chances of the cancer coming back.
- It will take time to recover after surgery. Usually it takes at least a few months and sometimes up to a year, but this is different for everyone.
- You and your family can get support from our specialist nurses by calling our free Support Line on **0808 801 0707** or emailing **nurse@pancreaticcancer.org.uk**

Who can have surgery?

Surgery is the best treatment for people with pancreatic cancer that is contained in the pancreas. It can help people live longer. Cancer that can be removed by surgery is called **resectable** or **operable cancer.**

Only a small number of people can have surgery. This is partly because pancreatic cancer may not be diagnosed early enough for it to be possible to remove the cancer.

You may be able to have surgery to remove the cancer if:

- there are no signs that the cancer has spread outside the pancreas
- you are fit and well enough to have the operation.

Your doctor will talk to you about whether surgery is an option for you. You may have an FDG-PET/CT scan to help check if it is possible to remove the cancer. FDG-PET/CT stands for fluorodeoxyglucose-positron emission tomography/computerised tomography. Your medical team will look carefully at your test results to work out if surgery is possible.

Read more about an FDG-PET/CT scan on our website at: **pancreaticcancer.org.uk/tests**

You need to be fit and well enough to have surgery and will have tests to check this. Some hospitals offer programmes to help people get fit enough. This is called prehabilitation. It focuses on diet and physical activity to help people recover more quickly after surgery. Read more about the tests and preparing for surgery on page 14. Surgery might not be possible for some people.

- If you have some other health problems, such as heart or lung disease, you may not be able to have surgery.
- Surgery is not usually possible if you have locally advanced cancer. This is cancer that has spread just outside the pancreas to large blood vessels or a number of lymph nodes (part of the immune system). Read more about cancer that is close to major blood vessels on page 4.
- If the cancer has spread to other parts of the body (advanced or metastatic cancer), you won't be able to have surgery.

If surgery isn't an option, you may be offered chemotherapy to help control the growth of the cancer and help with some symptoms. There are also other treatments to manage any symptoms you have.

If you have just been diagnosed with pancreatic cancer, you can read more at: **pancreaticcancer.org.uk/justdiagnosed**

Read about chemotherapy in our fact sheet:
Chemotherapy for pancreatic cancer
Or on our website at: **pancreaticcancer.org.uk/chemotherapy**

When the cancer is close to major blood vessels

Sometimes the cancer may grow very close to large blood vessels near the pancreas. It may be possible to have surgery to remove the cancer, but it depends which blood vessels are affected and how far the cancer has grown.

This is called **borderline resectable pancreatic cancer.** Your doctor may not call it this, they may just focus on whether your cancer can be removed with surgery.

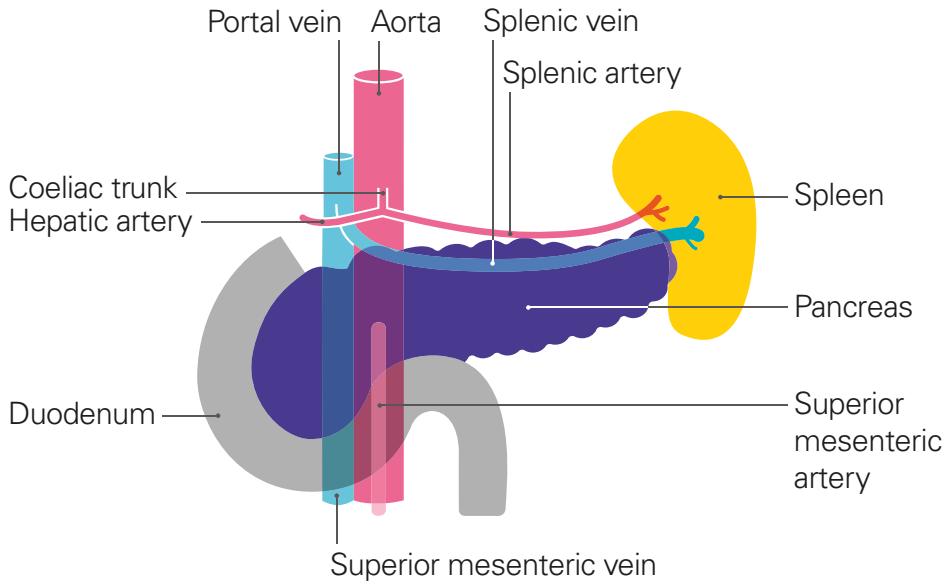
- If the cancer is **touching** an artery or vein, you may be offered chemotherapy on its own or with radiotherapy (chemoradiotherapy). If this shrinks the cancer, then surgery might be possible later on.
- Sometimes the surgeon may need to remove part of a vein – see page 11.
- If the cancer has grown around the artery or vein, it's less likely to be possible to remove the cancer, even after chemotherapy.

If it's not possible to remove the cancer, your doctor will discuss other treatments with you. This might include chemotherapy. Chemotherapy won't cure the cancer, but it may help you live longer and help your symptoms.

Speak to your doctor or nurse about whether surgery is an option for you, and whether you will have chemotherapy and radiotherapy.

Read more about **borderline resectable pancreatic cancer** at:
pancreaticcancer.org.uk/stage3

Pancreas with surrounding blood vessels diagram



Getting a second opinion

It can be difficult to tell how close the cancer has grown to blood vessels and whether it is possible to remove it. This means that different medical teams may have different opinions about whether surgery is possible. If your medical team don't think it's possible, you can ask for a second opinion from a different medical team. Be aware that the second team's opinion may not be any different.

Find out about getting a second opinion at:
pancreaticcancer.org.uk/secondopinion

You can also speak to our specialist nurses on our free Support Line with any questions about getting a second opinion.

When it's not possible to remove the cancer

Sometimes the surgeon may start the operation, but find that they can't remove the cancer. This may happen because:

- the cancer has spread to your liver or the lining of your abdomen (tummy area)
- the cancer has grown into or around the blood vessels near the pancreas which means that it can't be removed.

If this happens, the surgeon may do a different operation called bypass surgery. This type of surgery won't remove the cancer, but it can help manage any symptoms. After bypass surgery you may be able to have chemotherapy to help control the cancer.

What is bypass surgery?

During surgery the surgeon may connect the stomach to the small intestine to allow food to pass out of the stomach. Or they may connect the bile duct to the small intestine to stop the bile duct getting blocked.

Bypass surgery is a major operation. Recovery can take two to three months, or sometimes longer. The information in this fact sheet about what happens after surgery (page 15), side effects (see page 17) and going home after your operation (page 20) may be helpful for you.

It can be upsetting to find out that it wasn't possible to remove the cancer. You can read about support available on page 22.

Read more about bypass surgery on our website at:
pancreaticcancer.org.uk/bypass

Questions to ask your doctor or nurse

Can I have surgery to remove the cancer?

Is the cancer affecting any major blood vessels?

Will I need to have chemotherapy or radiotherapy before or after my surgery?

What happens if the surgeon finds that they can't remove the cancer as planned?

Types of surgery

There are different operations for pancreatic cancer. They involve removing part or all of the pancreas. This will depend on where the cancer is in the pancreas and how much of the pancreas is affected. The surgeon may need to remove other organs and tissues around the pancreas, such as part of the stomach or duodenum (the first part of the small intestine).

Your surgeon will discuss the best type of surgery for you and explain what will happen. Ask the surgeon any questions you have.

We have a phone service, called Side by Side, where you can speak to a trained volunteer who has already had pancreatic cancer surgery. They know what it's like to have surgery, and can share their experiences of it. Find out more at: **pancreaticcancer.org.uk/sidebyside**

" Side by Side has helped me get through some very low times. I always feel so much better after the calls."

Whipple's operation (pancreatoduodenectomy or PD)

The Whipple's procedure is the most common type of surgery for pancreatic cancer. It is used for tumours in the head or neck of the pancreas.

The surgeon will remove the head of the pancreas. They also remove:

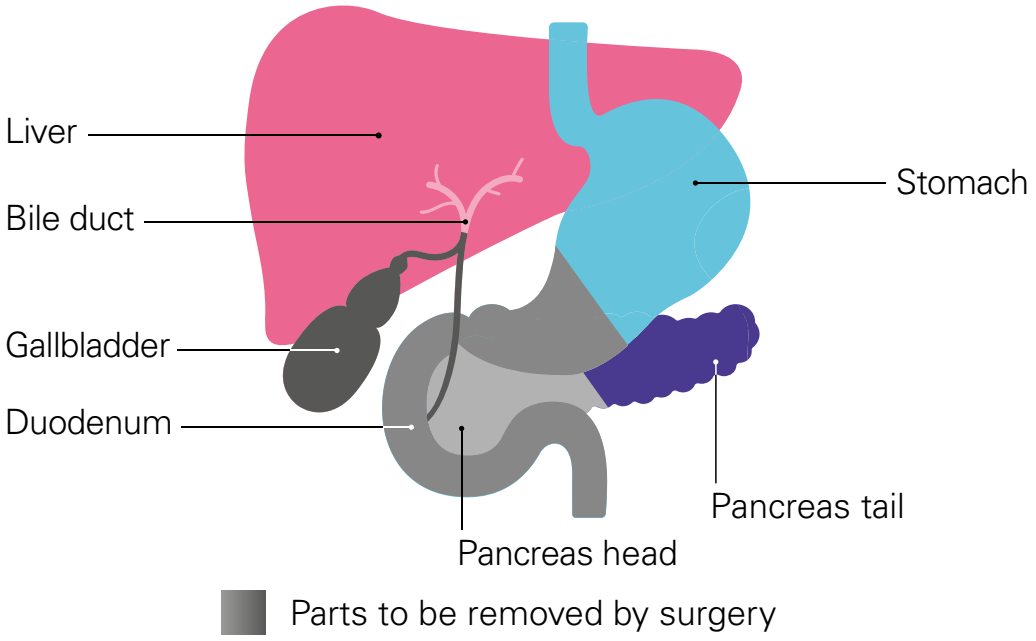
- the lower end of the stomach
- the duodenum (first part of the small intestine)
- the gall bladder (which stores a fluid called bile, which helps digestion)
- part of the bile duct (which carries bile from the liver to the duodenum)
- nearby lymph nodes (part of the immune system).

The surgeon will then join the remaining part of the stomach and bile duct to the small intestine. The pancreas is joined to the small intestine or to the stomach.

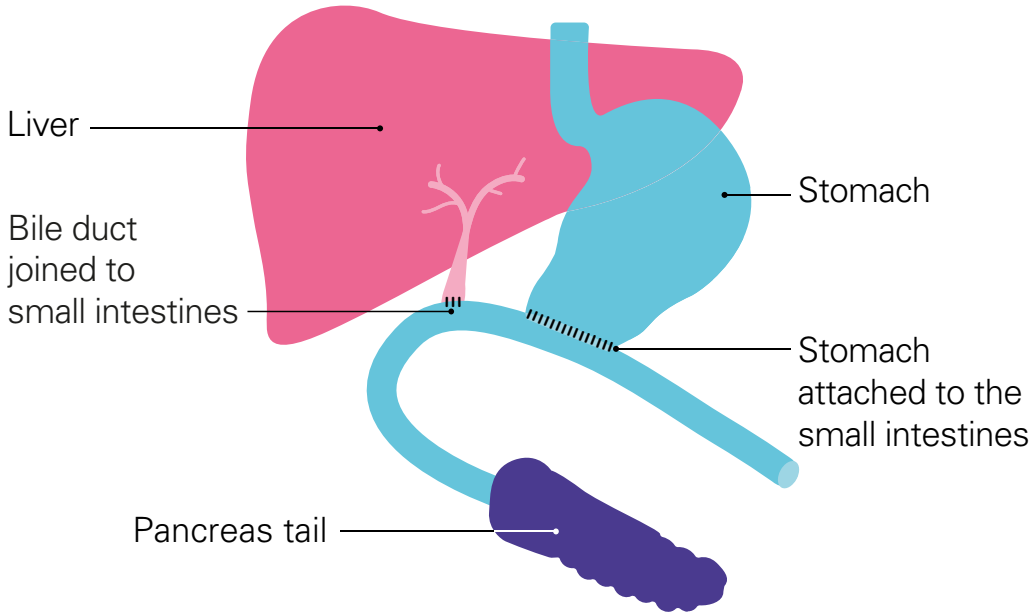
You may have an operation that's similar to the Whipple's, but none of the stomach is removed. This is called a pylorus-preserving pancreatoduodenectomy (PPPD).

As part of your pancreas is removed, your digestion may be affected. You may need pancreatic enzyme replacement therapy (PERT) to help you digest food. There is also a chance that you might get diabetes – this can happen at any time after your operation. Read more about side effects of surgery on page 17.

This diagram shows the parts of the body removed by a Whipple's operation



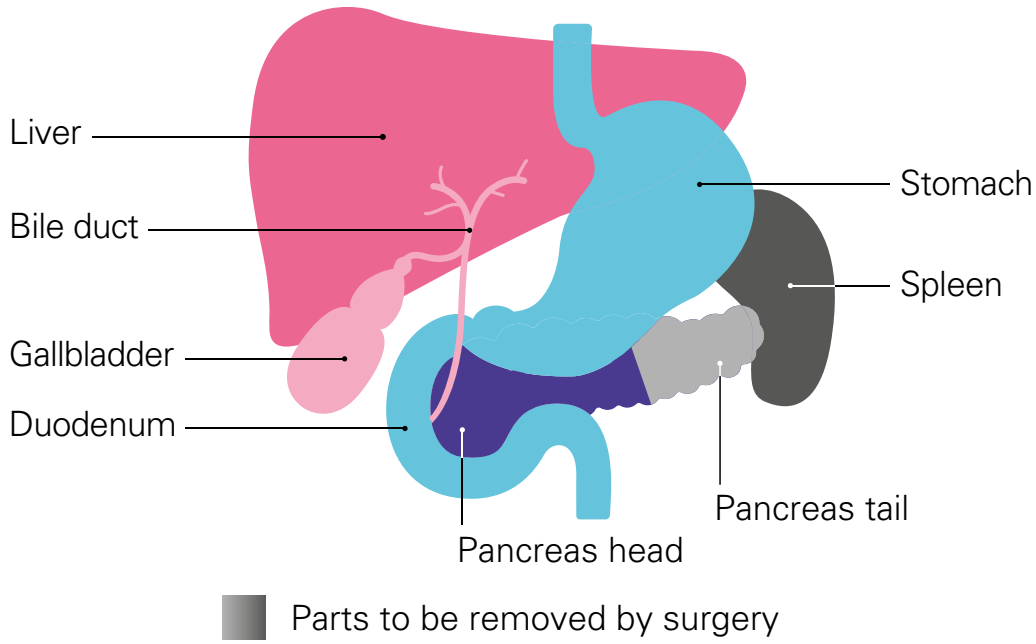
This diagram shows the pancreas and surrounding organs after a Whipple's operation



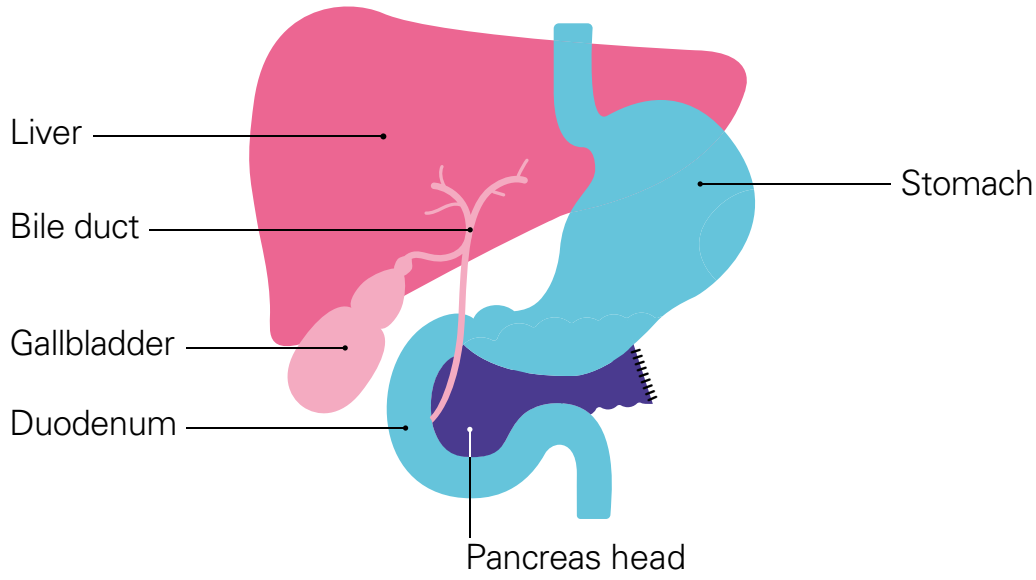
Distal pancreatectomy

A distal pancreatectomy removes the body and tail of the pancreas. The spleen is also often removed – this is called a splenectomy.

This diagram shows the parts of the body to be removed by a distal pancreatectomy



This diagram shows the pancreas after a distal pancreatectomy



The spleen helps your body fight infections. If it's removed, you may be more likely to get infections, so you will have vaccinations before or after surgery. You may also need to take antibiotics for the rest of your life. You can carry a card saying you have no spleen in case you become ill. You can get these from GOV.UK.

You will be more likely to get diabetes. You may need to take medicine, such as insulin, to manage this (see page 19). Your digestion may also be affected. You may need to take pancreatic enzymes (see page 18), but this is less likely than with the Whipple's operation.

Total pancreatectomy

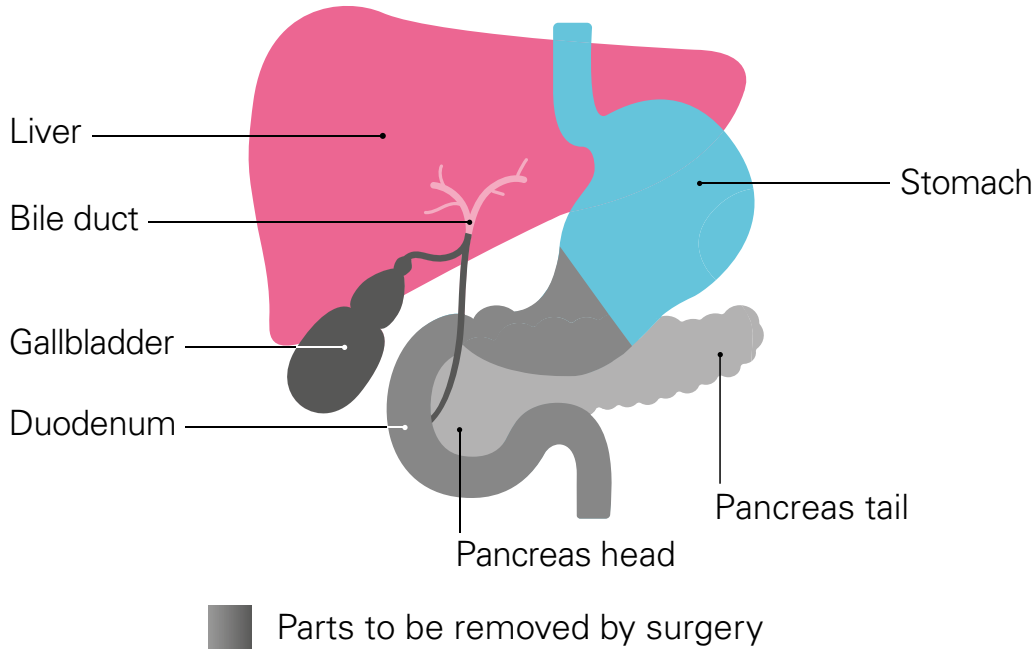
You may have a total pancreatectomy if there is a large tumour, more than one tumour, or if your pancreas isn't healthy.

A total pancreatectomy removes the whole pancreas and:

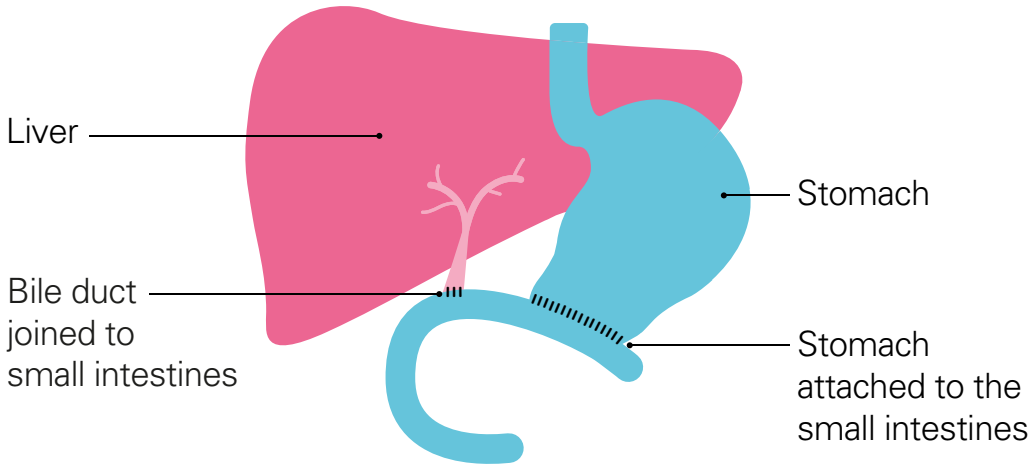
- the first part of the small intestine (duodenum)
- the gall bladder
- part of the bile duct
- and sometimes part of the stomach and the spleen (see above).

Exactly what is removed will depend on where the cancer is.

This diagram shows the parts of the body that will be removed by a total pancreatectomy



This diagram shows the organs after a total pancreatectomy



As the whole pancreas is removed, you will need to take pancreatic enzymes to help you digest food (see page 18). You will also develop diabetes and will need to take insulin to manage this (see page 19).

Removing part of a vein

Sometimes the cancer grows into or around major blood vessels near the pancreas – such as the superior mesenteric and portal veins (see diagram on page 5). To remove the cancer, the surgeon may need to remove part of the vein. The vein is then joined back together. This is called vein resection and reconstruction. It is sometimes done by putting in a piece of vein from somewhere else in the body or using an artificial material – this is called a graft.

Vein resection makes the surgery more complicated, and it may take longer. You need to be very fit and well to have this type of surgery.

This type of surgery might not be available at your nearest specialist centre (see page 14). You may be referred to another specialist centre to have the surgery. You can also ask for a second opinion (see page 5) from another surgeon who is experienced in doing vein resections.

Questions to ask your doctor or nurse

Which type of operation do I need?

What organs will be removed?

Will I need to take pancreatic enzymes or other medicines after my surgery?

How is surgery carried out?

You may have your operation as open surgery or as keyhole (laparoscopic or robotic) surgery. You will have a general anaesthetic, so you will be asleep and won't feel anything.

Open surgery is when one large cut (incision) is made in the tummy.

With keyhole surgery, several small cuts (about 1-2 cms) are made in the tummy. A long tube with a camera on the end is put into one hole. The camera guides the surgeon to put instruments through the other holes to do the operation. Robotic surgery is similar, but the surgeon controls the instruments through a computer.

Keyhole surgery is not suitable for everyone. In some specialist centres, it may be offered to some people who are having a distal pancreatectomy and, less often, to those having a Whipple's procedure. Sometimes the surgeon will start keyhole surgery and find that it is more complicated than they expected. If this happens, they will switch to open surgery.

What are the advantages and disadvantages of surgery?

Surgery is the most effective treatment for pancreatic cancer. If it is an option for you, ask your doctor or nurse any questions you have.

Advantages

- Surgery is the best treatment for removing the cancer and can help you live longer.
- Some of your symptoms, such as jaundice, pain and problems with digestion may improve after surgery.
- If the cancer does come back after surgery, you may be able to have further treatment with chemotherapy to control the cancer and your symptoms.

Disadvantages

- Pancreatic surgery is major surgery and as with any major operation there are some risks (see below).
- You will need to stay in hospital afterwards to recover. This may be between a week and two weeks, but could be longer if there are problems.
- Depending on the type of surgery, it can take three to nine months to recover. For some people it could take up to a year to fully recover.
- You may get side effects from surgery, such as problems digesting your food and diabetes (see page 17). But the cancer may cause these symptoms even if you don't have surgery.

What are the risks of surgery?

Surgery for pancreatic cancer can be complicated and as with any major surgery, there are some risks.

- There is a risk of bleeding and you may need a blood transfusion. Your medical team will manage this if it happens. Any major operation has a risk of bleeding.
- You may get an infection such as a chest or wound infection – you will be given antibiotics to reduce this risk.
- There is a risk of a leak from where the pancreas, bile duct or stomach are joined to the small intestine. These leaks often heal without needing more treatment. Your surgeon may put a tube into your tummy during surgery to drain any fluids from a leak.
- As with any major operation, there is a risk of a blood clot in a vein (deep vein thrombosis or DVT) after surgery. The risk can be reduced by wearing support stockings and daily injections afterwards to prevent blood clots.
- The general anaesthetic, which puts you to sleep during the operation, may cause problems. These are very rare. They include an allergic reaction.
- There is a small risk of dying during or after the surgery.

Speak to your surgeon or nurse about the risks of your surgery and how they will check for these and manage them.

Preparing for your operation

Once you have decided to have surgery you may have to wait a few weeks for the operation. This will depend on many things, including how well you are, if you need further tests, and when the surgeon can do your operation.

Where will I have surgery?

In the UK, surgery should only be carried out in specialist centres where there is a specialist team to treat pancreatic cancer. This means the surgeons are experienced in pancreatic surgery and usually do at least 12 of these operations a year. Your surgeon should be able to tell you how many operations they have done.

This means the surgery may not be at the local hospital. But other appointments, such as chemotherapy or check-ups, might be at a hospital that's closer to you.

Before the operation

Pre-op assessment

Before your surgery you will have a check-up at the hospital to make sure that you are fit enough for surgery and a general anaesthetic. This is called a pre-op assessment. It may include blood tests, x-rays and tests to check how well your heart and lungs are working, and a physical examination.

Diet and physical activity before surgery

The fitter you are before surgery the better. Try to eat as well as possible in the weeks before your operation and be as active as you can. This will help you recover from surgery.

Pancreatic cancer may affect how well you can digest food. If you have lost weight, you may need to put weight back on. Speak to your medical team about pancreatic enzyme replacement therapy to help with this (see page 18). They may also suggest foods or nutritional supplements to help you put on weight.

You may be referred to a dietitian, who is an expert in diet and nutrition. They can help you manage any digestion problems before surgery. If you haven't seen a dietitian, ask your doctor about this.

If you exercise regularly you should carry on with this. If you don't usually exercise, try to move about as much as possible. Try setting yourself small targets each day, such as increasing the number of times you go up and down the stairs.

Read more about diet and physical activity in our booklet: **Diet and pancreatic cancer.**

Going into hospital

You will go into hospital either the day before or the morning of your operation.

Your medical team will tell you when you need to stop eating or drinking before your surgery. They will also tell you what to do about taking any regular medicines, especially medicine to thin your blood or medicine for diabetes.

Most operations to remove pancreatic cancer take four to seven hours, though some may take longer.

After your operation

Recovering from pancreatic surgery takes time and you will probably feel very weak after your operation. It may take several months to a year to fully recover. This will be different for each person.

When you wake up after surgery

You will be in the intensive care unit (ICU) or high dependency unit (HDU) for the first 24–48 hours. This is so that the nurses can monitor you closely.

Once the doctors are happy with how you are recovering, you will be moved to a ward. You may spend five to ten more days in hospital, or longer, depending on how you are recovering.

Some hospitals have enhanced recovery programmes which aim to get you eating, drinking and moving about as soon as possible after surgery. Your medical team will help you to sit out of bed and slowly get moving as soon as you are able to. Ask your medical team if they have an enhanced recovery programme.

Eating and drinking after surgery

For the first few hours after surgery you won't be able to eat or drink anything. You will slowly start to drink and eat normally again, starting with drinks and then softer foods. Once you can manage this, you can slowly have more normal food.

You may be fed through a tube to begin with, or if you have problems eating normally. This gives your digestive system time to recover. The tube may go through your nose or through a small hole in your tummy. Not all hospitals use feeding tubes. If you have a leak where the pancreas, bile duct or stomach are joined to the small intestine you may need to have food into a vein (intravenously) for a few days.

You may see a dietitian after your surgery. They can give you advice on what to eat and how to maintain or put on weight. If you don't have a dietitian your nurse can help you with this. There are no foods which you should totally avoid. You may need to eat smaller portions, and need more calories and protein to help you put on weight and recover.

After surgery, most people need to take pancreatic enzymes to help them digest food (see page 18). A dietitian or your nurse can help with this.

Going to the toilet

A thin tube called a catheter will be put in to drain your urine until you can get out of bed to use the toilet. Once you can do this, the catheter will be taken out.

Your bowels won't start working normally for a few days. When they do you may have runny poo (diarrhoea), or constipation (when you find it harder to poo). But this should settle down. Constipation can also be caused by painkillers called opioids.

Your poo may also be pale, oily, smell horrible, and be hard to flush. This happens because the pancreas can't produce enough enzymes to digest the fat in your food. You should be given pancreatic enzymes to help with this (see page 18).

Your wound

You will have stitches or surgical staples closing the wound. These will be removed about 10–14 days after your operation. This may be done at hospital or at your GP surgery. The area around your wound may be sore for a few weeks, and may feel numb – this is normal.

There is a risk that your wound could become infected. If this happens, it may look swollen, red around the edges or may ooze a smelly, yellow liquid (pus). If you think it's infected tell your GP. You should also let your specialist nurse know.

What are the side effects?

Surgery can cause side effects. These will affect everyone differently, and you may not get all the side effects. If you are worried, talk to your doctor or nurse.

Short term side effects

Pain

It is normal to have some pain and discomfort for a few weeks after surgery. Straight after the operation, you may have painkillers through an epidural (a drip in your spine). Or you may have patient controlled analgesia (PCA). This is where you have painkillers through a drip in your arm. You press a button to get the pain relief. As your pain gets better, the epidural or PCA will be removed.

After a few days you will have painkillers as tablets. Take these regularly, as advised by your doctor or nurse and tell them if you have any pain. Your pain will reduce over time.

If you get sudden tummy pain after you leave hospital, or any pain gets worse, call your surgical team. If it's outside office hours, go to A&E and let them know about your surgery.

Read more about pain and pancreatic cancer in our booklet: **Pain and pancreatic cancer.**
Or at: **pancreaticcancer.org.uk/pain**

Feeling sick

Some medicines, such as painkillers, may make you feel sick. You will be given anti-sickness medicines for this.

You may also feel sick because it can take time for your digestive system to start working properly again. Your doctor or nurse can help you manage this, and it is usually only temporary. Eating smaller meals more often can help. If you start being sick, tell your doctor or nurse as soon as possible.

Longer term side effects

Diet and digestion

It will take time to get back to eating normally after surgery. You may have lost your appetite, or feel full quickly. Eating smaller meals may help.

The pancreas plays an important role in breaking down (digesting) food. Removing all or part of the pancreas may affect how well you can digest food and may cause symptoms such as weight loss, diarrhoea, tummy discomfort or bloating.

Problems with digestion can be managed with pancreatic enzyme replacement therapy (PERT). These are capsules that replace the enzymes your pancreas would normally make. They help to break down food and can make a big difference to how you feel.

The dietitian, doctor or nurse should check whether you need pancreatic enzymes before and after surgery. If you haven't seen a dietitian and you are having problems with digestion, ask your medical team or GP to refer you.

Read more about digestion and how to take pancreatic enzymes in our booklet: **Diet and pancreatic cancer**
Or at: **pancreaticcancer.org.uk/diet**

" I was surprised at both what and how little I could eat after my surgery – a spoon of cereal rather than a large bowl. I hadn't expected it to be so extreme, but my appetite and ability to eat and digest a greater variety of food gradually returned."

Diabetes

Diabetes is a condition where the amount of sugar in your blood is too high. Your pancreas makes a hormone called insulin, which helps to control your blood sugar level. Having part or all of your pancreas removed can cause diabetes.

If you get diabetes you may need to take medicine to manage it. You should see a doctor, specialist dietitian or a diabetes nurse for help with this. It's important to get the right advice. **There are different types of diabetes. Information on the internet may not be right for you because of your pancreatic cancer.**

Read more about diabetes and pancreatic cancer on our website at: **pancreaticcancer.org.uk/diabetes**

Discomfort and pain

It is normal to feel some discomfort and pain for a few weeks after surgery. If the pain is bad, it could mean that you have an infection, so contact your surgical team straight away. **If the pain is really bad or you have a high temperature or feel generally unwell, go to A&E and tell them about your operation.**

You may still have pain and discomfort a few months after your operation. You may feel tingling, butterfly feelings and occasional sharp pains in your tummy. This is normal and may be a sign that your muscles and nerves are starting to repair. It can also be a sign that you are doing too much lifting and bending, and your body just needs more time to heal. Sometimes the scar from the wound can be numb.

If you have any new pain and painkillers don't help, speak to your medical team or GP.

Tiredness and fatigue

An operation to remove pancreatic cancer is major surgery. It can take several months, or sometimes longer, to fully recover. Feeling tired and weak is normal. Fatigue is extreme tiredness. You may feel drained or exhausted.

There are ways to manage fatigue. Try to balance resting with being active. Aim to gradually get back to daily activities, such as walking and light household tasks. Slowly build up how much you do, but don't overdo it.

Read more about managing fatigue in our booklet:
Fatigue and pancreatic cancer: How to deal with tiredness
Or at: **pancreaticcancer.org.uk/fatigue**

If you have any questions about side effects, speak to your doctor or nurse.

You can also speak to our specialist nurses on our free Support Line about any side effects.

Questions to ask your doctor or nurse

Should I do anything to prepare for surgery?

Who can I see for help with managing side effects?

How will any pain be managed?

How will surgery affect my eating and digestion?

Should I take pancreatic enzyme replacement therapy (PERT)?

What should I do if my side effects don't get any better?

Going home

You may spend one to two weeks in hospital. This will depend on how well you recover and whether you can eat and drink normally.

You will be given the details of someone to contact if there are any problems. This is usually a specialist nurse. You can also speak to your GP for support, for example with pain relief. They may arrange for a district nurse to visit you at home to help with things like changing your wound dressing.

What support will I need at home?

When you first go home you will need to take things easy as you will get tired. You will need help with things like shopping and cleaning. Ask family and friends if they can help.

You may need to have injections of blood thinning medicines to prevent a blood clot. Your nurse will show you how to do these injections yourself. If you need help, let them know. They can arrange for a district nurse to help you at home.

Slowly increase how much you do and make sure you move around during the day, even if it's just around the house to begin with. This can help with your recovery and reduce the risk of blood clots.

If you think you need some extra help at home, tell your nurse. They should be able to arrange for social services to look at what help you need. Most people manage well at home and don't need extra help.

Longer term recovery

Coming to terms with changes to your body such as scars and weight loss can take time. Once the wound has completely healed the scar will fade over time.

You might find it helpful to talk to a volunteer who has had surgery through our Side by Side service (see page 7). Macmillan Cancer Support have more information about body image and cancer.

" I didn't find it hard to learn to live with the scars – seeing them reminds me how lucky I have been. I did find it hard to adjust to the weight loss and lack of muscle tone – my clothes were hanging off me."

It's fine to have sex once your wound is fully healed and you feel well enough. If you are worried about it, talk to your partner or GP.

Regular gentle physical activity, such as walking, can help your recovery and help you to feel better emotionally. Try setting yourself a small target every day and slowly increase how much you do.

" It took a lot longer to recover my fitness, energy and weight than I imagined, particularly as I had been so fit and active beforehand. You can't just pick up where you left off."

Driving after surgery. You shouldn't drive for a few weeks after your operation. Check with your doctor how soon you can drive and anything you should be aware of. You will need to tell your insurance company about your surgery – it may affect your driving insurance.

If you develop diabetes and are taking insulin you will need to tell the Driver and Vehicle Licensing Agency (DVLA), or the Driver and Vehicle Agency (DVA) if you live in Northern Ireland. You won't be able to drive until they tell you that you can.

Going back to work may take at least three months, but this will depend on the type of work you do and whether you are having chemotherapy after surgery. Talk to your employer about your options. You have rights at work, and your employer must make reasonable changes to help you return to work. For example, you may be able to work reduced hours to begin with or take more breaks than normal.

" I went back immediately, with some flexi-time and home working. Psychologically I felt it showed my recovery, but in hindsight it was too much too soon."

We have information about work and money at: **pancreaticcancer.org.uk/money**

If you have any questions or worries about longer term recovery, speak to our specialist nurses on our free Support Line.

Coping with pancreatic cancer

Surgery to remove pancreatic cancer is a major operation and can affect you emotionally as well as physically. People find different ways to cope and there is support available. Your family and friends may also need support.

Read about dealing with the emotional impact of pancreatic cancer at: **pancreaticcancer.org.uk/coping**

Read about how we can support you on page 25 and at: **pancreaticcancer.org.uk/support**

Check-ups

Check-up after your operation

Your surgeon will aim to take out all the cancer during surgery. They will also take out some of the normal tissue around the cancer. This is called the surgical margin. The aim is to make sure that all the cancer has been removed.

A doctor called a pathologist will look at the tissue that was removed during surgery. They will check whether there are any cancer cells in the surrounding area or lymph nodes. Your surgical margins will be either negative or positive.

- **Clear or negative:** there are no cancer cells in the outer edge of the tissue that was removed.
- **Positive or involved:** not all the cancer cells were removed and there may be some cells at the edge of the tissue that was removed.

You will have an appointment a few weeks after you leave hospital to get these results. You can also talk to your doctor about any side effects or problems you might be having at this appointment.

You may be offered chemotherapy once you have recovered from the surgery (see page 24).

Longer term checks-ups (follow-up)

You will have longer term check-ups (also called follow-up) after your operation. For these you may have blood tests and a scan.

You may have appointments with your surgical team, and/or the oncologist if you have chemotherapy. After the first few appointments, your follow-up may be at your local hospital.

Each hospital will do things slightly differently. If you haven't been told about follow-up appointments, ask your medical team about these.

- For the first two years after surgery, you may have an appointment every three to six months.
- After two years you may have an appointment every six months, or yearly. You may have these over the telephone. This will vary between hospitals.
- After five years your check-ups are either done by the hospital or your GP.

You may also have appointments for support with your digestion, taking pancreatic enzymes (see page 18) or any other medicines. These appointments may be with other health professionals, such as a dietitian.

The check-ups are a chance for you to ask any questions you have. If you have any problems you can ask for an appointment earlier. You can also contact your nurse for advice. If you get any new symptoms, contact your medical team – they should check what is causing them.

If your check-ups find any signs that the cancer has come back, you may be offered more treatment with chemotherapy.

Questions to ask your doctor or nurse

How often will I have check-ups after my surgery?

What tests will I have to check the cancer hasn't come back?

Who should I call if I have any problems?

Chemotherapy after surgery

You should be offered chemotherapy after surgery to try to reduce the chances of the cancer coming back.

- Chemotherapy called FOLFIRINOX may be offered to people who are well enough to deal with any possible side effects.
- If you are not suitable for FOLFIRINOX, then the chemotherapy drugs most often used are gemcitabine with capecitabine (GemCap).
- If you aren't well enough to have GemCap, you may be offered gemcitabine alone, as it has fewer side effects.

You should be given time to recover from surgery before starting chemotherapy. This is because you need to be well enough for around six months of chemotherapy. Chemotherapy may begin up to 12 weeks after your surgery.

If you are having any problems with digestion (see page 18), speak to your doctor, nurse or dietitian. They can make sure this doesn't delay the chemotherapy.

More information and support

Pancreatic Cancer UK services

We are here for everyone affected by pancreatic cancer.

Our specialist nurses are here to talk now

If your world has been turned upside down by a pancreatic cancer diagnosis, we are here to talk now. We can answer your questions, recommend practical steps and provide the emotional support you and those close to you need, when you need it most.

Call free on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Expert information

Our free information covers everything about pancreatic cancer to help you understand your diagnosis, ask questions, make decisions and live as well as you can.

Go to: **pancreaticcancer.org.uk/information**

Download or order our free publications at **pancreaticcancer.org.uk/publications** or call **0808 801 0707**

Our online forum

The forum is a supportive online space where everyone affected by pancreatic cancer can be there for each other at any time.

Go to: **forum.pancreaticcancer.org.uk**

Living with Pancreatic Cancer Online Support Sessions

Our online support sessions are hosted by our specialist pancreatic cancer nurses and will give you the chance to connect with others who have also been diagnosed.

Go to: **pancreaticcancer.org.uk/supportsessions**

Real life stories

Read other people's experiences of pancreatic cancer to find out how they coped with their diagnosis and treatment and their tips on looking after themselves.

Go to: **pancreaticcancer.org.uk/stories**

Useful organisations

Cancer Research UK
www.cancerresearchuk.org
Helpline: 0808 800 4040 (Mon-Fri 9am-5pm)
Information for anyone affected by cancer.

GOV.UK
www.gov.uk
DVLA Medical Enquiries tel: 0300 790 6806
Provides information about government services, including the **Driver and Vehicle Licensing Agency** (DVLA), and the card to carry if you have had your spleen removed.

Macmillan Cancer Support
www.macmillan.org.uk
Support Line: 0808 808 00 00 (7 days a week, 8am-8pm)
Provides practical, medical and financial support for anyone affected by cancer.

Maggie's Centres
www.maggies.org
Tel: 0300 123 1801
Centres around the UK and online offer free, practical, emotional and social support for anyone affected by cancer.

National Institute for Health and Care Excellence (NICE)
www.nice.org.uk
NICE have guidelines for health professionals diagnosing and caring for people with pancreatic cancer. These guidelines cover England, Wales and Northern Ireland. Read more at: **pancreaticcancer.org.uk/NICE**

Neuroendocrine Cancer UK
www.neuroendocrinecancer.org.uk
Helpline: 0800 434 6476 (Tues-Thurs 9am-5pm, Fri 9am-1pm)
Information and support for people with neuroendocrine tumours (NETs).

nidirect
www.nidirect.gov.uk
Driver and Vehicle Agency Tel: 0300 200 7861 (Mon-Fri, 9am-4pm)
Information about local services in Northern Ireland, including the **Driver and Vehicle Agency** (DVA).

This fact sheet has been produced by the Support and Information Team at Pancreatic Cancer UK.

We make every effort to make sure that our services provide up-to-date, accurate information about pancreatic cancer. We hope this will add to the medical advice you have had, and help you make decisions about your treatment and care. This information should not replace advice from your medical team – please speak to your doctor, nurse or other members of your medical team about any questions.

We would like to thank the following people who reviewed this information.

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- Pancreatic Cancer UK Lay Information Reviewers
- Pancreatic Cancer UK Specialist Nurses

Email us at **publications@pancreaticcancer.org.uk** for references to the sources of information used to write this fact sheet.

Give us your feedback

We hope you have found this information helpful. We are always keen to improve our information, so let us know if you have any comments or suggestions. Email us at **publications@pancreaticcancer.org.uk** or write to our Information Manager at the address on the back cover.

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