Pancreatic CANCER UK

# Surgery to remove pancreatic cancer

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

You can contact our specialist nurses on our Support Line with questions about surgery. Call free on **0808 801 0707,** email **nurse@pancreaticcancer.org.uk** or send a WhatsApp message on **07418 304789.**

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There is a lot of information here so you might find it helpful to dip in and read the information that's relevant for you.

All hospitals do things slightly differently. Speak to your surgeon or nurse (the clinical nurse specialist or CNS) if you have any questions about surgery.

# Key facts

- Surgery to remove pancreatic cancer can help people live longer. It is the only treatment that might offer a cure. Read more about this on page 12.
- Surgery is only suitable for people who are fit and well enough to have the operation, and if there is no sign the cancer has spread.
- There are different types of surgery, depending on where the cancer is in the pancreas. The Whipple's operation is the most common type.
- If the cancer is close to major blood vessels, you may be offered chemotherapy, sometimes followed by chemotherapy with radiotherapy (see page 4). This may shrink the cancer so that surgery is then possible.
- Most people will be offered chemotherapy after surgery to reduce the chances of the cancer coming back (see page 25).
- 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. Read more at: **pancreaticcancer.org.uk/coping**
- You and your family can get support from our specialist nurses. They can talk through treatment options and questions you have about surgery. Read more about the nurses on page 26.

Watch our video about surgery, which explains what it involves, at: **pancreaticcancer.org.uk/surgery**

# Who can have surgery?

Surgery (followed by chemotherapy) is the best treatment for pancreatic cancer that has not spread. It can help people live longer.

- Only a small number of people can have surgery. This is partly because the cancer is often diagnosed when it has spread outside the pancreas and can't be removed.
- If you have been diagnosed with pancreatic cancer, you will have scans to check whether surgery is an option for you. Your medical team will look carefully at these scans to work out if surgery is possible.
- You also need to be well enough to have surgery and will have tests to check this. Read about the tests and preparing for surgery on page 14.

Cancer that can be removed by surgery is called **resectable** or **operable** cancer. Your doctor will explain whether surgery is an option for you.

## Why can't everyone have surgery?

Surgery is not suitable for everyone.

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

If surgery isn't an option for you, your doctor may offer you chemotherapy. This uses drugs to kill cancer cells. It may slow the growth of the cancer and help you live longer. There are also other treatments to help manage symptoms.

Read about locally advanced cancer on our website at:
**pancreaticcancer.org.uk/stage3**
And advanced cancer at: **pancreaticcancer.org.uk/stage4**

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

## If the cancer is close to major blood vessels

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

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

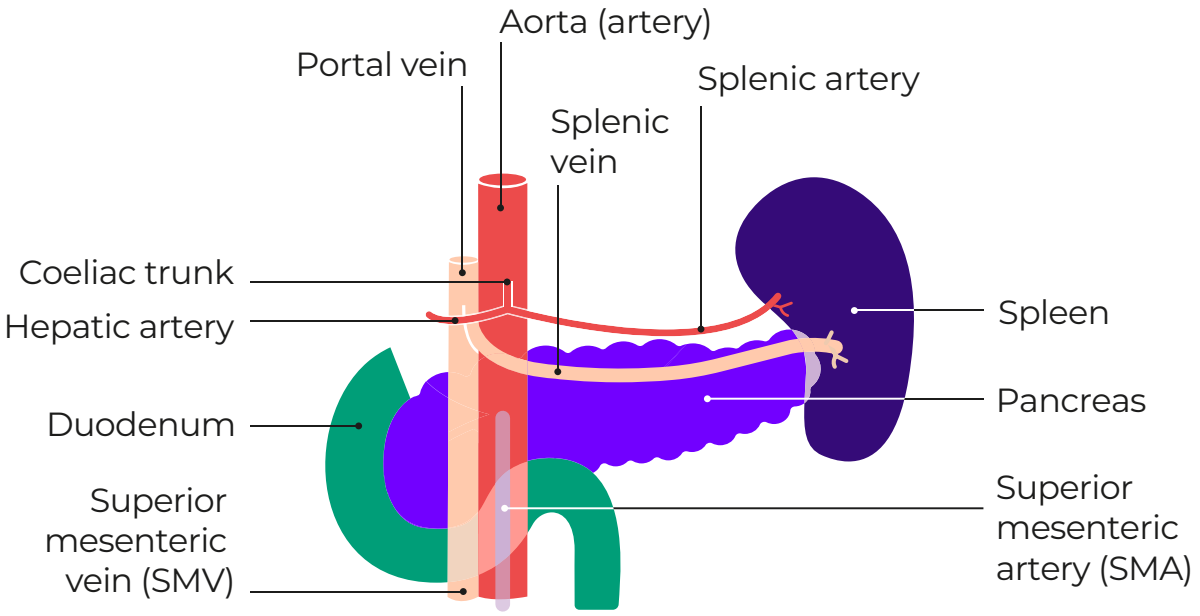
### What are the treatment options for borderline resectable cancer?

You may be offered chemotherapy on its own first. This is called neoadjuvant chemotherapy. Some people then have chemotherapy with radiotherapy (chemoradiotherapy).

If the cancer is just **touching** an artery or vein, chemotherapy may shrink the cancer so that surgery is then possible. You will have a CT scan following chemotherapy to check this. The operation will usually happen around six to eight weeks after you finish chemotherapy, although this can vary. The surgeon might also need to remove part of the affected vein (see page 10).

But if the cancer has grown **around** the artery or vein, surgery is less likely to be possible, even after chemotherapy. If it is not possible to remove the cancer, your doctor will talk to you about other treatments, such as chemotherapy. This won't cure the cancer, but it may help you live longer.

**This diagram shows the major blood vessels near the pancreas**



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**

## Can I get 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 referral for a second opinion from a different team. This may mean going to a different hospital. Be aware that the second team may have the same opinion.

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

You can also contact our specialist nurses on our free Support Line if you have any questions about getting a second opinion.

## 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 chemotherapy or radiotherapy before my surgery?

What happens if the surgeon can't remove the cancer?

# Types of surgery

There are different operations for pancreatic cancer. They involve removing part or all of the pancreas. The type of surgery you have will depend on where the cancer is in the pancreas and how much of the pancreas is affected. The surgeon may also need to remove other organs and tissues around the pancreas.

Your surgeon will explain which operation is suitable and what will happen. Ask them any questions you have.

## Whipple's procedure (pancreatoduodenectomy or PD)

This is the most common type of surgery for pancreatic cancer. It is used for cancers in the head of the pancreas (see diagram on page 7).

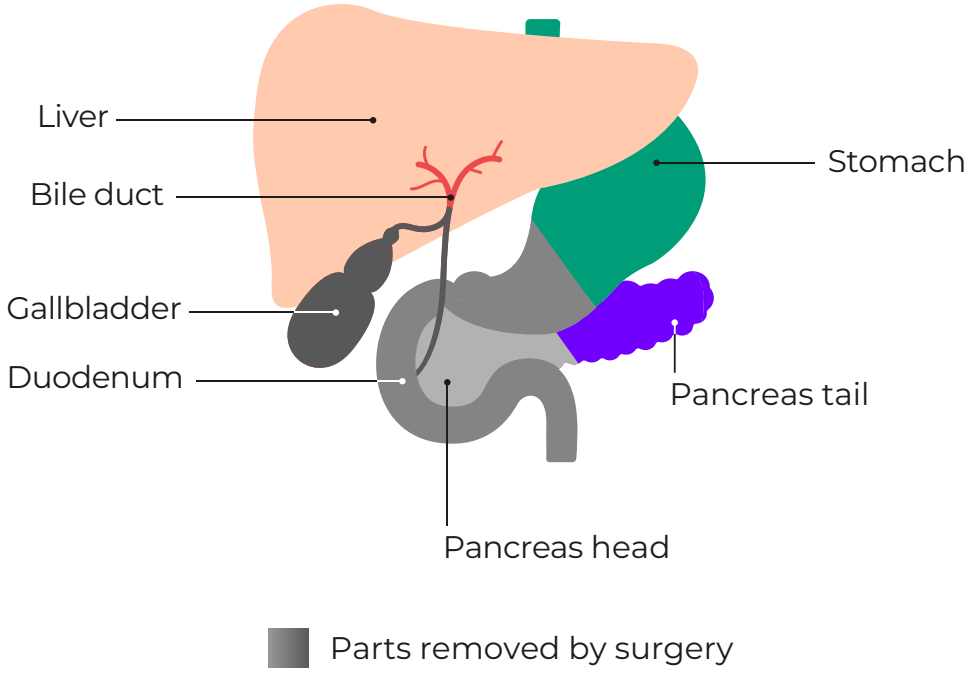
The surgeon will remove:

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

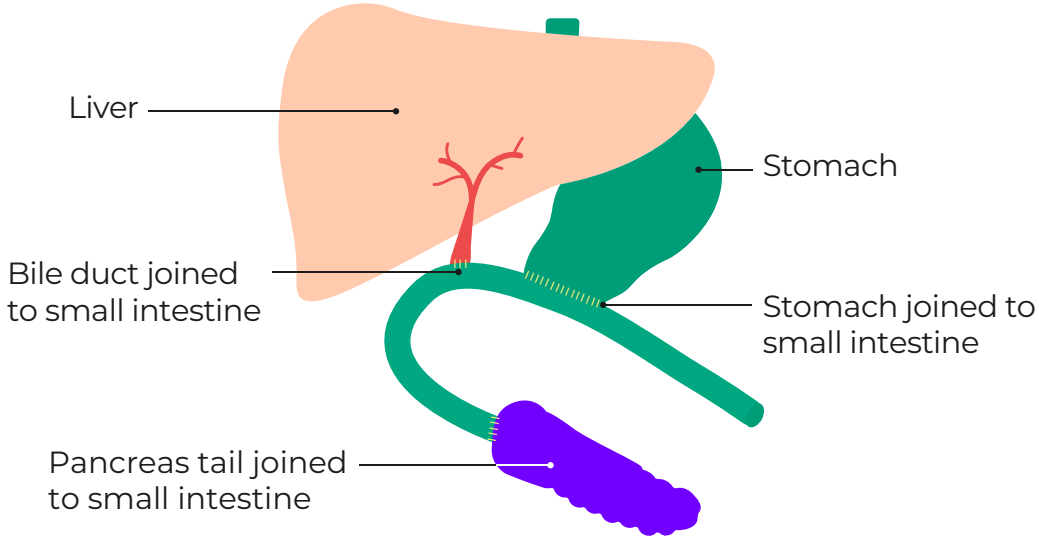
The surgeon will then join the remaining part of the stomach and bile duct to the small intestine. The remaining pancreas is joined to the small intestine or to the stomach.

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

## The parts of the body removed by a Whipple's procedure




## The pancreas and nearby organs after a Whipple's procedure




## Side effects of a Whipple's operation

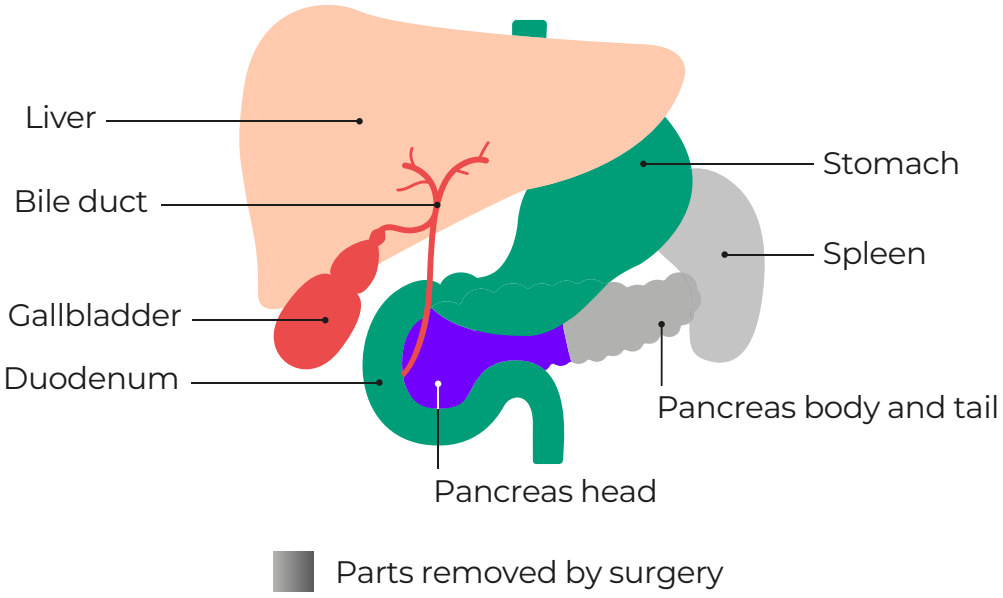
- As part of your pancreas is removed, this may **affect your digestion.** You may need to take pancreatic enzyme replacement therapy (PERT) when you eat to help you digest food.
- You might get **diabetes.** This can happen any time after surgery.

Read more about side effects of surgery on page 17.

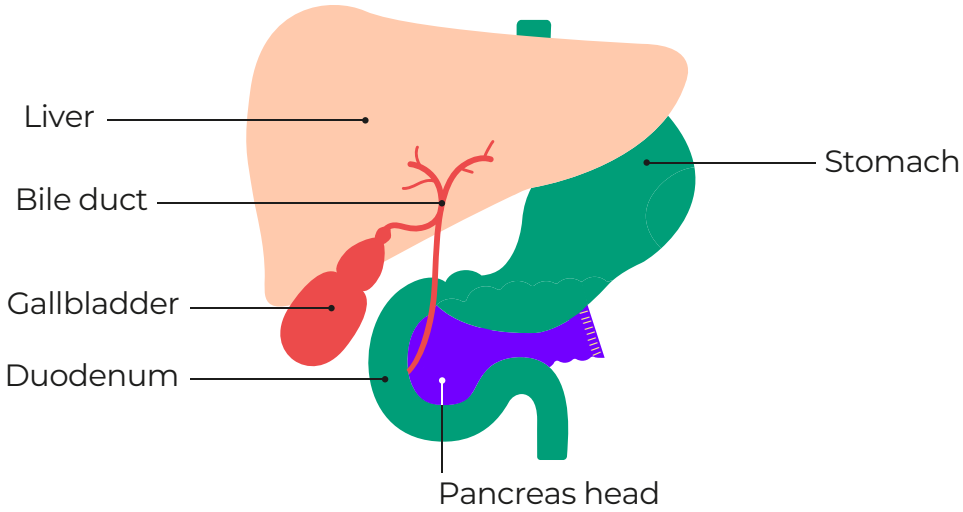
# Distal pancreatectomy

This removes the body (middle) and tail of the pancreas. The surgeon removes the spleen as well. This part of the operation is called a splenectomy.

### This diagram shows the parts removed by a distal pancreatectomy




### The pancreas and nearby organs after a distal pancreatectomy




## Side effects of a distal pancreatectomy

- You may get **diabetes** and need medicine for this (see page 20).
- Your **digestion may be affected,** and you may need to take PERT (see page 19). This is less likely than after a Whipple's operation.
- As the spleen is removed, you are more likely to get infections (see page 20).

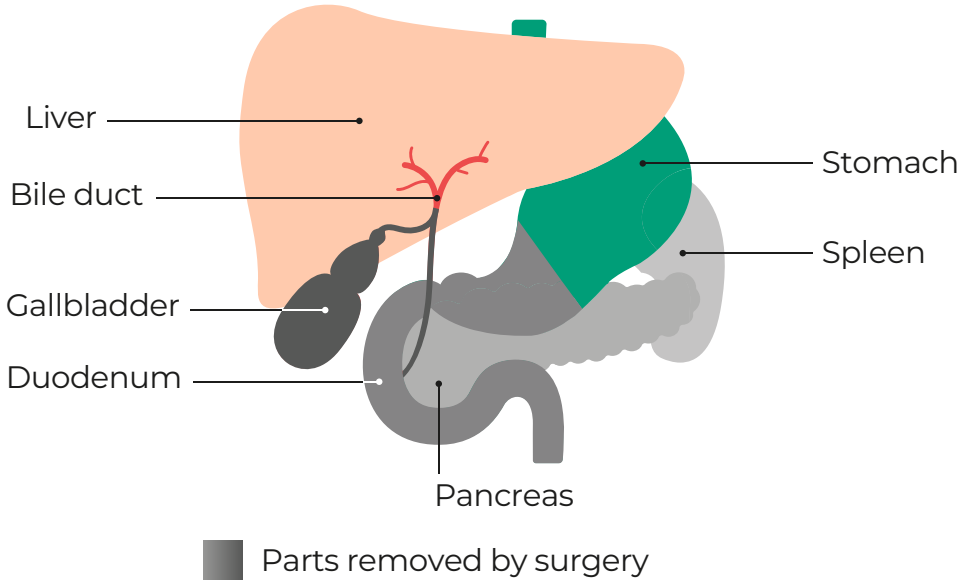
# Total pancreatectomy

You may have a total pancreatectomy if the cancer is large, or you have more than one tumour in your pancreas. The surgeon will remove:

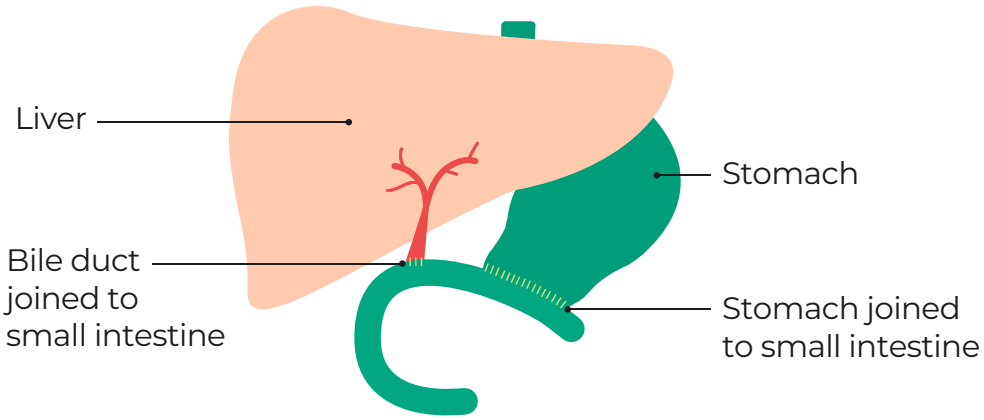
- the whole pancreas
- the duodenum
- the gallbladder and part of the bile duct
- the spleen.

Depending on where the cancer is, the surgeon may also remove part of your stomach. They will join the stomach and bile duct to the small intestine.

### This diagram shows the parts removed by a total pancreatectomy




### This diagram shows the organs after a total pancreatectomy



### Side effects of a total pancreatectomy

- As the whole pancreas is removed, **you will need to take pancreatic enzyme replacement therapy** to help you digest food.
- You will also get **diabetes** and will need insulin to manage this.
- As the spleen is removed, you are **more likely to get infections.**

Read more about side effects of surgery on page 17.

## Removing part of a vein

If the cancer has grown into or around major blood vessels near the pancreas (see diagram on page 4), the surgeon may need to remove part of the vein. The vein is then joined back together. This is called vein resection and reconstruction. The surgeon may put in a piece of vein from somewhere else in the body or use an artificial material – this is called a graft.

Vein resection makes the surgery more complicated. You need to be very fit and well to have this surgery. If your surgeon is unsure if vein resection is possible, you could ask for a second opinion from another surgeon who is experienced in these. Read about getting a second opinion on page 5.

Vein resection might not be available at your nearest specialist centre (see page 13). You may be referred to another specialist centre to have the surgery.

### 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 enzyme replacement therapy (PERT) or other medicines afterwards?

Am I likely to develop diabetes?

# If the surgeon finds during the operation that they can't remove the cancer

Sometimes the surgeon may start the operation but find that they can't remove the cancer. For example, the cancer may have:

- spread to your liver or the lining of your tummy (peritoneum)
- grown into or around major blood vessels that can't be removed.

If this happens, the surgeon may switch to a different operation called bypass surgery.

## What is bypass surgery?

Bypass surgery aims to prevent the cancer blocking the duodenum (first part of the small intestine) or bile duct (tube that carries bile from the liver to the duodenum). This is because blockages can cause symptoms. Bypass surgery won't remove or treat the cancer, but it can help with symptoms.

During bypass surgery, the surgeon may connect:

- the stomach to the small intestine, so that food can pass out of the stomach
- the bile duct to the small intestine, so that bile can pass from the liver to the small intestine
- both the stomach and the bile duct to the small intestine (double bypass).

You may be offered chemotherapy afterwards, to help control the cancer.

Bypass surgery is still a major operation. Recovery can take at least two to three months. The information about what happens after surgery (page 16), side effects (page 17) and going home (page 21) may be helpful.

Read more about bypass surgery, including diagrams of what it involves, on our website at: **pancreaticcancer.org.uk/bypass**

Finding out that it wasn't possible to remove the cancer can be upsetting. You can read about support available on page 26.

# What are the pros and cons 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 only treatment that can remove pancreatic cancer. It can help you live longer, and might offer a cure (see below).
- Some symptoms, such as jaundice (yellow skin and eyes), pain and problems digesting food, may improve after surgery.

## Disadvantages

- As with any major operation, there are some risks (see page 13).
- You will need to stay in hospital for a while afterwards. This may be for one to 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. Read more about recovery on pages 16 and 21.
- 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.

### Can surgery cure pancreatic cancer?

Surgery is the most effective treatment for pancreatic cancer. It may help you to live longer, and is the only treatment that might offer a cure. After surgery, you may be offered chemotherapy to try to reduce the chances of the cancer coming back (see page 25). If the cancer does come back, you may be offered further treatment with chemotherapy.

If you want to know more about the outlook, prognosis and survival rates for pancreatic cancer, speak to your doctor about your own situation. You can also read more at:
**pancreaticcancer.org.uk/operableprognosis**

## What are the risks of surgery?

Surgery can be complicated and, as with any major surgery, there are some risks. Speak to your surgeon or nurse about these.

- Any major operation has a risk of bleeding and you may need a blood transfusion. Your medical team will manage this if it happens.
- You may get an infection such as a chest or wound infection. You will be given antibiotics to reduce this risk.
- The place where the surgeon joins the pancreas, bile duct or stomach to the small intestine could leak. Read more on page 18.
- Any major operation has a risk of a blood clot in a vein, called deep vein thrombosis (DVT). You can reduce this risk by wearing support stockings. You may also need daily injections of a blood thinning medicine for about a month afterwards to prevent blood clots.
- The general anaesthetic may cause problems, such as an allergic reaction. This is very rare.
- There is a small risk of dying during or soon after the surgery.

# 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?

Your surgery should be done in a specialist centre where there is a specialist team to treat pancreatic cancer. This will include surgeons who are experienced in pancreatic surgery. 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 called a pre-op assessment. This is to make sure you are fit enough for surgery and a general anaesthetic. You may have a physical examination, blood tests and tests to check how well your heart and lungs are working.

## Keeping fit enough for surgery

The fitter you are before surgery the better, as this will help your recovery.

### What is prehabilitation?

Your hospital may offer a **prehabilitation programme** (sometimes called prehab). This helps to make sure you are as ready as possible for your operation. It aims to reduce complications and help you recover afterwards.

Prehabilitation advice and support usually includes diet and nutrition, physical activity, drinking less alcohol and stopping smoking. It also supports your emotional wellbeing. If there isn't a prehabilitation programme at your hospital, your medical team will give you advice about diet, physical activity and emotional support.

### Diet

Try to eat as well as possible in the weeks before your operation. Pancreatic cancer may affect how well you digest food. If you have lost weight, you may need to put weight back on before your surgery. Ask your medical team about taking pancreatic enzyme replacement therapy to help with this (see page 19). They may also suggest foods or nutritional supplements that can help.

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.

### Physical activity

Try to be as active as possible before your operation, as this will also help your recovery. If you aren't used to exercise, try setting yourself small targets, such as going up and down the stairs more each day.

Read more about diet on our website at: **pancreaticcancer.org.uk/diet**
And physical activity at: **pancreaticcancer.org.uk/exercise**

### Preparing for when you go home after the operation

Think about what help you will need when you go home from hospital. You may need family or friends to help with things like shopping. You could also freeze some meals before your operation, for when you get home.

Most people manage well at home. If you don't have anyone to help, speak to your GP and nurse before your surgery about what support is available. Read more about going home from hospital on page 21.

# How is surgery carried out?

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

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

## What is open surgery?

Open surgery is when one large cut (incision) is made in the tummy. This is the most common surgery for removing pancreatic cancer.

## What is keyhole surgery?

Keyhole surgery aims to avoid large wounds. Several smaller cuts are made in the tummy. This is known as minimally invasive surgery, though it is still a major operation.

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 a type of keyhole surgery where the surgeon uses a robotic system to control the instruments.

### Who can have keyhole surgery?

Keyhole surgery is not suitable for everyone. If you are having a distal pancreatectomy, keyhole surgery might be an option at some specialist centres. It is used less often for a Whipple's operation. Sometimes the surgeon will start keyhole surgery and find it is more complicated than they expected, so they will switch to open surgery.

## How long does surgery take?

The surgery may take four to ten hours, depending on how complicated it is.

# After your operation

You will probably feel very weak after your operation, and recovering from it will take time. 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. You may have various tubes and drains in. These are removed once they are no longer needed.

Once the doctors are happy with how you are recovering, you will be moved to a ward. You may spend one to two weeks in hospital, or longer if needed.

### What is an enhanced recovery programme?

Some hospitals have enhanced recovery programmes which aim to get you eating, drinking and moving about as soon as possible. The medical team will help you to get 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 drinking and eating, starting with drinks and then softer foods. Once you can manage this, you can slowly have more normal food.

### What if I have problems eating?

Your stomach may not empty normally for the first few days after surgery. If you have problems eating, you may be fed through a tube up your nose until your stomach works normally again. Not all hospitals use feeding tubes.

If there is a leak where the pancreas is joined to the small intestine, you may have food into a vein (intravenously) to begin with. Read about leaks on page 18.

### What should I eat after surgery?

After surgery, most people need to take pancreatic enzyme replacement therapy (PERT) to help them digest food (see page 19). You may see a dietitian who can give you advice on what to eat, how to maintain or put on weight and PERT. If you don't have a dietitian your nurse can help you with this.

There are no foods that you should totally avoid. To start with you may need to eat smaller portions and need more calories and protein to help you put on weight and recover.

## Going to the toilet

A thin tube called a catheter will be put into your bladder to drain your urine during the operation, and for a few days afterwards.

Your bowels won't start working normally for a few days. When they do you may have diarrhoea (runny poo) or constipation (when you find it harder to poo). This should soon settle down. You may also get constipation if you take painkillers called opioids.

Your poo may also be pale, oily, smelly, and hard to flush down the toilet. This is because the pancreas can't produce enough enzymes to digest the fat in your food. You should be given PERT for this (see page 19).

## Your wound

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

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

# What are the side effects?

Surgery can cause side effects or complications. These will affect everyone differently, and you may not get all of them. Talk to your doctor or nurse about what side effects you might get, and how they can be managed.

# Short term side effects

## Pain

It is normal to have some pain and discomfort for a few weeks after surgery. The pain should improve over time. Tell your doctor or nurse if it doesn't.

For the first few days, you may have painkillers through a drip. As your pain gets better, you will have painkillers as tablets instead. Take these regularly, as advised by your doctor or nurse.

If your pain suddenly gets worse after you leave hospital, and painkillers don't help, call your surgical team straight away. If it's outside office hours, or if you also have a high temperature, shivering or feel generally unwell, go to A&E. Make sure you tell them about your surgery.

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

## Feeling sick (nausea)

It can take time for your digestive system to start working properly again. This can make you feel sick. This is usually only temporary, and your doctor or nurse can help manage it. Eating little and often can help. If you start being sick, tell your doctor or nurse as soon as possible.

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

## Leaks from joins made during surgery

There is a risk of leaks from any of the joins made during the surgery. You will have drains to drain away any fluid and monitor leaks. Sometimes the drain may stay in for a few weeks and you may go home with it – your hospital will tell you what to do.

These leaks often heal without treatment. The drain can then be removed. But if you have a large leak that doesn't improve, you may develop an infection. You may need antibiotics and medicine to manage this. Much less commonly, a further operation may be needed.

### Mouth problems

Speak to your doctor if you have any mouth problems. They can check for oral thrush and other infections. Oral thrush causes white spots on your tongue, a sore mouth and unpleasant taste, and can affect your appetite. It is common after surgery but is usually easy to treat with medicine.

## Longer term side effects

### Diet and digestion

It will take time to start eating normally again after surgery. You may lose your appetite or feel full quickly. Eating little and often may help.

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

#### Pancreatic enzyme replacement therapy

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

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

Read more about digestion and PERT 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 a type of diabetes called type 3c diabetes.

While in hospital, your blood sugar level is likely to be checked to see if you get diabetes. If you get signs of diabetes after returning home, speak to your GP. Signs to look out for include feeling thirsty and needing to pee more often.

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

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

## Problems if your spleen has been removed (splenectomy)

If your spleen has been removed you are more likely to get infections, though this risk is small. You will need vaccinations to help protect against these, such as for flu and meningitis. You will also need to take antibiotics for the rest of your life. You will be advised to carry a splenectomy card saying you have no spleen, in case you become ill. Go to GOV.UK to get one.

## Discomfort and pain

You may still have pain and discomfort a few months after your operation. Your scar might still feel numb, and you may have tingling, fluttering feelings and occasional sharp pains in your tummy. This is all normal. It may be a sign that your muscles and nerves are healing. But it could also be a sign that you are lifting and bending too much, and your body needs more time to heal.

If you have any new pain that painkillers don't help, speak to your medical team or GP. You should contact your surgical team straight away, or go to A&E, if the pain is really bad or you have a high temperature (see page 18).

## Tiredness and fatigue

Surgery to remove pancreatic cancer is a major operation. It can take several months, or sometimes longer, to fully recover. It is normal to feel tired and weak. But you may have more extreme tiredness, called fatigue, where you feel completely 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**
Or at: **pancreaticcancer.org.uk/fatigue**

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

You can also contact our specialist nurses about any side effects or problems after surgery.

### Questions to ask your doctor or nurse

Should I do anything to prepare for surgery?

How will the pain be managed?

How will surgery affect my eating and digestion?

Should I take pancreatic enzyme replacement therapy?

Who can I see for help with managing side effects?

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

# Going home

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

You will be told who to contact if you have any problems when you go home. This is usually a specialist nurse. You can also speak to your GP, for example about pain relief.

# What support will I need at home?

When you first go home, you will get tired and will need to take things easy. You may need help from family or friends with things like shopping.

Slowly increase how much you do and move around, even if it's just indoors to start with. This can help your recovery and reduce the risk of blood clots.

## Blood-thinning medicines

You may need to have injections of blood-thinning medicine for about four weeks, to prevent blood clots. Your nurse will show you how to do these yourself. Tell them if you need help or don't feel confident. They can arrange for a district nurse to help you at home if needed.

# Longer term recovery

- **Coming to terms with changes to your body** such as scars and weight loss can take time. The scar will slowly fade once the wound has healed. Macmillan Cancer Support have information about body image.
- **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 lift your mood. Try setting yourself a small target every day and slowly increase how much you do.
- **Check with your doctor how soon you can drive** and anything you should be aware of. You shouldn't drive for a few weeks after your operation. You will need to tell your motor insurance company about your surgery, as it may affect your insurance.
- **If you get diabetes and take 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 say 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. 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 fewer hours to begin with. Read about work at: **pancreaticcancer.org.uk/money**
- If you are **thinking about a holiday after surgery,** speak to your medical team. They can talk to you about when you might have recovered enough, and when you can fly. You may need to buy specialist travel insurance. Macmillan Cancer Support have information about this.

"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."

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

# Check-ups

## Check-up after your operation

You will have an appointment with your surgeon a few weeks after going home. At this appointment, you will get the results of tests carried out on the tissue removed during your surgery. You can also talk about any side effects or other problems you are having.

### Your test results

As well as removing the cancer, the surgeon removes some of the tissue around it. This is called a surgical margin. A doctor called a pathologist will check for signs of cancer near the edges of this tissue, and in the lymph nodes that were removed.

They will describe your surgical margins as either:

- **clear (negative or R0):** this means there are no cancer cells near the outer edges of this tissue
- **not clear (positive, involved or R1):** this means there are cancer cells near the outer edges of this tissue.

They will also tell you if cancer was found in any of the lymph nodes that were removed. Your doctor will explain what your results mean. Even if there was no cancer in your surgical margins or lymph nodes, your doctor should talk to you about having chemotherapy (see page 25).

You may get a letter with more information about your results. This may use another way to describe the cancer, called TNM (Tumour Nodes Metastases)

staging. Your TNM stage gives more detail about the size and location of the cancer, and about any lymph nodes that had cancer.

If you have any questions about your results or need help to understand them, speak to your medical team.

Read more about TNM staging at: **pancreaticcancer.org.uk/check-ups**

You can also contact our specialist nurses if you need someone to talk you through your results.

## Longer term check-ups (follow-up)

You will continue to have check-ups (known as follow-up) after your operation. You may have blood tests and a scan for these. They are also a chance for you to ask your medical team any questions you have.

The appointments may be with your surgical team, or with an oncologist if you have chemotherapy. After the first few appointments, your follow-up may be at your local hospital, rather than the specialist centre.

You may also have appointments for support with your digestion, taking PERT (see page 19) or other medicines. These appointments may be with other health professionals, such as a dietitian.

### How often will I have check-ups?

Each hospital will do things slightly differently. Ask your medical team if you haven't been told what to expect.

- **For the first two years,** you may have a check-up every six months.
- **After two years,** you may have a check-up every 12 months. These may be phone calls, rather than in person. This varies between hospitals.
- **After five years,** you probably won't have routine check-ups. You can speak to your GP if you feel unwell or have any concerns.

### What if I have a problem between check-ups?

If you have any problems between check-ups, ask your nurse for advice or an extra appointment. If you get any new symptoms, contact your medical team so they can find out 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.

If you have any concerns or need emotional support, contact our specialist nurses on our free Support Line.

### Questions to ask your doctor or nurse

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

Do I need to book these, or will the hospital or GP contact me?

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

Who should I call if I have any problems?

Who can I contact for emotional support?

# Chemotherapy after surgery

Most people will be offered chemotherapy after surgery. This is called adjuvant chemotherapy. It may help to reduce the chances of the cancer coming back. If your doctor doesn't mention chemotherapy, ask them about this.

Your chemotherapy should begin in the first 12 weeks after surgery. You need to have recovered from the surgery and be well enough for chemotherapy. If you have problems with digestion (see page 19) or any other issues, speak to your medical team. They can make sure this doesn't delay the chemotherapy.

Treatment usually lasts for six months, but this will depend on the type of chemotherapy you have and how it affects you.

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

# More information and support

## We are here for you

If you or someone you care about has pancreatic cancer, we are here to help.

Find out more at: **pancreaticcancer.org.uk/support**

### Our specialist nurse Support Line

Our specialist nurses are experts in pancreatic cancer. They can talk for as long as you need, as often as you like. Whether you have a long list of questions or don't know where to start, they will provide practical, honest information to help you make the right choice for you.

Call free on **0808 801 0707,** email **nurse@pancreaticcancer.org.uk** or send a WhatsApp message on **07418 304789**

### Information about pancreatic cancer

Our website, videos and publications can answer your questions. The information can help you understand what you have heard from your medical team, and make decisions about your treatment and care.

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

### Our online community, Circles

Circles is our supportive online community which connects you to others currently affected by pancreatic cancer. You can join groups on Facebook and WhatsApp. Share the highs and lows with people who understand and 'just get it'.

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

### Webinars

Our regular webinars cover topics including diet, wellbeing and treatment. They are hosted by our friendly nurses and other experts, are informal, and you can ask questions. You can look back at previous sessions, or sign up to one.

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

# Useful organisations

### Cancer Focus Northern Ireland
**cancerfocusni.org**
**Nurse line: 0800 783 3339** (Mon, Weds, Fri, 9am-1pm)
Care and support for people affected by cancer and their families in Northern Ireland.

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

### GOV.UK
**gov.uk**
**DVLA Medical Enquiries Tel: 0300 790 6806**
Information about government services, including the **Driver and Vehicle Licensing Agency** (DVLA), and the card to carry if your spleen is removed.

### Macmillan Cancer Support
**macmillan.org.uk**
**Support Line: 0808 808 0000** (7 days a week, 8am-8pm)
Provide practical, medical, emotional and financial support for anyone affected by cancer.

### Maggie's
**maggies.org**
**Tel: 0300 123 1801**
Centres around the UK and online offer free, comprehensive support for anyone affected by cancer.

### nidirect
**nidirect.gov.uk**
**Driver and Vehicle Agency Tel: 0300 200 7861** (Mon-Fri, 9am-5pm)
Information about local services in Northern Ireland, including the **Driver and Vehicle Agency** (DVA).

### Tenovus Cancer Care
**tenovuscancercare.org.uk**
**Tel: 0808 808 1010**
Advice and support for people affected by cancer in Wales.

## 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.

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


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

Jeremy French, Consultant HPB, Sarcoma and Transplant Surgeon, The Newcastle upon Tyne Hospitals NHS Foundation Trust

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Pancreatic Cancer UK Specialist Nurses


## 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 below.


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