Pancreatic CANCER UK

Surgery to remove pancreatic cancer

This fact sheet is for people with pancreatic cancer who have been offered surgery (an operation) 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 also speak to our specialist nurses on our confidential Support Line. Call free on **0808 801 0707**
or email **nurse@pancreaticcancer.org.uk**

Contents

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 doctor, 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.
- 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. The Whipple's operation is the most common type.
- If the cancer is close to major blood vessels, you may be offered chemotherapy, and sometimes radiotherapy, before surgery (see page 4). This may shrink the cancer so that surgery is then possible.
- Both the cancer itself and removing part of the pancreas may cause problems with digesting food, fatigue (extreme tiredness) and diabetes. Your medical team can help manage these problems.
- You may be offered chemotherapy after surgery, as long as you are well enough (see page 24). This is to reduce the chances of the cancer coming back.
- It usually takes at least a few months to recover after surgery, and sometimes longer. This is different for everyone.
- You and your family can get support from our specialist nurses. Call our free Support Line on **0808 801 0707** or email **nurse@pancreaticcancer.org.uk**

Who can have surgery?

Surgery is the best treatment for people with pancreatic cancer that has not spread outside 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 is often diagnosed when it has spread and can no longer be removed. Surgery may only be an option if there is no sign the cancer has spread.

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.

Read more about scans on our website at:
pancreaticcancer.org.uk/tests

You also 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, and can help you recover more quickly after surgery. Read more about preparing for surgery on page 13.

When is surgery not an option?

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 lymph nodes further from the pancreas. 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.

Your doctor will explain whether surgery is an option. If it isn't, they may offer you chemotherapy. This uses drugs to kill cancer cells. It may slow the growth of the cancer and help with symptoms. There are also other treatments available to help manage symptoms.

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

Read about ways to manage symptoms at:
pancreaticcancer.org.uk/managingsymptoms

If the cancer is close to major blood vessels

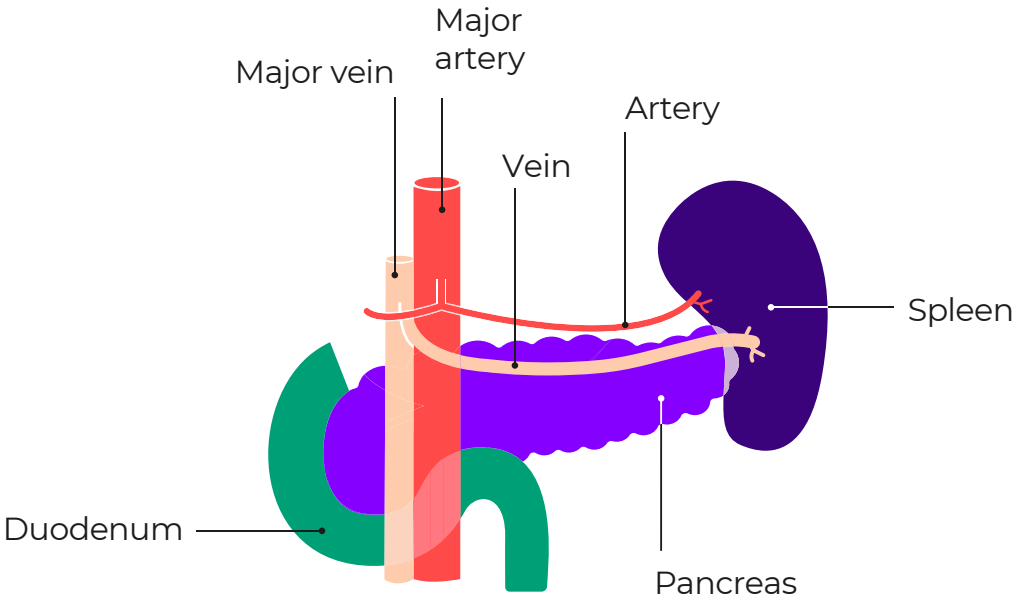
Sometimes the cancer may grow very close to large blood vessels near the pancreas. It may be possible to have surgery to remove the cancer. But this will depend on which blood vessels are affected and how far the cancer has grown.

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.

You may be offered chemotherapy, sometimes with radiotherapy (chemoradiotherapy). If the cancer is just **touching** an artery or vein, chemotherapy may shrink the cancer so that surgery is then possible. The operation will usually happen around 6–8 weeks after you finish chemotherapy, although this can vary. The surgeon might also need to remove part of the affected vein (see page 11).

But if the cancer has grown **around** the artery or vein, surgery is less likely to be possible, even after chemotherapy.

This diagram shows the major blood vessels near the pancreas



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 your symptoms and help you live longer.

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

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 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 speak to our specialist nurses on our free Support Line if you have any questions about getting a second opinion.

If it's not possible to remove the cancer during surgery

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 abdomen (tummy area)
- 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. Sometimes the cancer blocks the duodenum (first part of the small intestine) or bile duct (tube that carries bile from the liver to the duodenum). This can cause symptoms. Bypass surgery gets around the blockage, or stops future blockages. This 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.

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

Bypass surgery is still a major operation. Recovery can take at least two to three months. The information about what happens after surgery (page 15), side effects (page 16) and going home after your operation (page 20) may be helpful.

Read more about bypass surgery, including diagrams of what it involves, 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 chemotherapy or radiotherapy before my surgery?

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

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**

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.

Watch our video about surgery, which explains the different operations, at: **pancreaticcancer.org.uk/surgery**

Whipple's operation (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 8).

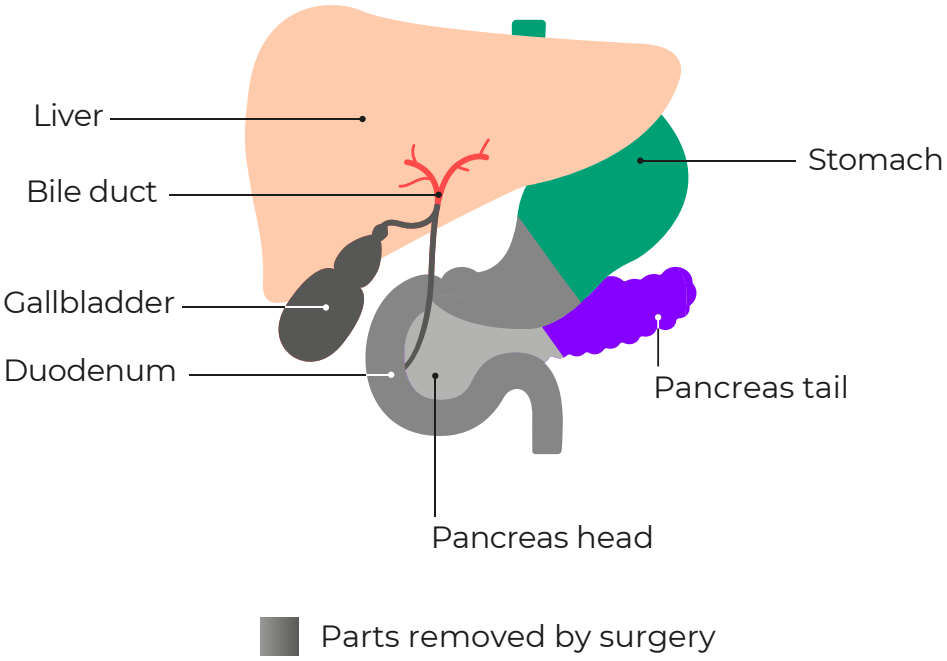
The surgeon will remove:

- 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).

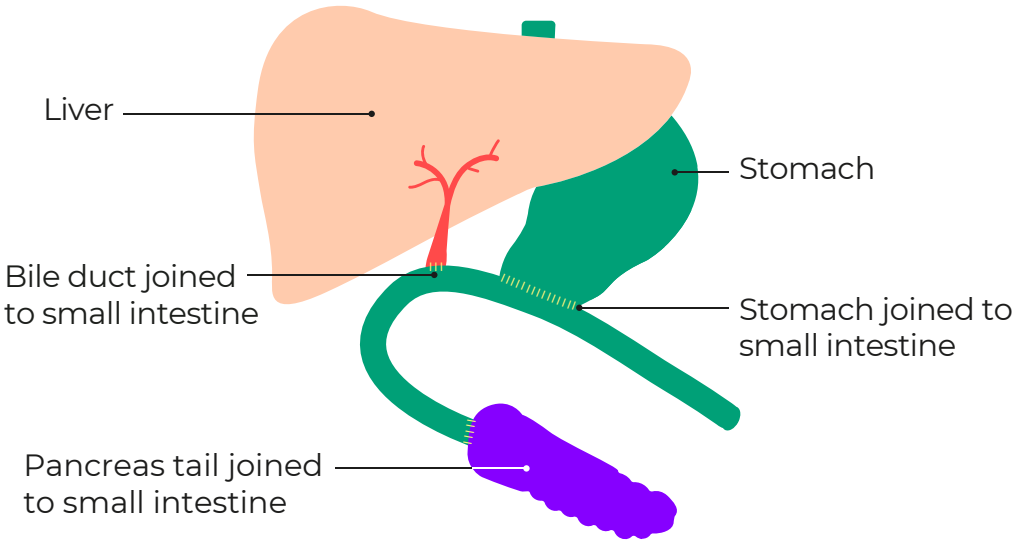
The surgeon will then join the remaining part of the stomach and bile duct to the small intestine. The pancreas is joined to the small intestine or to the stomach.

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).

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



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



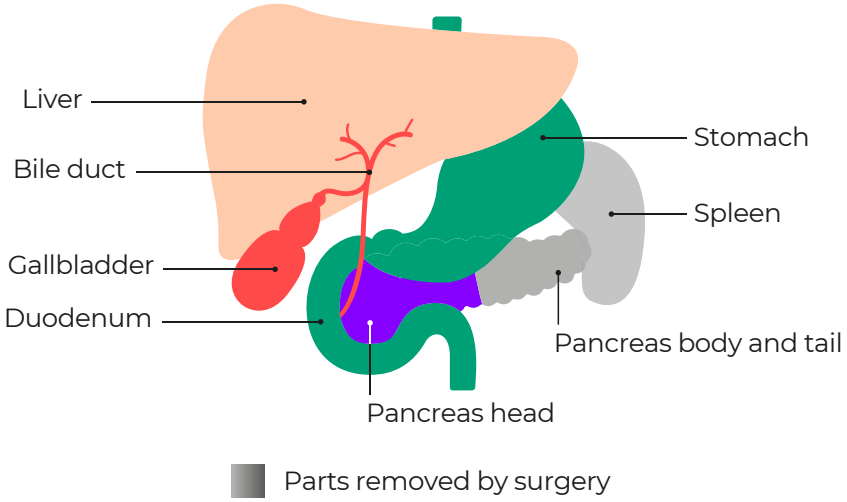
Side effects of a Whipple's operation

As part of your pancreas is removed, this may affect your digestion. You may need to take capsules when you eat that contain enzymes to help you digest your food. This is called pancreatic enzyme replacement therapy (PERT). Read more on page 18. You might also get diabetes – this can happen at any time after your operation. Read more about side effects of surgery on page 16.

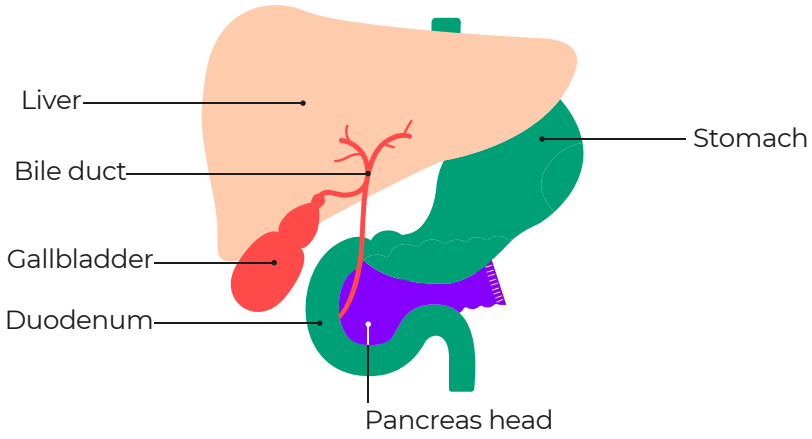
Distal pancreatectomy

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



This diagram shows the pancreas and nearby organs after a distal pancreatectomy



Side effects of a distal pancreatectomy

You are more likely to get diabetes after a distal pancreatectomy. You may need medicine for this (see page 18). Your digestion may also be affected and you may need to take pancreatic enzyme replacement therapy (see page 18). This is less likely than after a Whipple's operation.

The spleen helps your body fight infections, so you are more likely to get infections if it is removed. You will need vaccinations to help protect against these. 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. Go to GOV.UK to get one.

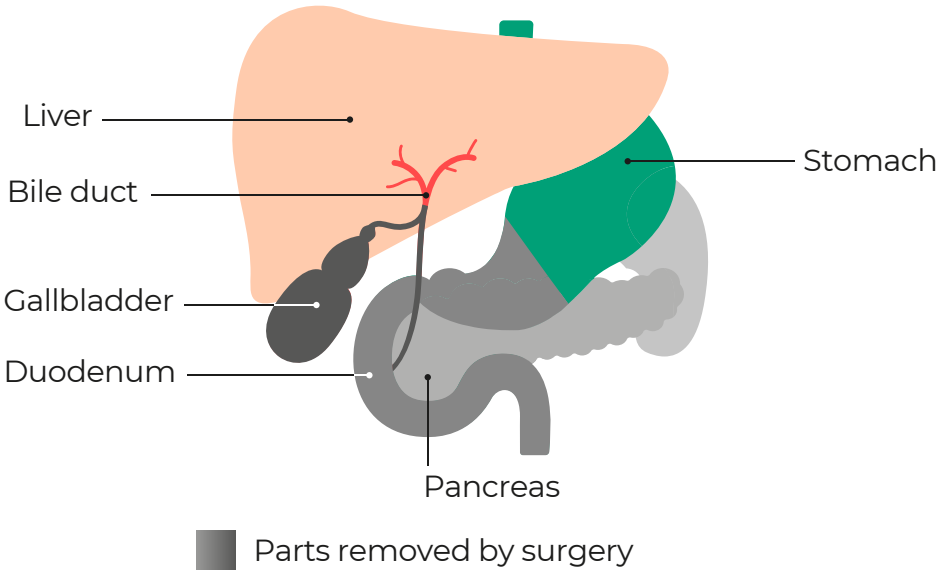
Total pancreatectomy

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

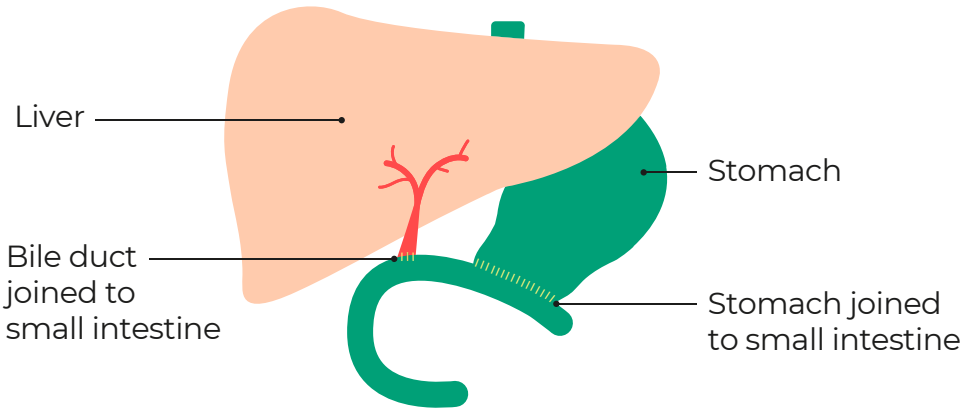
- the whole pancreas
- the duodenum
- the gallbladder and part of the bile duct
- the spleen.

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 capsules to help you digest food. Read more about this on page 18.
- You will also get diabetes and will need insulin to manage this (see page 18).
- As the spleen is removed, you are more likely to get infections (see page 9).

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 type of surgery. If your surgeon is not sure if vein resection is possible, you could ask for a second opinion from another surgeon who is experienced in these. Read more about getting a second opinion on page 5.

The operation 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 PERT or other medicines afterwards?

How is surgery carried out?

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

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-assisted surgery is a type of keyhole surgery where the surgeon uses a computer to control the instruments.

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 that the operation is more complicated than they expected. If this happens, they will switch to open surgery.

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.
- Some symptoms, such as jaundice (yellow skin and eyes), pain and problems digesting food, may improve after surgery.
- Other treatments may be an option if the cancer comes back after surgery, including chemotherapy. These will aim to slow the growth of the cancer and improve symptoms.

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. For some people it could take longer.
- You may get side effects from surgery, such as problems digesting your food and diabetes (see page 18). But the cancer may cause these symptoms even if you don't have surgery.

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 17.
- 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 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 will have a physical examination, blood tests, x-rays, and tests to check how well your heart and lungs are working.

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 your recovery.

Pancreatic cancer may affect how well you digest food. If you have lost weight, you may need to put weight back on before your operation. Ask your medical team about taking pancreatic enzyme replacement therapy to help with this (see page 18). 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.

Try to be as active as possible. 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

It's a good idea to think about what help you might need when you go home from the hospital. For example, you may need family or friends to help out with things like shopping. You could also freeze some meals before your operation, so that you don't need to cook at first.

Most people manage well at home. If you don't have anyone to help out, speak to your GP before your surgery about what support is available. Your nurse should also be able to ask social services to look at what help you will need. Read more about going home from hospital on page 20.

Going into hospital

You will go into hospital either the day before or on 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 for diabetes.

An operation to remove pancreatic cancer could take four to ten hours, depending on how complicated it is.

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 one to two weeks in hospital, or longer if needed.

Some hospitals have enhanced recovery programmes which aim to get you eating, drinking and moving about as soon as possible after surgery. 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.

Your stomach may not empty normally for the first few days after the operation. If you have problems eating, you may need to be fed through a tube until your stomach works normally again. The tube may go up your nose or through a small hole in your tummy. Not all hospitals use feeding tubes.

If you have 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 17.

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 that 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 enzyme capsules to help them digest food (see page 18). A dietitian or your nurse can help with this.

Read about seeing a dietitian at: **pancreaticcancer.org.uk/dietitian**

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 pancreatic enzyme replacement therapy for this (see page 18).

Your wound

Your wound will be closed with stitches or surgical staples. 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.

You may have a thin tube called a drain in your wound. This is put in during the operation to drain fluid. It is usually removed after a few days.

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. These will affect everyone differently, and you may not get all of them. 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. For the first few days, you may have painkillers through:

- a drip in your spine (epidural)
- small tubes on each side of your wound
- a drip in your arm, which you control by pressing a button – this is called patient controlled analgesia (PCA).

As your pain gets better, you will have painkillers as tablets instead. Take these regularly, as advised by your doctor or nurse. The pain should improve over time. Tell your doctor or nurse if it doesn't.

If your pain suddenly gets worse after you leave hospital, and painkillers do not 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)

Some medicines, including 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 to work properly again. 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.

Pancreatic leak

The place where the surgeon joins the pancreas (or, less commonly, the bile duct or stomach) to the small intestine can sometimes leak. If you had a drain put into your wound during your surgery (see page 16), this can be used to check that the leak is improving. Or you may have a new drain put in.

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, less commonly, another operation.

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, 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. 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 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 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 going 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. Other information on the internet may not be right for you because of your pancreatic cancer.**

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

Discomfort and pain

You may still have pain and discomfort a few months after your operation. Your scar might still feel numb. You may feel 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 and 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 your pain is really bad or you have a high temperature.

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 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?

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 given the details of someone to contact if you have any problems. This is usually a specialist nurse. You can also speak to your GP, for example about 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 get tired and will need to take things easy. You may need help from family or friends with things like shopping and cleaning.

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.

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

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 slowly fade. Macmillan Cancer Support have information about body image and cancer.

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 and your 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.

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 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 or take more breaks than normal.

Read more about work at: **pancreaticcancer.org.uk/money**

"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."

"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."

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 to go, and when you can fly. You may need to buy specialist travel insurance. Macmillan Cancer Support has information about this.

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

Check-ups

Check-up after your operation

A doctor called a pathologist will look at the tissue that was removed during your surgery. You will have an appointment with your surgeon a few weeks after going home, to get the results of these tests. 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. The pathologist checks for any signs of cancer near the edges of this tissue and in the lymph nodes that were removed. The aim is to make sure all the cancer has been 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 tell you if cancer was found in lymph nodes that were removed.

Your doctor will explain what your results mean for you. Even if there was no cancer in your surgical margins or lymph nodes, your doctor may talk to you about having chemotherapy (see page 24).

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 inside.

Read about TNM staging after surgery at:
pancreaticcancer.org.uk/check-ups

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

You can also speak to our specialist nurses on our free Support Line 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.

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.

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.

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

Check-ups are a chance for you to ask questions. 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, speak to 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

You may have chemotherapy after you have recovered from your surgery. This may help to reduce the chances of the cancer coming back. But if the cancer was small and hadn't spread to lymph nodes, you may not need chemotherapy.

You will need to have recovered from the surgery and be well enough for chemotherapy.

Your chemotherapy should begin in the first 12 weeks after your surgery. How long you have treatment for will depend on the type of chemotherapy you have and how it affects you.

If your doctor doesn't mention chemotherapy, ask them about this.

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

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

More information and support

Pancreatic Cancer UK support

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**

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**

Find out about all the support we offer at:
pancreaticcancer.org.uk/support

Useful organisations

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 and financial support for anyone affected by cancer.

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

nidirect
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.

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

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- Pancreatic Cancer UK Lay Information Reviewers
- 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 on the back cover.

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