



Royal Free London
NHS Foundation Trust

Information about pancreas surgery

Information for patients

Proposed admission date:

.....

Expected length of stay:

.....

You have been advised that you need to have an operation to remove a tumour from your pancreas. This may be for a pancreatic cancer or for a type of tumour that can turn into pancreatic cancer in the future.

For patients with pancreatic cancer, we know that completely removing the tumour is the only way in which we can cure it. One patient in five who have their cancer successfully removed will be cured and the cancer will not come back. However for the remaining four out of five patients, the cancer will come back within about two years.

Some pancreatic tumours may be very close to major blood vessels or may have grown into them. The surgeon may still be able to remove the tumour but it depends on which blood vessels are involved and to what extent.

Sometimes, the surgeon may begin an operation to remove the tumour but find that it isn't possible. This might be because the blood vessels are more involved than we thought or that it has spread to other areas. In this case, removing the tumour may cause you more harm than good, and the surgeon will either stop the operation or will do a different operation called a bypass. This is where they leave the tumour but bypass the stomach and the bile duct so that the cancer doesn't block it and cause you discomfort later on.

Pancreatic surgery

The operations used to treat pancreatic tumours are:

- **PPPD (pylorus preserving pancreaticoduodenectomy)**

This operation involves removing the head of the pancreas, the duodenum (first part of the small bowel), the gallbladder and part of the bile duct (highlighted in orange). Fig 1 shows what the surgery will remove and Fig 2 shows the reconnections.

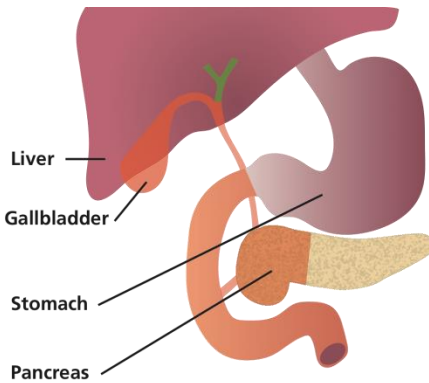


Fig 1

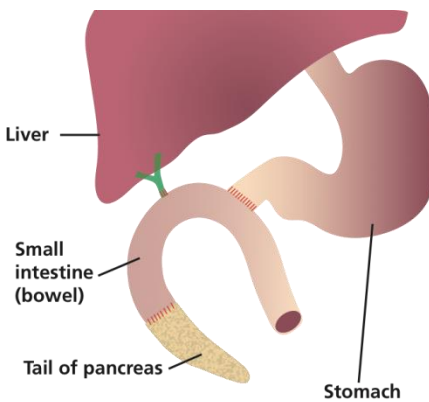


Fig 2

- **Whipples operation**

This is the same procedure as a PPPD, but with a small part of your stomach also being removed. Fig 3 shows what the surgery will remove and Fig 4 shows the reconnections.

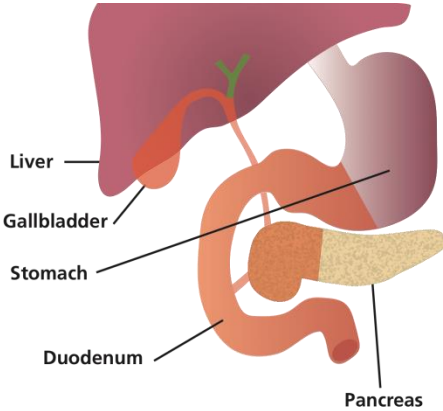


Fig 3

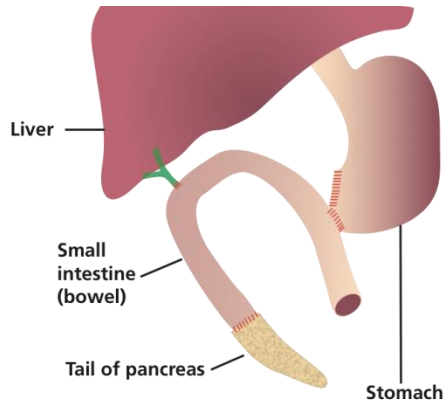


Fig 4

After a PPPD or the Whipples operation, it will take time to get back to eating normally and you may need to take enzymes to help with digestion. One in three patients may develop diabetes.

- **Distal pancreatectomy**

This operation removes only the tail of the pancreas, leaving the head. The spleen is usually also removed. With this operation, you are less likely to have problems with digestion but 7 out of 10 patients will develop diabetes. Losing your spleen will mean that you will be more prone to infections. As a result of this, you will need to have an influenza (flu) vaccination every year and take a penicillin tablet (a type of anti-biotic) every day for the rest of your life.

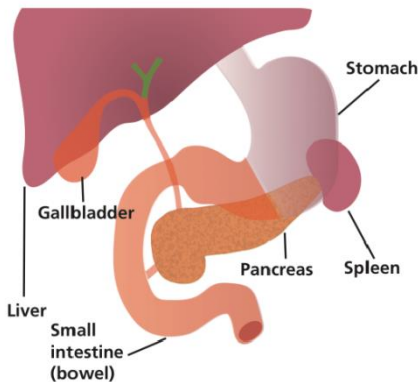


Fig 5: Before

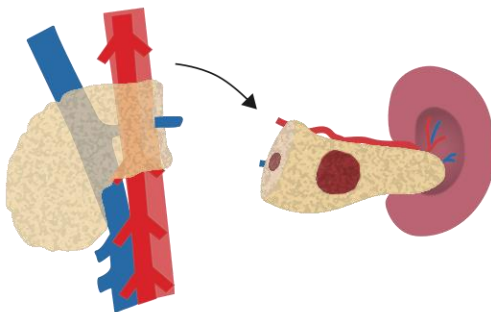


Fig 6: After

- **Total removal of the pancreas (total pancreatectomy)**

This operation removes the whole of the pancreas, the duodenum, part of the stomach, the gallbladder, part of the bile duct, the spleen and many of the surrounding lymph nodes. Fig 7 shows what the surgery will remove and Fig 8 shows the reconnections.

This is major surgery and is performed if there is a concern that the cancer cannot be removed completely with a smaller operation. It may also be performed if the surgeons think that the risk of a bile leak is too high. After this operation, you will have problems with digesting food and will need to take enzyme tablets to help with this. You will also become diabetic and will need regular insulin injections. This surgery involves removing your spleen, which will make you more prone to infections. You will therefore need to have an influenza (flu) vaccination every year and take antibiotics every day for the rest of your life.

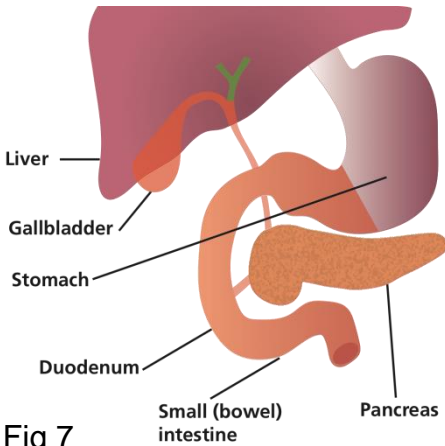


Fig 7

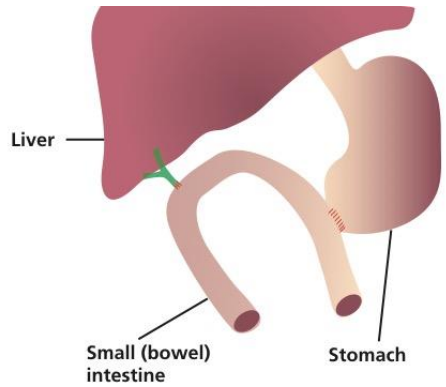


Fig 8

Before surgery

Following your initial appointment with the consultant, you will be able to speak to the hepatobiliary (HPB) clinical nurse specialist (CNS) who can answer any questions about your condition and proposed treatments and provide you with leaflets on all aspects of your care.

Scans and procedures:

These may be required to clarify your diagnosis and help decide on your best treatment options. We may need to repeat a scan you've already had or you may need some different ones and can include any of the following:

- CT, MRI or ultra sound scan
- nuclear medicine investigations, eg a PET scan
- endoscopic investigations, eg an ERCP (endoscopic retrograde cholangiopancreatography) and/or an EUS (endoscopic ultrasound)
- laparoscopy

Information is available on the scans and procedures so please ask a member of staff if you would like a leaflet or visit our website:

www.royalfree.nhs.uk/services/services-a-z/radiology/radiology-services

Please do ask your healthcare team as many questions as you need to, as it is very important that you fully understand all aspects of your operation.

Once you have had your results, discussed your treatment options with the consultant and agreed on the operation, you will be asked to sign a consent form.

Giving your consent (permission)

We want to involve you in decisions about your care and treatment. Before carrying out any procedure, staff will explain the procedure to you, along with the associated risks, benefits and alternatives. If you have any questions about your care, or any concerns, please do not hesitate to ask for more information.

If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

Pre-admission appointment

Whenever possible we will give you an estimated admission date for your surgery and length of stay in hospital.

We need to assess your medical fitness before you can have pancreatic surgery.

The nurse will complete a general health check. Blood will be taken for cross matching should you need a transfusion during the operation, and to also check your liver and kidney function, your blood count and clotting factors.

If further investigations are needed, for example on your heart or your lungs, you may have to come back at a later date. Your CNS will discuss this with you.

Admission

Patients are usually asked to come in to the surgical admissions area (SAA) on the day of surgery. If you live a long way from the hospital you will be offered overnight accommodation in a local hotel. If your condition requires it, you may be admitted to the hospital the day before your surgery.

Possible cancellation of surgery

Though we do everything we can to ensure that your surgery goes ahead as planned, because we are a leading centre for transplants, occasionally operations have to be rescheduled at short notice if a transplant organ becomes available. We do appreciate how disappointing this can be so it may be worthwhile preparing yourself beforehand for this possibility.

Day of surgery

You will be asked to have nothing to eat from midnight before your operation, but you can drink water up to 6am.

During your surgery your surgeons will take samples from the tissues they remove and send them to the laboratory for close examination. The results should be available for when you return for your follow-up appointment.

Throughout the operation you will be looked after by the specialist team of surgeons, anaesthetists and theatre nurses and you will be closely monitored until you are fully awake.

After your surgery, you will be taken to the intensive treatment unit (ITU) for close monitoring for the first 12 to 24 hours. Some patients may need to stay longer and some stabilise more quickly. Once you are able to, you will move to a specialist ward.

Your family and friends can call your CNS for information about your progress. Their contact details are at the back of this leaflet.

Possible risks and complications

All major surgery carries risks, but as these operations are undertaken to try to cure your cancer you may decide that the risks are worth taking. You can discuss all the possible complications and risks with your consultant and specialist nurse. Please ask all the questions you need to.

Complications can occur both during the operation and afterwards as you recover. In the main, these can be dealt with by your consultant and the specialist team.

Please be aware that you are unlikely to develop all of these conditions and may develop none of them:

- **Bile leak** – if part of the internal stitching to the digestive system has come apart or broken down, some of the digestive juices are able to get into your abdomen. Around 1 in 10 patients will develop a bile leak and it will be treated by inserting a drain until it dries up. Antibiotics will be given to prevent infection.
- **Pancreatic leak** – around 1 in 10 patients will develop a leak of pancreatic fluid. This is usually minor but it may extend your hospital stay and some patients may go home with a drain for a few weeks. This will be removed in an out-patient clinic.
- **Infection and abscesses** – infections can develop because there is blood or tissue fluid collecting internally around the operation site. You will be given antibiotics through a drip to treat this. If an abscess develops, this will be drained.
- **Bleeding** – some bleeding during the operation is normal but 2% to 5% (between two to five in every hundred patients) of patients will have bleeding after the operation which can be

very serious. Sometimes a blood transfusion will be given, but in more serious cases specialist x-ray doctors can block the blood vessel to control the bleeding. Very occasionally we have to take patients back to theatre to perform another operation to stop the bleeding.

- **Chest infection** – this is a common complication and can occur if you are not moving around enough or breathing deeply enough after surgery. The physiotherapists will show you breathing exercises and encourage you to be mobile as soon as possible in order to minimise the risk of chest infections.
- **Heart problems** – you will have had heart tests before the operation but this is major surgery and places an increased strain on your heart. Sometimes heart problems can develop after surgery.
- **Delayed gastric emptying** – after pancreatic surgery, the stomach might be slow to empty. This might make you feel bloated or nauseous after eating or drinking and can cause vomiting. This generally settles after a few days but some patients need to stop eating and drinking for a period of time until it settles. If this happens, you will be given nutrition either through a drip in your neck or a tube down your nose.
- **Wound infection** – you will have a fairly large wound over your upper abdomen. 30 to 50% of patients will get an infection in this wound. This is usually a minor infection and can be treated with antibiotics. The wound can usually be dressed by the practice nurse at your GP surgery or by district nurses in your home.

Is there a chance of dying from this operation?

Yes there is a risk of death. There are risks associated with all

operations, even with surgery that is considered to be minor and the risk of dying from having pancreatic surgery is about 2% to 3%.

Because pancreatic surgery is generally performed after a diagnosis of cancer, the risks to you of not having the surgery are balanced against the risks of having the surgery in making the final decision.

You will be able to discuss your own specific risks with the team before you make your decision. This is very individual and is based on several factors including how well you are in general. Please do not hesitate to ask your healthcare team any questions you may have.

After surgery – the first few days

Following your operation you will have several tubes in place:

- **Oxygen** – after a long operation you will require extra oxygen and this is given via a face mask or small tubes into your nostrils.
- **Pain control** – it is essential that you are as comfortable as possible following your operation so that you can breathe properly and move about as freely as possible. You will usually be given an anaesthetic injection into your spine just before your operation. When you wake up you will have a button which you can press whenever you need pain relief.
- **Catheter** – we need to monitor your urine output as this is a sign that your kidneys are working. You will have a catheter inserted during the operation and this will generally be removed when you are able to walk to the toilet.
- **Drains** – a tube will be inserted into your abdomen after the operation so that any excess fluid can drain away. The fluid is tested to see if there has been any leakage of pancreatic fluid and can usually be removed after five days.

There are several routine checks that will take place every few hours, which will reduce in frequency as you progress from day to day:

- **Blood pressure, pulse and temperature** – these will be monitored throughout the day and night initially to check for any signs of surgical complications.
- **Blood tests and blood sugar levels** – blood samples will be taken to monitor the progress of your liver after the operation and as one of the liver functions is to help control blood sugar levels, monitoring this also helps to check your progress.

A physiotherapist will see you very soon after your operation. They will give you breathing exercises to keep your lungs clear and reduce the risk of chest infections. They will help you to get out of

bed for the first time and walk a few steps. This will help you to reduce the risk of blood clots in your legs and improve your rate of recovery.

Going home

Your healthcare team on the ward will support you to get back home as soon as you are medically fit to do so.

We aim to let you know the day before you are able to go home so you can make suitable arrangements to be collected from hospital the next day and to allow us to prepare your discharge letter and any medicines or equipment you need to take home with you.

Patients are usually well enough to go home 7 to 14 days after their operation.

We encourage all patients to discuss arrangements for their return home with their family and local GP before their operation, as you will not automatically receive help from nurses or carers at home unless there is a specific problem. If you are worried about coping at home, please contact your CNS or talk to the nurses on the ward.

Before leaving the ward you will be given any medication you need.

Please let your friends and family know that you will be ready to leave the ward around 10am on the morning of discharge and that they should make arrangements to collect you at this time. We have a discharge lounge on the ground floor should you need to wait for your transport or last minute medications.

Your wound clips will be removed approximately 10 days after surgery by the practice nurse at your GP surgery. This will be organised by the ward nurses. They will also organise a nurse to change your dressings if needed.

We know that there is an increased risk of blood clots after major abdominal surgery; therefore we start patients on daily injections

of a blood thinning drug called 'tinzaparin' for 28 days following surgery.

Patients will be given the option to inject themselves, have a partner/carer trained to inject them or have a local nurse inject them.

While on tinzaparin, patients will need to monitor themselves for any side-effects such as increased bruising or bleeding. Patients will need to have a blood test with their GP between 5 to 14 days after starting the injections. This is to monitor you for low platelets levels which can occur in some patients (1%) and increase the risk of bleeding.

If you have any questions about this, please ask the ward pharmacist during your in-patient stay or speak to your CNS.

Once you are at home you can really begin the process of getting back to normal.

You will feel tired and weak for several weeks after surgery. You will gradually start to feel more normal but be aware that this can take quite a long time and is different for everyone. It can take a minimum of three months before you start to feel normal again. If you are concerned, please talk to your CNS.

There are no dietary restrictions after pancreatic surgery. You should be able to eat whatever you want to, however you might find that you are unable to eat as much as you used to. This could be because you do not have an appetite or because you feel full quickly. This is normal and we advise patients to eat little and often until their digestive system is more settled. This can take several months to settle completely but please speak to your CNS if you are having problems. They will be able to discuss your diet in more detail and will be able to answer questions about

enzyme supplements (Creon®). If you have ongoing problems, we will refer you to a specialist dietician.

You should try to keep as active as possible when you go home. We encourage you to take mild exercise such as walking, but please remember that you will tire easily so you may also need regular rests. You should not drive or do any heavy lifting for about six weeks.

If you have any concerns at all about your recovery or you feel unwell, please contact your CNS. Some things to look out for are:

- raised temperature
- red, hot or painful wound
- nausea or vomiting
- diarrhoea
- sudden leg swelling and/or pain
- new onset of shortness of breath
- jaundice (yellowing of the eyes and/or skin)

If you have any of these problems, it is not necessarily anything to worry about, but it is better to check with your CNS in case you have developed a new complication.

Further treatment

At your first follow-up appointment, you will either see a doctor or your CNS. They will give you the results of the tissue sample that was sent off during your operation. They will discuss this with you and let you know if you require any further treatment.

If you have had your operation to remove cancer:

- You will need to be closely monitored for 5-10 years after your surgery. Please ask your doctor or nurse what your follow-ups will involve.
- You may need further treatment and an appointment will be made for you with the oncology team to discuss your options.

Where can I get support from if I have cancer?

Your CNS will speak to you regarding having a Holistic Needs Assessment (HNA) to identify concerns that they can help you with.

Support is also available to you and your family through the Macmillan services and the CNS team at the Royal Free Hospital or from your local hospital. We also have a Maggie's Centre at the Royal Free Hospital where you can access further support and information.

- Website: www.maggies.org

The Macmillan cancer information and support centre at the Royal Free Hospital is located on the ground floor of the hospital, within the oncology out-patients department.

- Phone: 020 7794 0500 extension 31337
- E-mail: rf.cancerinfo@nhs.net
- Website: www.macmillan.org.uk

For further details of support services available, pick up a copy of our leaflet, 'What support is available to you at the Royal Free Hospital on a diagnosis of cancer?' Alternatively you can read it online here: www.royalfree.nhs.uk/services/services-a-z/cancer-services/#tab-patient-leaflets

How your HPB CNS can help you

Support is given on an individual basis and can include any or all of the following:

- Support for you and your family at all stages of your illness
- Provision of written and verbal information about your condition, your investigations and your planned treatment
- Teaching you and your family about your care and treatment
- Assisting in the co-ordination of your care by liaising on your behalf with other members of the team to ensure that everything goes as smoothly as possible
- We can be your first point of contact at the hospital
- We are easily contactable which ensures that the hospital is easily accessible to you

Please contact your CNS if you or your family needs support. Their working hours are Monday to Friday, 9am to 5pm. If you have an urgent problem outside of these hours, please call 111 or contact 9 West ward for advice.

Where can I get help to stop smoking?

If you smoke, now would be a very good time to consider stopping. Help is available from NHS SmokeFree:

- Phone: 0800 1690 169 or 0300 123 1044
- Website: www.nhs.uk/smokefree

Contacts

Address: Royal Free Hospital
Pond Street
London, NW3 2QG

Main switchboard: 020 7794 0500 – please ask for the required extension or bleep number.

Your consultant is:

Your HPB clinical nurse specialist (CNS) and key worker is:

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Phone number:

Bleep:

E-mail address:

More information

For more information about the HPB service at the Royal Free London, please visit our website: www.royalfree.nhs.uk

Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf.communications@nhs.net

Alternative formats

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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