

Renal and transplant service

Your pancreas transplant

Information for patients, families and carers

Introduction

What is pancreas transplantation?

A pancreas transplant is a major surgical procedure to place a healthy pancreas from a deceased donor into a person whose pancreas no longer functions properly.

Your pancreas is an organ that lies behind the lower part of your stomach (fig 1). One of its main functions is to make insulin, a hormone that regulates the absorption of sugar (glucose) into your cells.

If your pancreas doesn't make enough insulin or your body is unable to make use of the appropriate amount of insulin made by your pancreas, blood sugar levels can rise to unhealthy levels, resulting in diabetes.

What does a pancreas transplant do?

A functioning pancreas transplant responds to your blood glucose levels by producing an appropriate level of insulin to maintain blood glucose levels within normal range. This means you no longer need to inject yourself with insulin on a day-to-day basis. However, the main advantage to you is an increased life expectancy and longer kidney transplant function.



Fig 1: Anatomical position of the pancreas.

How the diabetes can be divided?

Diabetes can be broadly divided in two types:

Туре 1	Туре 2
Your own pancreas does not make enough	Your body is unable to make use of the
insulin, leading to high blood sugars. This	appropriate amount of insulin made by your
condition is less common and typically seen	pancreas. This condition is increasing
in children and young adults.	rapidly across world, it is associated with
	obesity and is typically seen in adults.

Who can have a pancreas transplant?

Pancreas transplantation is usually reserved for treatment of type 1 diabetes, as the transplanted pancreas resolves the issue of insulin deficit. In selected cases, pancreas transplants may also be offered to treat type 2 diabetes.

A pancreas transplant can restore normal insulin production and improve blood sugar control in people with diabetes, but it is not the standard treatment for all patients with diabetes. This procedure is for selected people with diabetes who are considered to have developed or be at risk of developing complications due to the diabetes.

The decision to have a pancreas transplant is taken after a thorough discussion of the perceived (identified) risk and benefits of the procedure, and will be discussed in detail by the members of the transplant team.

For people with any of the following, a pancreas transplant may be worth considering:

	Type 2 diabetes
 consistently poor blood sugar control despite optimised insulin treatment frequent low blood sugars severe kidney damage due to disk store 	glucose control despite insulin mass index <30

What are the benefits of having a pancreas transplant?

Diabetes affects the blood vessels of your body and causes progressive damage to vital organs such as kidneys, heart, brain, eyes and nerves. This results in various damages which you may already have been advised about, or have treatment for (kidney disease, heart attack, retinopathy needing laser or surgery to the eyes, poor sensation in your feet). Sometimes having low blood sugars (hypoglycemia) without any warning may put you at risk of having major life threatening event if you are unable to obtain immediate medical assistance.

Having a successful pancreas transplant will reduce the on-going damage caused by the high levels of blood sugar and over a period of years will help improve some of the reversible effects of diabetes.

As a result, if you have a successful pancreas transplant you are likely to live longer and have less chances of further heart related problems or strokes that may affect your lifespan. Also, performed as a combination with a kidney transplant, you are likely to have the kidney transplant work much longer if performed with a pancreas in people with diabetes.

On a day to day basis, a successful pancreas transplant will offer you the opportunity to be completely free of insulin treatment and have normal glucose control with a healthy mixed diet.

What types of pancreas do we perform?

We perform three different types of pancreas transplant:

• Simultaneous pancreas kidney transplant (SPK)

If your kidneys have been damaged by diabetes and you are on dialysis or close to needing dialysis, you will receive a pancreas and a kidney during the same operation. More than two-thirds of pancreas transplants worldwide are done simultaneously with a kidney transplant (SPK).

• Pancreas-after kidney transplant (PAK)

If you already have a functioning kidney transplant, and considered to benefit from a pancreas transplant, you will receive the pancreas transplant as a separate operation (PAK).

 Pancreas transplant alone (PTA). If you suffer from frequent hypoglycaemic events, life-threating complication due to your inability to respond to low blood sugars (hypoglycaemia), you will receive a pancreas transplant alone (PTA)

Where do donor pancreases come from?

Although it is possible for a living donor to donate part of a pancreas, all pancreas transplants in the United Kingdom are obtained from deceased donors.

How long will I have to wait for a transplant?

Once you are assessed as being suitable for a pancreas transplant, you will join the national waiting list.

The waiting time is not possible to predict and mostly depends on the type of transplant you are expecting; it may be several months, or possibly years, before a suitable donor pancreas becomes available. In the UK, half of the people waiting for a pancreas transplant will have had one by around 13 months.

(The waiting time for a transplant depends on your blood group and how long it takes for a suitable donor meaning someone whose blood and tissue types match yours to become available).

What happens while I am on the waiting list?

It is important to stay as healthy as possible to increase your chances of a successful transplant:

- take your medications as prescribed
- follow your diet and exercise guidelines
- keep all appointments with your health care team
- stay involved in healthy activities, including those that benefit your emotional health, such as relaxing and spending time with family and friends.

Make sure the transplant team knows how to reach you at all times.

Once a donor pancreas becomes available, it must be transplanted as soon as possible, ideally within 12 hours. You should keep a packed hospital bag handy and make arrangements for transportation to the transplant centre in advance.

You will usually be able to stay at home until the transplant team notifies you that a suitable pancreas is available.

Living with severe diabetes can be strenuous enough – the added anxiety of waiting for a pancreas to become available can make the situation even more difficult. Contact your GP or the transplant centre for advice if you are struggling to cope emotionally with the demands of waiting for a transplant. You may also find it useful to contact a support group, such as Diabetes UK or Diabetes.co.uk, or a local kidney patients association if you are also waiting for a kidney transplant.

What happens when I am called in?

When an organ will be available for you, a Renal Registrar will call you; you will be asked about your general health and, if you are on dialysis, what mode of dialysis you are on and when you last had dialysis.

You will be asked to come to the DeWardener ward at the Hammersmith Hospital and you will be advised about eating and drinking in preparation for the operation.

Time is extremely important in transplantation in order to maintain the vitality of the organs - it is vital that you remain contactable at all times which is most often in the

night. When you receive the call you must arrive as soon as possible and by your own means of transport if possible.

If you cannot be contacted in a limited time, the organs may be offered to another patient. Unfortunately, it is also possible that even once you have been called in, the transplant operation may not go ahead for a variety of reasons, usually for issues related to the donor or the pancreas itself. The transplant team will keep you constantly informed.

What is the surgery like?

This operation is performed under general anaesthesia, so you are unconscious during the procedure. The anaesthetist gives you an anaesthetic medication as a gas to breathe through a mask and injects a liquid medication into a vein.

After you are unconscious:

You will have one vertical incision or two incisions (cuts), depending on the consultant surgeon on call, made in the lower part of your abdomen (stomach). The surgeon places the new pancreas along with a small portion of the donor's intestine, usually on the right side of your lower abdomen. The pancreas' blood vessels are connected to the blood vessels that supply blood to your legs and the donor intestine is attached to your small intestine. Your own pancreas is left in place to aid digestion.



If you are also receiving a kidney transplant, the blood vessels of the new kidney will be attached to blood vessels in the lower part of your abdomen, on the opposite site, usually the left.

The kidney's ureter — the tube that links the kidney to the bladder — will be connected to your bladder. Unless your own kidneys are causing problems, such as high blood pressure or infection, they are left in place (fig 2).

Fig 2: Illustration of the position of the new pancreas and kidney lower part of your abdomen (pancreas usually on the right and kidney on the left).

Pancreas transplant surgery usually lasts about three to four hours. Simultaneous kidneypancreas transplant surgery takes a few more hours (six to eight hours).

What will happen after the operation?

After the surgery, which is carried out at Hammersmith Hospital in the main theatres – you will be moved in the recovery area where you will be monitored for two or three hours.

While you are in the recovery area you will have an ultrasound scan. This is a scan just like a pregnant mother has using an ultrasound scan machine. The scan is needed to assess the blood flow in and out of the new organ(s).

When the transplant and renal teams are happy that your condition is stable, you will be transferred to the De Wardener high dependency unit. Once you are fully conscious from the general anaesthesia, you will be aware that you are attached to several tubes, monitors and machines. This equipment was put into position while you were asleep.

They may include:

- **the PCA:** which is a machine that delivers painkillers through a tube into your body, and is controlled using a handheld device that you can control. It's full name is: patient controlled analgesia (PCA)
- an oxygen mask
- cannulas: tubes that provide nutrients (the goodness of food) and fluid into your veins
- **NG (nasal gastric) tube:** a plastic tube that goes through your nose into your stomach to keep your stomach empty
- **drains:** plastic tubes that are placed to remove blood and other fluid from the operation site;
- **catheter:** a tube in your bladder that allows you to urinate without going to the toilet (urinary catheter).
- **stent:** An internal tube between the bladder and your transplant kidney (in simultaneous pancreas kidney transplantation) called a 'stent' to protect the joining with your urinary bladder this will need to be removed by a short procedure a few weeks after the transplant.

The PCA, which is for pain control, will be removed gradually during the first 48 hours and you will have other intravenous (in the vein) or oral (by mouth) painkillers to help you with any pain you may have.

Your oxygen mask is required to help your breathing for 24 to 48 hours after your surgery.

The urinary catheter stays in place for about five days. This is so we can monitor your urine output and in case of a simultaneous (done at the same time) kidney transplant, the catheter helps to keep your bladder empty and to protect the joining between the ureter and the bladder (if you have a new transplanted kidney).

If you have only had a pancreas transplant either a pancreas-after kidney transplant (PAK) or a simultaneous pancreas kidney transplant (PTA), the catheter may be removed once you are well enough to go to the toilet.

The nasogastric tube helps to keep your stomach empty or 'decompressed', until normal bowel function returns, to protect the area where your new pancreas is attached to your small intestine.

The abdominal drains placed to remove any excess fluid from your abdomen, are usually removed after few days as your recovery progresses.

After few days, as your condition improves and the plastic tubes start to be removed, you will be moved to one of the renal wards. During your entire hospital stay, nurses, doctors and surgeons will closely monitor you.

Every day there will be two consultant-led ward rounds. Nursing staff will regularly measure your blood pressure, pulse and temperature, blood sugar levels (to monitor if your new pancreas is working) and urine output several times a day. You will have daily blood samples taken for analysis in the laboratory, to accurately check on the function of your new organ(s), as well as the drug levels of your anti-rejection medication.

You may receive some insulin in the early days after your operation.

During your hospital stay you will receive a further repeat ultrasound scans and/or CT scans of your new pancreas. These tests look specifically at the blood flow of your new pancreas (and kidney, if required) and will show up any narrowing or blockages of the blood vessels.

What to expect after your transplant

You may experience some pain and discomfort, but you will have a special infusion pump attached directly to a vein in the back of your hand or arm to give you pain relieving drugs as mentioned.

You can press a hand-held button when you feel pain or discomfort and the pump will deliver a pre-programmed dose of pain killing drugs directly into your vein, minimizing the risk of drug overdose.

It is fairly common to experience "bloating" (in your tummy) or abdominal distension in the first 48 - 72 hours after the operation. This is due to having a general anaesthetic and surgery. When your bowel starts to recover function, we will advise you to have tablet pain killers to help to get you mobile and pain free again.

You may get a cough. Having physiotherapy will help to clear your secretions effectively and to prevent chest infections.

If you have also had a kidney transplant, you may need to have temporary dialysis just until your new kidney starts to function.

How long I will be in hospital?

The average post-transplant hospital stay is about two weeks. This varies depending on how you are feeling and if additional tests or interventional procedures are necessary. Sometimes if special medications, such as antibiotics are needed to prevent infections, you may have to stay in hospital until the treatment course recommended has been completed.

Do I need follow up appointments?

Close monitoring with follow up appointments is very important. Your transplant team will develop a check-up schedule that is right for you. But be prepared for the first few weeks to come back to the clinic two or three times per week. If you live in another town you may need to make arrangements to stay close to the transplant centre.

If you have had a combined kidney and pancreas transplant then you will have had a stent (soft plastic tube) placed in the ureter (between the kidney and the bladder). This will need to be removed under local anaesthetic six to eight weeks after your transplant.

You will be asked to come to the Pam Sassoa Unit (PIU) at the Hammersmith Hospital to have the stent removed under local anaesthetic as a day case and you should be able to go home in the same day.

How long might I be off work?

This depends on your rate of recovery from the effects of transplant. In the first few weeks after your operation, you will need to attend up to three times a week follow up appointments.

Also, it is very normal not to have an appetite and feel very tired on a daily basis. This will improve as weeks follow after transplantation. Most patients can be off work for about three months, some longer. Please discuss your progress with the transplant team who will be very happy to advise you.

What are the complications of the operation?

Pancreas transplant surgery carries a risk of complications which can occur during and/or after the operation. They may be some of the following:

Bleeding

As with all operations, there is a risk of bleeding. This is more common in pancreas transplantation, as a number of medications and infusions are given after the operation to keep the blood thin and prevent thrombosis (clotting) of the pancreas graft. Approximately 10 per cent of patients (10 in 100) have some bleeding after transplantation that may require blood transfusions or a return to the operating room.

Thrombosis

There is a risk of a blood clot forming in the blood vessels of the transplant. This is called thrombosis and can occur in 10 per cent of patients (10 in 100). This is most likely during the first week after the transplant and may result in the organ being removed. You will be monitored very closely for signs of this while you are in hospital and when you return home. You will have regular blood samples taken to perform special clotting tests to measure how effectively your blood is clotting, in order to balance the risk of blood clot forming and the risk of bleeding.

Pancreatitis

Pancreatitis is an inflammation of the pancreas.

A certain degree of pancreatitis is almost inevitable and it is due to the damage to the pancreas during the process of removal from the donor, storage in ice during transportation and rewarming with your blood, (this is called ischemia reperfusion injury).

This settles spontaneously (by itself) in the majority of the transplants within a few days. If this graft pancreatitis is not getting better on its own, you may need to have further surgery to wash out any fluid collections, or you may have tubes placed into your abdomen, to drain these fluid collections. The vast majority of pancreatitis gets better on its own, but approximately five to 10 per cent of patients (five to 10 in 100), may need the transplanted pancreas to be removed.

Further operations

Approximately one out of every five people who have a pancreas transplant will need to go back to theatre for a further operation to deal with any of the above complications, if they occur.

Other complications

The general risks are similar to those following any type of major abdominal surgery, including wound infection, infection inside the abdomen, cardiac (heart) complications, deep vein thrombosis (blood clots in the legs) and pulmonary embolism (blood clots which move to the lungs).

Complications of immunosuppression

In the early days following a transplant, the surgery and the immunosuppression drugs make your body more vulnerable to chest, urinary and other types of infections. You will be given antibiotics and anti-viral drugs to help prevent and treat any active infection.

Rejection

Your body's natural immune response is to try and get rid of the new organ(s), by organising a planned response against the donor's cells. Immunosuppression medications help to control this response. However, despite the immunosuppression medications, rejection does occur in about one in four transplants. Rejection can affect the pancreas or the kidney, or both organs at the same time. It is important to identify signs or symptoms of rejection early so effective treatment can be given..This is usually done by giving additional immunosuppression medications.

To find out whether your body is rejecting the organ you may need a biopsy of the transplanted organ(s). This means a sample of the organ is collected using a long needle. This is done using local anaesthetic which numbs the area where the needle is inserted.

Do I need to take medications?

Yes you do. Drugs called immunosuppressions help to keep your immune system from attacking your new pancreas. Stopping or irregular intake of these medications will inevitably lead to transplant loss and serious problems for your health. More drugs may be given to help reduce the risk of other complications, such as infection and high blood pressure, after your transplant. Once you are comfortable after the operation you will begin to learn about your new medications.

These will be listed on a medication record card and the pharmacist will see you to go through and explain what they do and how to take them. You will then start to take your medications yourself, closely supervised by the nursing staff. Once you are confident with taking your new medications, you will be able to take your medications unsupervised, as you would do at home. This training aims to help you become familiar and confident with taking all your new medications before you go home.

What drugs do I need to take?

In order to protect your transplanted pancreas (and kidney, if also transplanted) from rejection by your immune system, you will need to take powerful medications called immunosuppression drugs. The dose of the immunosuppression medications will be progressively reduced following your transplant, but if you were to stop taking the immunosuppressive medications your new pancreas (and kidney, if transplanted) would stop working and would be rejected by your body. After your operation, you will receive treatment with a drug called alemtuzumab (Campath). This drug reduces the ability of your immune system to reject your transplanted organs. This is then followed by long-term drug therapy, most commonly with a combination of two different types of tablet medications, Tacrolimus (Adoport) and Mycophenolate mofetil (MMF). You may be given additional medications such as tablet steroids if there is concern regarding graft rejection or intolerance to any of the other immunosuppression medications.

What are the side effects of these medications?

As with all medications, the anti-rejection medications can cause a variety of side effects. However, it is important to remember that you may not experience all or any of these, the most common are listed below.

Tacrolimus (Adoport) – immunosuppression medication

- tremor (shaky hands)
- upset stomach (usually in early period of treatment, normally resolves)
- sleep disturbances
- increase in blood pressure
- increase in blood sugar (diabetes) usually with high blood concentration of the drug
- hair loss
- mood changes
- headaches

Mycophenolate mofetil (MMF) – immunosuppression medication

- reduction in your white blood cell count (and the consequent risk of infection)
- upset stomach including diarrhoea, nausea and vomiting
- risk of birth defects (discuss this in detail with the transplant pharmacist if you or your partner are planning on getting pregnant).

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What are the risks of the long-term immunosuppressive medications?

As the anti-rejection medications suppress your immune system, you will be at greater risk of infections. These infections can potentially become life threatening as your body is not able to provide its usual response to infection while your immune system is lowered.

You are most vulnerable for the first three to six months after your transplant. You will be on preventative doses of medications against common infections that occur after transplantation, these medications will be gradually withdrawn as the risk reduces.

Long-term immunosuppression medication increases the risk of you developing some forms of cancer, relating to your skin or lymph glands (lymphoma). We will monitor you closely for any signs of these cancers after your transplant, as they can usually be effectively treated if found early. We will also give you advice about skin care protection, including sun protection.

What happens if the pancreas transplant fails?

If your new pancreas fails, you can resume insulin treatments and consider a second transplant. This decision will depend on your current health, your ability to withstand surgery and your expectations for maintaining a certain quality of life.

Patient and transplant survival

Success rates of transplants are usually reported in 2 ways:

- patient survival: the percentage of patients who are alive after transplant. It is usually measured at one and five years after transplant.
- graft survival: the percentage of the transplanted organs, still functioning. It is usually measured at one and five years after transplant.

At the West London Renal and Transplant Centre, the patient survival at one year and five years after pancreas transplant is 97.9 per cent and 87.5 per cent respectively. In other words, after a pancreas transplant almost 98 out of 100 patients are still alive at one year and more than 87 out of 100 patients at five years.

In the SPK (Simultaneous Pancreas kidney transplant) patients, the pancreas graft survival at one year and five years is 83.5 per cent and 78 per cent, respectively. In other words, after SPK more than 83 out of 100 pancreases will still be functioning at one year and 78 out of 100 pancreases after five years.

In PTA (pancreas transplant alone – where there is no kidney transplanted), the pancreas graft survival at one and five years is 59.5 per cent and 52 per cent, respectively. In other words, after PTA more than 59 out of 100 pancreases will be still functioning at one year and 52 out of 100 pancreases after five years.

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any suggestions or comments about your visit, please either speak to a member of staff or contact the patient advice and liaison service (PALS) on 020 3313 0088 (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or 020 3312 7777 (St Mary's and Western Eye hospitals). You can also email PALS at pals@imperial.nhs.uk. The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to express your concerns in writing to:

Complaints department, Fourth floor, Salton House, St Mary's Hospital, Praed Street London W2 1NY

Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on 020 3312 5592.

Wi-fi

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK_FREE or WiFiSPARK_