

# Your Pancreas Transplant

## Information for patients



**Blood and Transplant**

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## 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 has diabetes.

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 can be increased life expectancy and longer kidney transplant function.

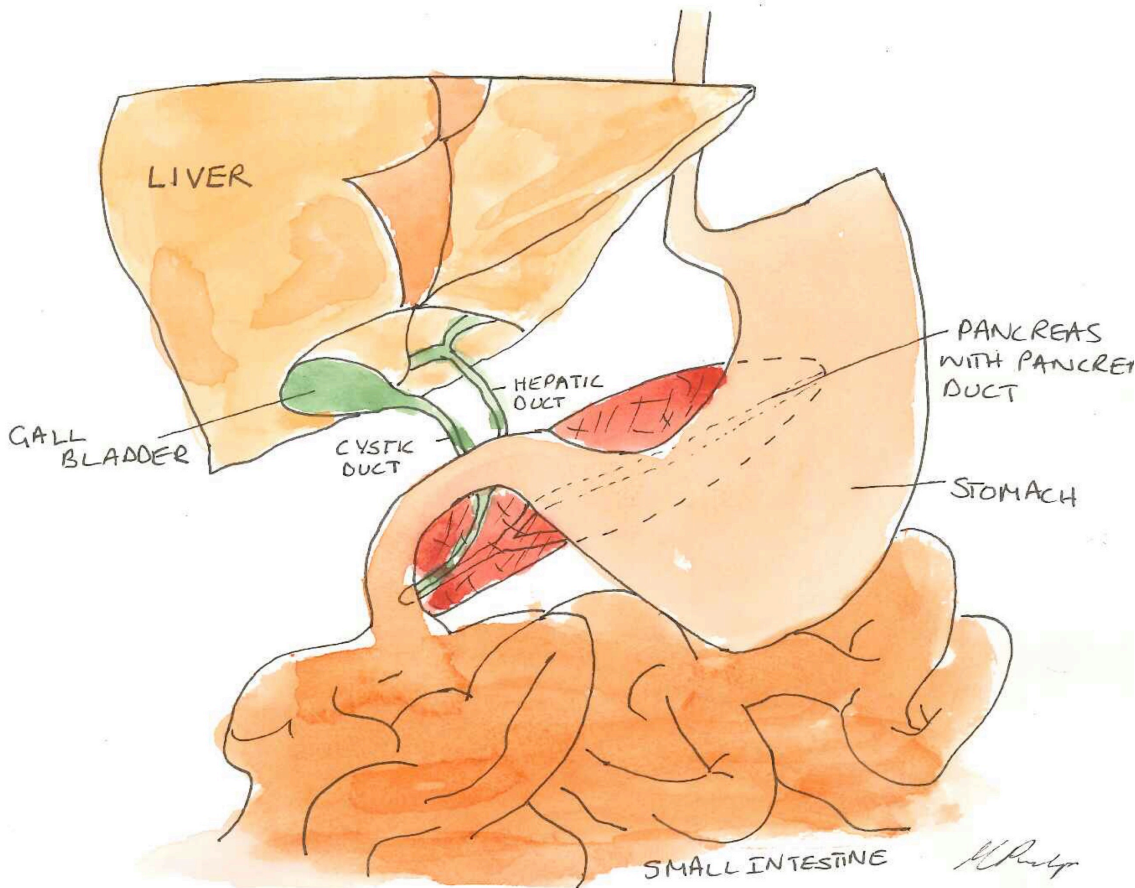


Figure 1: Anatomical position of the pancreas.

## Who can have a pancreas transplant?

Diabetes can be broadly divided in two types:

**Type 1 diabetes:** Your own pancreas does not make enough insulin, leading to high blood sugars. This condition is less common and typically seen in children and young adults.

**Type 2 diabetes:** Your body is unable to make use of the appropriate amount of insulin made by your pancreas. This condition is increasing rapidly across the world, it is associated with obesity and is typically seen in adults.

Pancreas transplantation is usually reserved for treatment of type 1 diabetes. In selected cases, pancreas transplants may also be offered to treat type 2 diabetes if their Body Mass Index is less than 30. The majority of pancreas transplants are done combined with a kidney transplant for people whose kidneys have been damaged by diabetes (simultaneous pancreas kidney transplant, SPK). Pancreas transplant alone (PTA) is usually reserved for type 1 diabetics that suffer from frequent life threatening hypoglycaemic events due to an inability to respond to low blood sugars.

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 potential risks and benefits of the procedure, and will be discussed in detail by the members of the transplant team during your assessment.

## 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 a 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 may 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, the kidney transplant is likely to work longer.

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 transplants 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 can 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 it is considered you may benefit from a subsequent pancreas transplant.

**Pancreas transplant alone (PTA):** If you suffer from frequent life-threatening hypoglycaemic events, you can be considered for a pancreas transplant alone (PTA)

## What tests will I need for assessment for transplantation?

As with all surgical procedures you will be assessed to make sure that you are fit enough for the operation. We usually ask for you to have a scan of your heart called an echo-cardiogram and a trace of your heart called an ECG. You will also have blood test results and you will have a detailed history taken of your diabetes and any complications that you may have.

As the majority of the complications occur around the time of transplant and are related to the heart and lungs, you will have rigorous tests of these organ functions. This may involve exercise tests to look at your heart and lung function. We may also need some specialist tests that look at the blood supply to your heart and the quality of your blood vessels that go to your legs.

## What are the alternatives to pancreas transplant?

**Optimisation of medical treatment:** Your diabetic team will aim to optimize your diabetic management, improving blood sugar control and reducing hypoglycaemic events.

**Islet transplantation:** If you suffer from type 1 diabetes without kidney failure and you have frequent hospital admissions due to impaired awareness of your hypoglycemia then you could be considered for islet cell transplant. Islet cells are insulin producing cells that can be removed from a deceased donor pancreas. These are then injected into your liver and can improve glucose control and restore awareness of hypoglycaemia. Most people require two islet transplantations. Some people become insulin independent for a limited period but the primary aim of islet cell transplant is to restore awareness and reduce the number of hypoglycaemia events.

**Simultaneous islet kidney transplant (SIK):** If you have been considered from simultaneous pancreas kidney transplant but either you or we consider the risks of surgery to be too great, simultaneous islet kidney transplant may be a possibility for you. You will receive islets cells removed from the pancreas of the same deceased donor that you receive a kidney from. It is likely you will need a second islet cell transplant after your initial procedure and although some people become insulin independent for a limited period, the primary aim of the islet cell transplant is to improve blood glucose control and restore awareness of hypoglycaemia.

**Kidney transplantation from living donor:** If you have diabetes and renal failure you can also consider kidney transplant alone from a living donor. Living donor kidney transplant can often be a good option especially if you are not considered fit enough for a simultaneous pancreas and kidney transplant. A number of studies have shown that life expectancy can be similar in Type 1 diabetics with renal failure who have a living donor kidney transplant compared to those that have a Simultaneous Kidney Pancreas transplant. This is especially the case in older patients.

**Kidney transplantation from deceased donor:** You could opt to have a kidney transplantation from a deceased donor, either due to your personal preference, or upon advice from the transplant team if the risks relating to the operation appear to be high (after thorough assessment).

When you meet the transplant team you will have the opportunity to discuss alternatives to pancreas transplant.

## Where does a donor pancreas come from?

Although it is possible for a living donor to donate part of a pancreas, all pancreas transplants in the UK are obtained from deceased donors. Either people who have suffered brain death, usually as a result of an brain injury, known as Donation after Brain Death (DBD) or Donation after Circulatory Death (DCD) from patients who are declared dead following absence of breathing or heartbeat.

## How long will I wait for?

Once you are assessed as being suitable for a pancreas transplant you will join the national waiting list. Unfortunately, it is not possible to predict how long you may have to wait for a transplant and this 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 received one after at least 13 months. The waiting time also depends on your blood group and how long it takes for a suitable donor whose blood and tissue types match yours to become available.

## What should I do to help myself 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

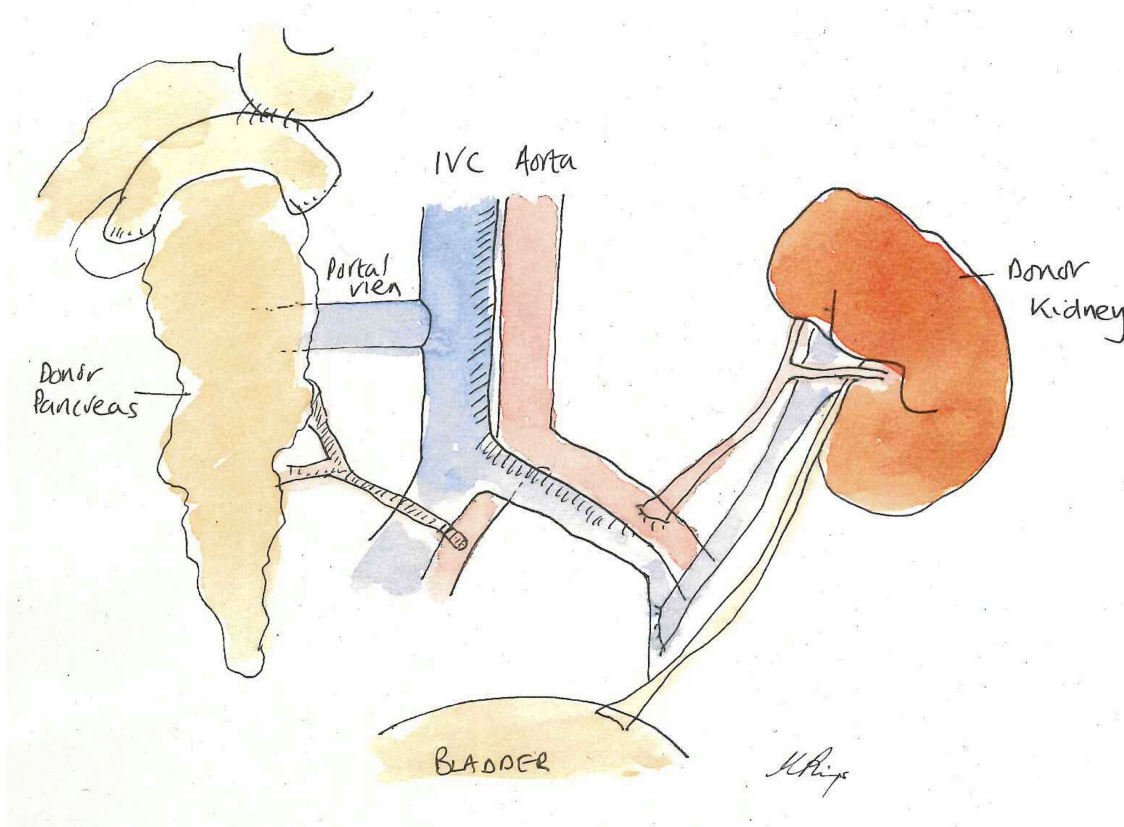
Once a donor pancreas becomes available, it must be transplanted as soon as possible and ideally within 12 hours. You should keep a packed hospital bag handy and make arrangements for transportation to the transplant centre in advance. You will usually be able to stay at home until the transplant team notifies you that a suitable pancreas is available. Living with severe diabetes can be stressful enough without the added anxiety of waiting for a pancreas to become available. Please 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 becomes available a member of the team will phone 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 attend the transplant unit and you will be advised about eating and drinking in preparation for the operation. Time is extremely important in transplantation to maintain the viability of the organs. It is very important that we can contact you at all times. This is most often in the night. When you receive the call you must arrive at the hospital 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. As the situation is constantly evolving with various crucial pieces of information being put together to proceed with the transplant, 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. You will have one vertical incision or two incisions (cuts) made in the lower part of your abdomen depending on the consultant surgeon and your transplant centre. 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 blood vessels of the pancreas are connected to the blood vessels that supply blood to your legs and the donor intestine is attached to your small intestine (figure 2). Your own pancreas is left in place.



**Figure 2:** This drawing shows the position of the new pancreas and kidney in the lower part of your abdomen (view inside the abdomen from the front).



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 ureter of the kidney which is 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.

Pancreas transplant surgery usually lasts about three to four hours. Simultaneous kidney and pancreas transplant surgery lasts about 5 to 7 hours.

## What will happen after the operation?

After the surgery you will be moved to the recovery area where you will be monitored prior to being transferred to either the High Dependency Unit or Intensive care. 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:

- **PCA (Patient Controlled Analgesia):** which is a machine that delivers painkillers through a tube into your body, and is controlled using a handheld device that you can control.
- **Epidural:** In some cases your pain will be controlled by a catheter which is placed around the spinal cord during your anaesthetic.
- **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. In some case you may also have a feeding tube inserted to help with your nutrition following your transplant.
- **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 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 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 the catheter may be removed once you are well enough to go to the toilet; in special circumstances where the pancreas is draining its secretions to the bladder, you may need to have the urine catheter until advised by the transplant team.

The nasogastric tube helps to keep your stomach empty or 'decompressed', until normal bowel function returns. This helps 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. When your condition improves and the plastic tubes start to be removed, you will be moved to one of the wards. During your entire hospital stay, nurses, doctors and surgeons will closely monitor your recovery.

Every day you will be reviewed on 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 (PCA) attached directly to a vein in the back of your hand or arm to give you pain relieving drugs. You can press a hand-held button when you feel pain or discomfort and the pump will deliver the correct pre-programmed dose of pain killing drugs directly into your vein..

It is fairly common to experience “bloating” or abdominal distension in the first 48 - 72 hours after the operation. This is due to the bowels being slow to start working after having a general anaesthetic and surgery.

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. However, please 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 you 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 four to eight weeks after your transplant.



## 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 clinic appointments for up to three times a week for follow up appointments.

Also, it is very normal to have little or no appetite. You may also 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 and some need even 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 include 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. 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 (blood clot)**

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 so we can carry out special clotting tests to measure how effectively your blood is clotting and to avoid the risk of bleeding.

### **Pancreatitis**

Pancreatitis is an inflammation of the pancreas. A certain degree of pancreatitis is inevitable (cannot be avoided). This is due to damage to the pancreas during the process of removal from the donor, storage in ice during transportation and re-warming with your blood - this is called ischemia reperfusion injury.

The symptoms usually settle spontaneously (by themselves) in the majority of the transplants within a few days. 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 operating theatre for a further procedure to deal with any of the above complications should they occur.

## **Kidney Transplant complications**

If you receive a simultaneous kidney pancreas transplant there are some risks specifically related to the kidney transplant. Up to 40 per cent (40 in 100) of kidneys can develop delayed graft function (DGF), when the kidney does not work immediately. This usually recovers but can up to 1 to 2 weeks and will often require a kidney biopsy. It is rare (less than 1 per cent, 1 in 100) for kidney to not work at all from the outset. There can also be complications related to the join between the ureter and the bladder (either a urine leak, or a narrowing or 'stricture' of the join). This occurs in less than 2 per cent of patients (2 in 100).

## **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).

## **Do I need to take medications?**

Yes will need to take drugs called immunosuppressives (anti-rejection drugs). These help to keep your immune system from attacking your new organ(s). 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. The drugs will be listed on a medication record card and the pharmacist will see you to explain what they do and how to take them. You will then start to take your medications yourself closely supervised (monitored) 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.

## **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 up to 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 (to reduce any discomfort for you), which numbs the area where the needle is inserted.

## What drugs do I need to take?

To protect your transplanted pancreas (and kidney, if that has been transplanted too) 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.

At the time of your operation, you will receive an injection of a drug that reduces the ability of your immune system to reject your transplanted organs. This is followed by long-term drug therapy most commonly with a combination of two different types of tablet medications, Tacrolimus and Mycophenolate mofetil (MMF). You may be given additional medications such as steroids if there is concern regarding graft rejection or intolerance to any of the other immunosuppression medications. 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.

## 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 anti-rejection drugs and potential side effects are listed below:

### Tacrolimus

- 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
- kidney damage (especially at high levels of tacrolimus)

### Mycophenolate mofetil (MMF)

- 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).

## 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.

## How successful is pancreas transplantation?

Success rates of transplants are usually reported in two 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.

In the UK the patient survival at one year and five years after pancreas transplant is 97 per cent and 89 per cent respectively. In other words, after a pancreas transplant 97 out of 100 patients are still alive at one year and more than 89 out of 100 patients at five years.

In SPK (simultaneous pancreas kidney transplants) the pancreas graft survival at one year and five years is 88 per cent and 78 per cent, respectively. In other words, after SPK, 88 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 80 per cent and 53 per cent, respectively. In other words, after PTA, 80 out of 100 pancreases will be still functioning at one year and 53 out of 100 pancreases after five years.



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