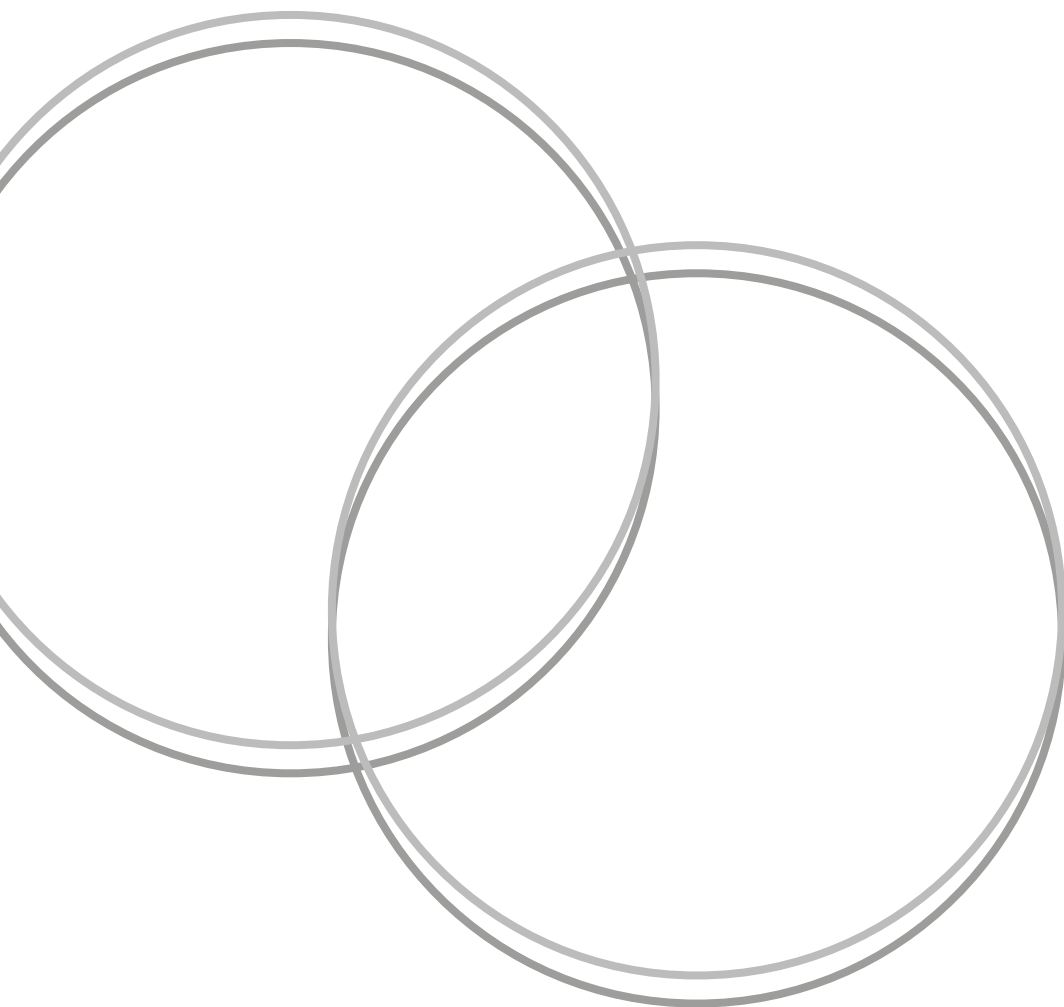




Oxford University Hospitals
NHS Foundation Trust

Your Pancreas Transplant

Information for patients



The Oxford Transplant Centre

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Introduction

A pancreas transplant is a treatment option for people with diabetes. A successful transplant can help you have normal blood sugar levels and will mean you will no longer need to inject insulin.

This booklet has been written to provide you with a range of information about pancreas transplant. Use it with information you will receive from the Transplant Surgeon and the Transplant Nurse Specialist during your first clinic appointment. This will give you a better understanding of what having a pancreas transplant means.

Transplant types

There are three different types of pancreas transplant done in Oxford.

Simultaneous Pancreas Kidney transplant (SPK)

This is for people who also have kidney failure. They may have already started dialysis.

A pancreas and a kidney that have come from a single donor are transplanted into a recipient in a single operation. A successful SPK means coming off insulin and not needing dialysis.

Pancreas After Kidney transplant (PAK)

This operation is done if you have diabetes and already have a kidney transplant that is working well.

This transplant can help the transplant kidney last longer by giving you normal blood sugar control.

Pancreas Transplant Alone (PTA)

This is for people who have type 1 diabetes and who suffer from a lot of hypoglycaemia (very low blood sugars), that usually needs urgent medical attention or help from someone else to treat it.

It is an option for diabetics who have very unstable sugar control that is difficult to manage, even if they are having maximum diabetic treatment.

There are other options to help with diabetic control that do not involve a pancreas organ transplant.

Simultaneous Islets and Kidney transplant (SIK)

For an islet transplant, the cells that make insulin are removed from a donor pancreas and infused into the recipient.

This is instead of having the whole pancreas organ transplanted. The recipient also receives a whole kidney from the same donor.

SIK may be a safer alternative for diabetic people with kidney failure for whom a whole pancreas transplant is felt to be a higher risk option than usual.

Islet transplant does not usually result in coming off insulin altogether. It can help reduce how much insulin is needed and stabilise difficult to control blood sugars.

Please see 'Your islet transplant' leaflet for more detailed information on islets.

Islet cell transplant

Please see 'Your islet transplant' leaflet for details.

Where do donor organs come from?

Cadaveric pancreas transplants

All transplant pancreases come from deceased donors. That is, they come from people who have died. There are two types of deceased donor; Deceased after Brain Death (DBD) and Deceased after Circulatory Death (DCD).

- **Deceased after Brain Death (DBD) donors**

DBD donors are patients who have suffered permanent brain injury that cannot be treated. They are described as having no brain stem activity.

Tests are done to confirm that there is no brain activity. If there is no response to these tests, a DBD donor is stem declared dead.

These donors are on a breathing machine right up to the moment when their organs are removed for transplant.

- **Deceased after Circulatory Death (DCD) Donors**

DCD donors are patients whose organs are removed soon after cardiac arrest, when their heart has stopped beating.

These patients have usually had a brain injury but are not brain stem dead. The brain injury is not survivable and a decision has been made to withdraw treatment and allow them to die. As soon as this has happened the organs for transplant are removed before they start to deteriorate.

The most recent survey of UK data by NHSBT (National Health Service Blood and Transplant) shows that success rates for DCD donor transplants are very similar to those for DBD donor transplants.

Living kidney donation

For some people with diabetes and kidney disease, a kidney transplant on its own from a living donor could be the best option, instead of a SPK transplant.

The assessment team will discuss this with you in clinic if it is thought to be best for you. This will be based on your specific situation and medical history

Living donors are healthy people who would like to volunteer to donate one of their kidneys. They are often a close relative, such as a parent, brother, sister, son or daughter. They can also be people who are not blood-related to you, but who you have a full relationship with, such as a partner or close friend.

A living donor's ability to give a kidney will depend on their overall health, whether they have any significant medical problems and whether both of their kidneys function normally.

The Living Donor Team can give further information to anyone who would like to be considered as a donor. Please ask your Transplant Nurse Specialist for details.

What does the pancreas do?

The pancreas is behind the stomach in the belly or abdomen and has two main functions. It produces juices that help with digestion, and it also produces insulin from small clusters of cells called Islet cells.

Insulin helps to pass glucose (sugar) into the cells of the body to feed them. Insulin lowers blood sugar levels.

If you have diabetes, you no longer produce insulin and need insulin injections to keep your blood sugars within normal limits.

What are the benefits of having a pancreas transplant?

The main aim of a pancreas transplant is to improve both the quality and the length of your life. A successful transplant offers freedom from insulin injections and, in the case of a SPK, freedom from dialysis as well.

Diabetes can damage the body in a lot of ways. This damage may be stopped after having a successful pancreas transplant.

Unfortunately, a transplant cannot reverse or heal diabetic damage that has already been done to eyesight, nerves or blood vessels. Well controlled blood sugars after successful pancreas transplant may prevent new damage, but this is not guaranteed.

In the case of Simultaneous Pancreas Kidney transplant (SPK), a working pancreas transplant can protect the new kidney from damage caused by poorly controlled blood sugars.

Having a transplant can also offer you freedom from diet and fluid restrictions that you had to follow before your transplant.

Consent

We will ask for your consent before we continue with certain parts of the transplant assessment process, for example, virology blood tests and some heart tests. Your consent will be needed to put you on the transplant waiting list and your consent will be needed specifically just before the operation itself.

So that you can make a full and informed consent about what is happening, this leaflet provides a lot of information and we will also discuss things in assessment clinics.

Please ask us questions so that you feel comfortable with what a transplant means and what we need to do to make sure you are suitable for it.

Assessment for the transplant waiting list

Not all people with diabetes are suitable for a transplant because you need to be in reasonably good health to have the operation.

Everyone being considered for pancreas transplantation will need to have a heart test and other tests before they can be put on the waiting list.

At your first clinic, you will have a detailed medical assessment with the Transplant Consultant and Transplant Nurse Specialist. They will talk with you about your health, as well as your psychological and social wellbeing. During the visit you will also have several blood tests and possibly a chest X-ray, if you have not had one in the past 12 months.

You will also be asked to arrange a dentist review if you have not visited the dentist recently. After your transplant you will take anti-rejection medications which can make you more likely to catch infections. Good dental hygiene helps to prevent dental and gum infections.

If you are not currently registered with a dentist, you can call NHS 111 for advice on finding an NHS dentist in your area.

If you are a woman, we will need you to be up-to-date with general health screening. This includes mammography (breast screening) every 3 years for women over the age of fifty, and cervical smear tests every 3 to 5 years for women between the ages of twenty-five and sixty-four. These should be arranged through your GP.

We will also review any other medical issues you may have. Depending on what these are, you may be referred for some extra tests.

Cardiac Tests

- **Myocardial perfusion scintigraphy (MPS)**

To make sure you are fit enough to go through transplant surgery, you will be referred for a special heart test. This can be done in Oxford, or in your local hospital if you live further away. It is sometimes called the 'stress test' and it looks at how well the heart is working when it is at rest and when it is working harder.

- **Coronary Angiogram**

If your MPS scan is not normal, the cardiologist (heart doctor) may want you to have an angiogram. This looks at the state of your heart blood vessels in more detail.

The results of these heart tests will be sent to the transplant team and the Transplant Nurse Specialist will call you to discuss them.

Further Tests

Extra tests may be done to check the health of the blood vessels in your tummy (abdomen) and legs. These blood vessels are used in the transplant operation and need to be in good health.

If you are being considered for SIK or islets as well as a pancreas organ transplant, you will have a scan of your liver to check its health.

This is because islets are infused into one of the big veins of the liver, and the liver needs to be in good health so that this is possible.

For more details about islet transplants, please see 'Your islet transplant' leaflet.

If these or any other extra tests are needed, the surgeon and Transplant Nurse Specialist will be able to discuss these with you in the clinic. We will try to make sure that you have them done in your local hospital.

Being on the transplant waiting list

How do I get onto on the waiting list?

Once your transplant assessment and all the necessary tests are done, the Transplant Nurse Specialists will put your name forward to the Listing Meeting. This meeting is held weekly by transplant surgeons, nephrologists (kidney doctors), nurse specialists, anaesthetists and clinical scientists to decide if patients are suitable and fit for listing. The Transplant Nurse Specialist will contact you after this meeting and let you know the decision.

Sometimes, some people are felt to be too high risk or not suitable to receive a pancreas transplant. If you are one of these people and you have been assessed for a SPK, then a kidney transplant alone could still be possible.

If you were not considered suitable for a pancreas transplant (with or without a kidney), your care would be sent back to the consultant who referred you to us. We would also explain the reason for this decision with you.

How long will I be on the waiting list?

Once you are active in the waiting list, it is not possible to say exactly how long you will wait for a transplant. The average waiting time is about 12 to 18 months. It may be shorter or longer than this, depending on your individual circumstances.

What happens while I am on the waiting list?

Your local diabetes or renal doctor will monitor your condition and kidney function. They can tell us if there is any important change in your medical condition.

Once a month, you must send a blood sample to the Transplant Immunology (Tissue Typing) laboratory in Oxford. This sample is very important for final 'matching' with any organs you are offered. If an up-to-date sample is not in the laboratory when you are offered a transplant, this may stop you from receiving it. We will send you the blood bottles to send the samples in.

While you are on the waiting list, you will still have an appointment with us each year. This is to check your health and fitness and that you still want a transplant. You will also have a new heart stress test each year.

Your level of health can change over time, so while you are on the waiting list it is important that you tell us about any big changes. We need to make sure you are still fit to have the operation.

While you are waiting, we strongly advise that you keep as fit and active as you can. Make sure you do not gain too much weight and if you smoke it would be a very good idea to stop.

We will take your contact details at your first appointment. This is so that we can always contact you at any time. If you change your phone number or address, make sure you tell us.

Always keep your phone with you. A transplant offer could come at any time, especially at night. We will not leave a message, and if we cannot get hold of you when there is an offer, you will miss out.

If you are going to be away (e.g. on a holiday or work trip) or if you are unwell, please let us know. We will temporarily take you off the waiting list. Once you are home again or you have got better, let us know and we will restart you on the list.

What happens when I am called in?

You will be called by a Recipient Transplant Coordinator (RTC) This could be at any time but is often at night. They will ask you about your general health and about your dialysis if you are on it. You will be told whether you are the 'primary' or the 'back-up patient'.

Organs are fragile and must be used within a certain time. We call more than one recipient so that if there is a problem with the primary patient, there will be less delay in finding a second patient and the organs will not go to waste.

The Transplant Recipient Coordinator will give you advice about eating and drinking and when you will need to go 'nil by mouth' for surgery. If you are the primary patient, you will be asked to come to the Transplant Ward at the Churchill Hospital. Sometimes we also ask you to come in if you are the back-up.

You will need to come straight in, but there is usually plenty of time when we call you, so there is no need to rush in. Drive safely!

There may be times when we call you in, but we cannot go ahead with your operation. This can be for many reasons. We might learn new information about the donor, or there are problems with the organs that we didn't know about until after they were retrieved.

Sometimes we may ask you to be a back-up at home. This means that you are still a back-up, but you can stay at home. We will tell you when to go nil by mouth, and please do not leave your home, as we may need you to come in at short notice. The RTC will give you their number so you can call them if you have any questions.

What happens on the ward?

When you arrive on the ward a nurse will show you to your bed. They will ask you some questions about your general health and dialysis. Sometimes we may have to admit you onto another ward if the Transplant Ward is full. Staff will do their best to make you feel comfortable and will find a bed on the Transplant Ward as soon as possible.

A surgeon and anaesthetist will come and examine you and ask questions to make sure you are in good health for the operation. You will have blood samples taken.

Before the transplant can go ahead a blood test called a 'cross match' is done. This is to check final compatibility between you and the organ donor. This test needs to be 'negative' to go ahead with the transplant. If the result is 'positive' this means that there is incompatibility between you and the donor and so the transplant cannot go ahead this time.

What does the operation involve?

A pancreas-alone transplant operation takes 3 to 4 hours.

A combined kidney and pancreas (SPK) operation usually takes 4 to 6 hours.

The surgeon will place the pancreas in one side of your tummy (abdomen), normally on the right side. The kidney (if you are having one) is placed on the other side. Your own pancreas and kidneys will be left alone.

The operation includes joining the blood vessels (veins and arteries) of the organs to the big blood vessels that take blood to and from your legs. The transplanted pancreas is either connected into your small intestine (SPK) or into your bladder (pancreas-alone) to drain out the digestive juices that it makes.

All this is done through one surgical cut in your abdomen from just under your breastbone to below your bellybutton. The muscles and tissues of your abdomen will be closed with stitches. The skin is closed with surgical glue.

If you have a diabetic complication called gastroparesis (a difficulty in digesting food and medications), the surgeon may put a tube (called a jejunostomy) directly into your small intestine. This will allow us to give you food, fluids and medications into your intestine immediately after your transplant. This tube will be removed as soon as possible. We will discuss this with you while you are on the ward.

Bladder-drained Pancreas

If you receive a pancreas-alone transplant, the surgeon may connect your new pancreas to your bladder. This is called 'bladder drainage'.

The new pancreas will produce juices including one called amylase. These juices drain into your bladder and are passed out in your urine. This lets us check the level of amylase in your urine to see how well the transplant is working.

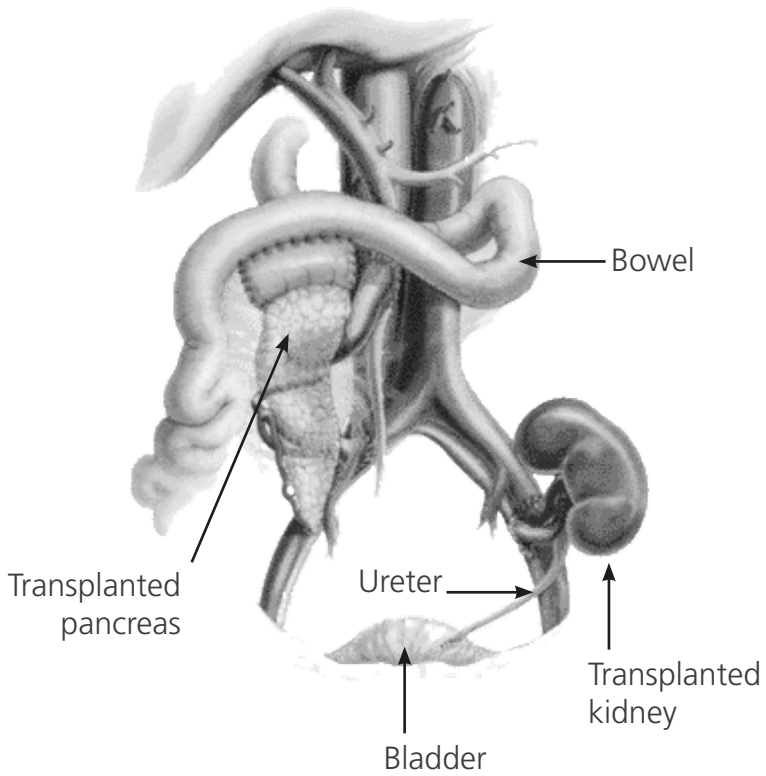
Using the bladder drainage technique appears to be linked with better survival of the transplant organ. However, it can cause a few side-effects. These include irritation of your bladder lining (called chemical cystitis) and dehydration.

To prevent and treat these symptoms you will need to drink plenty of fluids after your surgery and take additional medications.

If the side-effects are severe and are affecting your quality of life, the transplant surgeon may advise changing the connection from your bladder to your bowel. This would require another operation in Oxford. It is not normally done until at least 6 months after your transplant operation.

We may not use bladder drainage if you have existing bladder emptying problems caused by diabetes, or your kidney function is at a level where bowel drainage would be better for you.

Diagram showing where the pancreas and kidney are attached during the transplant operation.



Where will I be cared for following my transplant?

The operation is done at the Churchill Hospital in Oxford. You will spend the first 12 to 24 hours in the Intensive Care Unit (ICU) or Extended Recovery Unit (ER). This is because you will be under anaesthetic for a long time and we need to monitor you closely after your surgery. You will then be transferred to the Transplant Ward.

Waking up in Intensive Care or Extended Recovery

You will have **intravenous lines** (a sterile plastic tube inserted into a vein) in both your arm and your neck. These will be used to give you fluids and drugs for the first few days after surgery. You may have some pain and discomfort, but you will have pain medication through a special infusion pump attached to the intravenous line.

This is called a **PCA**, which stands for 'patient-controlled analgesia'. You press a hand-held button when you feel pain and the pump will send a dose of pain-killer directly into your vein.

You will also have a **urinary catheter** (a tube put up the urethra and into the bladder), so we can measure the amount of urine you are making. You will need to have this in for about 5 days.

You will have a **nasogastric tube**, which is a thin tube that is put into your nose, down the back of your throat and into your stomach. It helps to keep your stomach empty. This protects the area where your new pancreas is attached to your small intestine.

You may also have one or more abdominal drains in place. Your body will be making extra fluid that contains cells for healing. Sometimes more fluid collects in the abdomen than is needed, and the drains help to remove it.

You will need physiotherapy to help you to clear your chest and cough properly following your surgery. This might hurt, but you can use a 'cough pillow' to support your abdomen. Coughing and deep breathing is important because it clears your lungs and helps to prevent chest infections.

You will also have an oxygen mask on your face after your surgery to help with your breathing. This is normally worn for the first 24 to 48 hours, or until the medical team caring for you tells you that you no longer need it.

If you have also had a kidney transplant and the kidney is slow to recover, you may need to have temporary dialysis until your new kidney 'wakes up'.

On the Transplant Ward

When you are transferred back to the Transplant Ward you will be monitored closely by the nurses and surgeons. We will check your blood pressure, pulse and temperature several times a day.

Nurses will measure how much urine you are passing, and your blood sugar levels. These show us if the organs(s) are working. You may have insulin for a few days after your operation. The insulin can be given through your intravenous line. It will be stopped once you are eating again.

You will have daily blood tests to check on the function of your new organ(s), as well as the levels of your anti-rejection medication.

You will still have an intravenous line in your neck and/or arm for fluids and drugs, and the PCA for pain control.

The PCA will be removed when you can take your painkillers by mouth. The urinary catheter, nasogastric tube and abdominal drains will be removed as you recover and no longer need them.

You will also have a special ultrasound or CT scan. This scan looks at the blood flow through your new pancreas (and kidney, if you have one). It will show up any narrowing or blockages of the blood vessels.

How long will I stay in hospital?

How long you need to stay in hospital will depend on your progress after the operation. The usual length of stay is about 2 weeks.

Day by day you will feel stronger and become more able to move around. It is very important to sit out of bed, move around and to start taking care of yourself again.

If you do not get up and mobilise, it will take you much longer to recover. You will also be at greater risk of post-operation complications and infections.

You will be taught about your new medications and how to take care of yourself and your new transplant when you are discharged home.

Delayed graft function

Sometimes a transplanted kidney does not work immediately. This is called delayed graft function.

We will closely monitor you and tests are done to try to find out why the kidney is being slow.

If you were on haemodialysis before the transplant, you may need to continue with this until the new kidney starts to work properly.

If you were on peritoneal dialysis before transplant, you may need haemodialysis through a temporary line. This is because your peritoneal dialysis line is removed during the operation.

What medications will I need to take?

To stop your transplant being attacked and rejected by your immune system, you will need to take powerful medications called immunosuppressant or anti-rejection medications. You will need to take these for as long as you have the transplant organ(s) in your body.

The doses of these medications are often adjusted in the first few months. These changes are based on the results of your blood tests and to make sure you are on the right dose for you.

You should never stop taking these medications, unless told to do so by the transplant team.

If you stop taking them suddenly, your transplant will stop working and you could become very ill.

These medications can also affect your ability to fight infections. You are thought to be especially vulnerable in the first 3 months. You will need to take more care to stay away from people with an active infection (e.g. colds and flu) during this time.

During the first year after transplant, you will also need to take other medications to protect you from certain infections. Depending on your individual case, you may need more or less of these.

The most common immunosuppressant medications are: Tacrolimus and Mycophenolate. Common side-effects of these medications are listed below. Remember: if you do have side-effects **DO NOT** just stop taking your medications. Talk about any problems with your transplant team. Such problems can often be easily sorted out.

Tacrolimus

- shaky hands
- upset stomach (usually when first taking this medicine)
- sleep disturbances
- increase in blood pressure
- an increase in blood sugar (diabetes)
- hair loss
- mood changes
- headaches.

Mycophenolate

- the most common side-effect is a drop in white blood cell count. This can put you at risk of infection. We will monitor your blood count and adjust your medication dose if needed
- upset stomach including diarrhoea, nausea and vomiting
- a rash.

Self-medication training

After the operation you will learn about your new medications. These are listed on a medication record card. Make sure you do not lose this and that it is updated with any dose changes.

A pharmacist will go through the card with you and explain what the medications do and how to take them. You will then start to take your medications by yourself while being closely supervised by the nurses.

Once you are comfortable with your medications, you will be allowed to take them on your own, just like you will at home.

Long-term immunosuppression

Taking immunosuppression for the long term puts you at a higher risk of developing some forms of cancer, such as lymphoma (cancer of the lymph nodes/glands) and skin cancer.

You can help us monitor you for any signs of these after your transplant. This can be done by checking your skin regularly and telling us about any changes to your general health.

Infections

The immunosuppressant medications can put you at a higher risk of infections.

This means that it is more likely that you could develop an infection, and have it more intensely than you might have done before transplant. This is because the immunosuppressant medications work on parts of your immune system and make it less active. The medications do **not** remove your immune system completely.

We highly recommend that you have all the offered vaccinations for flu and Covid-19. These can help protect you from having these diseases too seriously.

Chicken pox may cause a serious illness while you are on immunosuppressant medication. Before we add you to the transplant list, we will check your immunity to chicken pox. If you are not immune, we will ask your GP to vaccinate you against this virus.

You cannot have the chicken pox vaccine after transplant because it is a live vaccine. You cannot have live vaccines after transplant because they can make you very ill. You can have inactive vaccines.

More information on medications, post-transplant self-care, vaccines and infections is available in the 'How to take care of your transplant' booklet that we will give you after a transplant.

What are the risks of having a pancreas transplant?

All transplants can have complications during the operation and afterwards. The most common problems are listed below.

Bleeding

As with all operations, there is a risk of bleeding. This is more likely for a pancreas transplant because a lot of medications are given after the operation to keep the blood thin and prevent thrombosis (clotting) in the new pancreas.

Approximately 10% of patients (10 in 100) have some bleeding after transplant that will need another operation to check on the pancreas and to control any bleeding.

Thrombosis (clotting)

There is a risk of a blood clot forming in the blood vessels around the transplant. This is called a thrombosis and can happen in 20% of all patients. Clots can stop blood flowing to the organ, and this can lead to the organ being lost.

This is most likely to happen during the first week after the transplant. If an organ is lost, it may be removed in another operation. You will be monitored closely for signs of clotting while you are in hospital and when you return home.

You will have regular blood samples taken to measure how well your blood is clotting. You will be given various medications to lower the risk of a blood clot forming. However, these drugs can also increase the risk of bleeding.

Pancreatitis

Pancreatitis is inflammation of the pancreas and can make you very sick.

It happens in transplant when a pancreas is damaged while it is being warmed up again with your blood. The transplant pancreas is stored on ice until it is used, and the shock of being warmed up again can be too much for some of them.

If you develop graft pancreatitis, you may have extra fluid collections in your abdomen that could need more surgery to wash out, or you may have drain tubes placed into your abdomen to remove them.

Transplant pancreatitis usually gets better on its own. About 5% to 10% of people who have transplant pancreatitis will need to have the transplant pancreas removed.

Further operations

Approximately 1 out of 5 people who have a pancreas transplant will need to go back to the operating theatre for more surgery to deal with any of the above complications. This often means a longer stay in hospital to recover from the extra surgery.

Other complications

The general risks are like those following any major abdominal surgery. These include 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 after a transplant, the surgery and the immunosuppressant medication 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 infection.

Rejection

Your body's natural immune system response is to try and get rid of the new organs. Immunosuppressant medications help to control this response.

However, rejection will still happen in about 1 in 4 transplants.

Rejection can affect the pancreas or kidney, or both organs at the same time.

To find out whether your body is rejecting a kidney, you may need a biopsy. This is when a tiny sample of the kidney is taken using a long needle that is inserted into the organ. This is done under local anaesthetic to numb the area.

Rejection of the pancreas can be detected using blood test results, regular blood sugar testing and with scans. You may also feel pain if the pancreas is not working properly.

Rejection can usually be treated with extra immunosuppressant medications. This is often a short run of steroid injections and increasing the doses of your medications.

Other risks

There have been very rare reports of an infection or cancer being present in a donor organ which was not diagnosed before transplant and was passed on to the organ recipient. All donor organs can transmit infections, including human immunodeficiency virus (HIV), hepatitis B, hepatitis C, hepatitis E or malaria.

All donors are screened for these diseases and their history is reviewed to reduce the risk of diseases being passed over. If we consider a donor to be a higher risk than normal (for example with a known history of infection or cancer) we will discuss this with you before your transplant to help you decide if you wish to proceed with the transplant.

Patient and transplant organ survival

The Oxford Transplant Centre has been performing pancreas transplants since 2002. The unit has now done this type of transplant over 1000 times.

As with any major abdominal surgery and general anaesthetic, there are risks to life. Your consultant transplant surgeon will discuss the risks and benefits with you at your assessment. This will include any special risks that may apply to you.

NHSBT statistics (2020) show that 1 year after SPK transplant in Oxford, 98% of patients are still alive. At 5 years after SPK transplant, 87% of patients are still alive.

Statistics published in 2020 also show that in SPK transplants done in Oxford, the transplant pancreas is still working in 94% of patients after 1 year. After 5 years, the transplant pancreas is still working in 86% of patients.

In pancreas alone transplant (when there is no kidney transplant), the data from the Oxford Transplant Centre shows the pancreas remains working after 1 year in 92% of patients. After 5 years the pancreas is still working in 65% of patients.

What happens to the transplant kidney if a SPK pancreas has to be removed?

In most cases the kidney will not be affected and will still work.

If you and your consultant decide that you want to be considered for another pancreas transplant later on, then your doctor can refer you back to the Oxford Transplant team.

We will then discuss with you the risks and benefits of another pancreas transplant. You will also need a new assessment.

What happens when I am discharged from the hospital?

If you are from an Oxford unit (Oxford, Banbury, Aylesbury, Milton Keynes, Swindon and High Wycombe), or from Northampton, Gloucester or Reading, you will be seen in the Oxford post-transplant clinic.

If you come from anywhere else, we will transfer you straight back to your referring unit. We will see you in Oxford at 1,3,6 and 12 months, then annually.

For those who are seen in Oxford transplant clinic:

- You will be seen once a week for a month.
- you will be seen at least fortnightly for months 2 to 5.
- After 5 months you will be seen monthly.
- At a year (or even before then), you will be sent back to the doctor who referred you for transplant.

Stents

If you have had a SPK transplant, then you will have had a stent (a small plastic tube) put into the ureter (the natural tube that connects the kidney to the bladder).

This will need to be removed under local anaesthetic 4 to 6 weeks after transplant.

If you are being seen in Oxford, then you will be asked to come to Wytham Wing Urology Outpatients to have it removed. If you are being followed up out of Oxford, your own centre will remove the stent.

Please let the clinic team know if you have not received an appointment letter by 4 weeks after your transplant operation.

At home you will need to have:

- a blood pressure machine
- a thermometer
- weighing scales
- blood sugar testing kit.

When you are discharged home, please record your blood pressure, temperature, weight, and blood sugar once a day. Please bring this record to clinic with you. It helps us see how you are doing at home between clinics.

Unfortunately, these items are not supplied on the NHS.

What happens if I feel unwell at home?

The Oxford Transplant Centre is open 24 hours a day, 7 days a week and help is always available.

The **Transplant Nurse Specialists** can be contacted from Monday to Friday, from 8.00am to 4.00pm

Telephone: **01865 228 662**

The **Transplant Ward** should be called Monday to Friday 4:00pm to 8:00am and at weekends and on bank holidays.

Telephone: **01865 235 011** or **01865 235 010**

Who can I call for advice?

Being in hospital or going through a big, life-changing event like a transplant can sometimes cause other problems at home or at work.

There are people to help support you. We have a transplant unit psychologist to help with emotional issues. Please ask the nursing or medical staff if you wish to speak to them.

Important points to remember

Change of circumstances: When you are listed on the transplant waiting list will need to be able to get hold of you on the telephone day and night.

Please tell the Transplant Team immediately of any change in your circumstances, such as holidays, change of address, telephone number, or if you are admitted to any hospital.

Dialysis

If you start haemodialysis or peritoneal dialysis for the first time after your assessment clinic, please tell your pancreas Transplant Nurse Specialist. It is important for us to be up to date on your dialysis status because it is recorded on your transplant waiting list profile and may change your waiting time for a transplant offer.

If you are on haemodialysis, you need to tell your dialysis centre when you are having a myocardial perfusion scintigraphy scan (MPS). This is because your dialysis centre needs to take special care with your blood for 24 hours after the test.

The scan includes having a small amount of a mildly radioactive tracer fluid put into your bloodstream. So your blood needs to be handled carefully for 24 hours after the scan. Please also avoid routine blood tests for 24 hours after you have had a MPS.

Monthly blood samples for antibody screening

Once you are on the transplant list it is essential that you have monthly blood samples taken and sent in. This because we need up-to-date information about your antibody levels.

You will be informed when you are made active on the transplant waiting list and the tissue typist will send you a pack with blood bottles for you to fill.

You can do this at your haemodialysis session before you dialyse, or at your GP practice. They need to be sent in the envelope provided and by first class post to the Churchill Hospital. Please send them on a Monday, Tuesday, or Wednesday.

If the blood tests are sent any later in the week, they will not reach us in time and will be too old to test.

If you need more blood bottles and envelopes at any point, call the Transplant Immunology (Tissue Typing) Laboratory, who will post these to you.

Telephone: **01865 226 102**
(Monday to Friday, 9.00am to 4.00pm)

24-hour availability

Please make sure that your mobile phone is always switched on and that you have given us all the phone numbers where we can contact you.

Please do not leave your answer machines on, especially at night. We could call you for transplant at any time and we will not leave a message.

The Transplant Recipient Coordinator only has a short amount of time to call you in when a donor organ becomes available. If we cannot get hold of you, you will miss out on a potential transplant.

Transport arrangements for your transplant

If you are called in for a transplant, it is important you have a plan in place to get to the Churchill Hospital as soon as possible. This could be at any time of the day or night.

Transport can be provided to bring you in, but if the transplant does not go ahead you will need to find your own way home.

Please have a plan ready for the care of any people or pets that you are responsible for, in case you are called in.

Useful contact telephone numbers and addresses

The Oxford Transplant Centre

Churchill Hospital Old Road Headington Oxford OX3 7LE

Telephone: 01865 225 355 or 01865 225 356

Churchill Hospital Switchboard

Telephone: 01865 741 841

Pancreas Transplant Nurse Specialists

Telephone: 01865 228 658 or 01865 228 657

Email: ouh-tr.oxfordpancreastransplant@nhs.net

Transplant Ward

Telephone: 01865 235 011 or 01865 235 010

Renal and Transplant Outpatients (Appointments)

Telephone: 01865 225 943

Renal and Transplant Nurse Practitioners

Telephone: 01865 228 662

Email: orh-tr.posttransplantnurse@nhs.net

Secretary to Consultant Transplant Surgeons

Telephone: 01865 228 675

Patient Transport Service (Oxfordshire only)

Telephone: 0300 100 0015 (Monday to Friday, 7.00am to 7.00pm)

Here for Health

Health Improvement Advice Centre Oxford University Hospital drop-in centre for advice and support on healthy living, including physical activity, diet, smoking, alcohol and emotional wellbeing.

Telephone: 01865 221 429 (Monday to Friday, 9.00am to 5.00pm)

Email: hereforhealth@ouh.nhs.uk

Website: www.ouh.nhs.uk/HereforHealth

Oxford Transplant Centre

Information about the Transplant Centre, the procedures we carry out and how to contact or find us.

Website: www.ouh.nhs.uk/services/departments/renal/transplant

Oxford Transplant Foundation

Information about the surgeons who form part of our transplant team.

Website: www.oxfordtransplant.org.uk

Citizens Advice Bureau (CAB)

Offers independent advice and help to individuals and families on financial issues and debt management. Check local phone books for your nearest centre or visit their websites.

Websites: www.adviceguide.org.uk

Government advice and information on benefits and social and health matters

Website: www.dh.gov.uk

Carers UK

Information and support for carers.

Telephone: 020 7378 4999

Website: www.carersuk.org

Global Dialysis

Information on holidays and travel information for dialysis patients.

Website: www.globaldialysis.com

Diabetes UK

Useful information and support on many aspects of diabetes.

Website: www.diabetes.org.uk

Careline: 0345 123 2399

NHS Blood and Transplant - Organ Donation

Facts and figures on transplantation in the UK.

Website: www.nhsbt.nhs.uk/organ-transplantation

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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The Oxford Transplant Centre

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Oxford University Hospitals NHS Foundation Trust

www.ouh.nhs.uk/information



Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

