

Oxford University Hospitals **NHS**
NHS Trust

The Oxford Transplant Centre

Your Pancreas Transplant

Information for patients



Contents

	Page
1 Introduction	3
2 Where do donor organs come from?	4
3 What does the pancreas do?	6
4 What is the benefit of having a pancreas transplant?	6
5 Who can have a transplant?	7
6 Relevant investigations	7
7 How long will I wait on the waiting list?	11
8 What happens when I am called in?	12
9 What does the operation involve?	14
10 Where will I be cared for after following my transplant?	17
11 How long will I stay in hospital?	19
12 Delayed graft function	19
13 What drugs will I need to take?	20
14 What are the risks?	23
15 What happens to the kidney if the pancreas has to be removed?	26
16 What happens when I am discharged from the hospital?	27
17 What happens if I feel unwell at home?	28
18 Who can I call for advice?	28
19 Important points to remember	29
20 Useful contact numbers and addresses	31
21 Further information	33

1. Introduction

This booklet has been written to provide you with a range of information about pancreas transplantation. Together with information which you will receive from the Transplant Surgeon and the Transplant Recipient Coordinator during your presentation clinic appointment, it will give you a greater understanding of what having a pancreas transplant involves.

Pancreas transplantation is a treatment option for people with diabetes. A successful transplant can help you to achieve normal blood sugar levels and means you will no longer need to inject insulin. It also has beneficial effects on the other complications of diabetes, including damage to eyesight, nerves or the heart and blood vessels. There has been a rapid increase in the number of pancreas transplantations world-wide since the early 1990's. In the UK, the number of combined kidney/pancreas transplants has increased rapidly since this procedure was first funded by the NHS in 2004. The Oxford Transplant Centre performs 70 to 80 of these transplants a year and is one of the busiest centres in the world.

Transplant types

There are three different types of pancreas transplant that we carry out:

Simultaneous Pancreas Kidney transplant (SPK):

This procedure is performed if you have diabetes and progressive renal failure, are on dialysis, or are close to needing dialysis. You will receive a pancreas and kidney transplant during the same operation.

Pancreas after Kidney transplant (PAK):

This procedure is performed if you have diabetes and have already received a kidney transplant that is working well, but would benefit from a return to normal blood sugar control without insulin. You will receive a pancreas transplant only.

Pancreas Transplant Alone (PTA):

This procedure is reserved for people who have type 1 diabetes and who suffer from frequent hypoglycaemia (very low blood sugars), which usually requires urgent medical attention or help from another person to treat it. It is an option for diabetics who have very labile (or unstable) sugar control that is difficult to manage, despite maximum treatment. Your referring Consultant may decide with you that a pancreas transplant may be the best treatment for you.

2. Where do donor organs come from?

Cadaveric pancreas transplants

The term 'deceased donor (or cadaveric) transplant' is used to describe a transplant pancreas that has been removed from someone who has died. There are two types of cadaveric donor; Deceased after Brain Death (DBD) and Deceased after Circulatory Death (DCD). Consent is always sought from the donor's relatives before the pancreas is used, even if the donor's wishes were already known.

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

'DBD' donors are patients who have suffered permanent and irreversible brain injury, and are classed as 'brain stem dead'. A number of clinical tests are performed to confirm that there is no brain activity. Once these tests have been done, and if there is no response, a DBD donor can be legally declared dead. Such donors can be kept on a life support machine right up to the point at which organs could be removed for transplantation. Once tests have confirmed that their brain cannot recover from the injury, their relatives will be asked for permission for donation. When this is given, the donor will be taken to the operating theatre where their pancreas and other organs for donation can be removed whilst their heart is still beating.

- **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. They have an extremely poor prognosis and a decision has usually been made to withdraw treatment.

Consent is given by the family to remove the organs and then treatment is withdrawn. The patient usually dies a short time later from cardiac arrest (their heart stops beating). As soon as this has happened the organs for donation are retrieved before they start to deteriorate.

The most recent survey of UK data by NHSBT (National Health Service Blood and Transplant) indicates that success rates for DCD donor transplants are very similar to those achieved for DBD donor transplants. However, delayed graft function (see page 19) is more common with DCD transplants.

Living kidney donation

In some circumstances it may be worth considering whether a kidney transplant on its own from a living donor is the best option for you, instead of the combined kidney and pancreas transplant. Your assessing team will discuss this possibility with you in clinic, if it is felt to be appropriate based on your individual situation or medical history.

Living donors are people who are otherwise well and would like to donate one of their healthy kidneys to you. They are often a close relative, such as a parent, brother or sister, son or daughter. They can also be people who are not related to you but with whom you have an established emotional relationship, such as a partner or close friend. Whether a person is suitable for giving you one of their kidneys will depend on their overall health, whether they have any other significant medical problems and whether both of their kidneys function normally. Please ask for further information about eligibility for donation and what happens when someone wants to donate you their kidney.

3. What does the pancreas do?

The pancreas lies behind the stomach in the abdomen. It has two main functions. It produces juices that help with the digestion process and it also produces insulin from small clusters of cells called 'islet' cells within the pancreas. Insulin is responsible for lowering blood sugar levels. If you have diabetes, you no longer produce insulin and need insulin injections to keep your blood sugars within normal limits.

4. What is the benefit of having a pancreas transplant?

The main aim of a pancreas transplant or a combined kidney and pancreas transplant is to improve both the quality and the length of your life. Transplantation offers freedom from insulin injections and, in the case of a combined kidney and pancreas transplant, freedom from dialysis.

Diabetes causes a number of life threatening complications which may well be reduced or halted as a result of having a pancreas transplant.

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

Having a transplant can also offer you freedom from dietary and fluid restrictions, which you would have had to follow before your transplant.

5. Who can have a transplant?

A combined kidney and pancreas transplant is an option for people with kidney failure and diabetes who require insulin.

A Pancreas Transplant Alone (PTA) is the treatment of choice for most people who experience erratic blood sugar control (such as hypoglycaemic unawareness) despite taking insulin, but who also have normal or near normal kidney function. Not all people with diabetes are suitable for a transplant because of the need to be in relatively good health to have an operation. Most importantly, we need to know that your diabetes has not affected your heart. It is for these reasons that all people with diabetes being considered for pancreas transplantation will need to have a number of pre-operative cardiac (heart) investigations.

6. Relevant investigations

At your initial consultation, you will go through a thorough medical assessment with the Transplant Consultant and Transplant Recipient Coordinator (Specialist Nurse). During the visit you will have a number of blood tests and a chest X-ray, if you have not had these done in the past 12 months.

You will also be asked to arrange a dental review if you have not visited the dentist recently. This is important, because after your transplant you will take anti-rejection medications which can alter your body's ability to fight infections. It is important to have good dental hygiene in order to avoid dental infections or other problems such as gingivitis (gum inflammation) after a transplant. If you are not currently registered with a dentist, you can call NHS 111 for advice on finding an NHS dentist in your area. To access NHS 111, just dial 111 from your telephone. It is a Freephone number from both landlines and mobiles.

If you are a woman, we will need you to be up to date with relevant general health screening. This includes mammography (breast screening) every 3 years for women over the age of 50

and cervical smear tests every 3 to 5 years between the ages of 25 and 64. These should be arranged through your GP.

Included in your review will be an assessment of any other medical conditions you may have. Depending on what these are, you may then be referred for some additional tests.

Cardiac tests

These tests may include a **myocardial perfusion scintigraphy scan (MPS)** which, depending on the results, may be followed by a more detailed test called a **coronary angiogram** (see next page). This decision is made by the cardiologist (heart specialist).

■ Myocardial perfusion scintigraphy

The test is usually performed at the Nuclear Cardiology Imaging Centre at the John Radcliffe Hospital in Oxford, or at your local hospital. If you need this test, an appointment will be sent to you following your initial consultation. **It is vital that you come for this test, as without this we cannot move on to discuss placing you onto the transplant list.**

The purpose of this test is to compare the blood flow to your heart muscle when it is at rest and then under stress (usually from exercise). By comparing these images, it shows if there are any areas of decreased blood flow to your heart muscle during stress (when your heart beats faster and needs more blood) or can give an assessment of previous damage to your heart muscle. If you are not able to exercise, you will be given an injection of intravenous medication that will make your heart work harder, to mimic the effects of exercise.

During the scan, a camera will take pictures of your heart after a special drug (radioactive tracer) is injected into a vein in your arm. This will show up clearly on the X-ray pictures. The tracer travels through your blood and into your heart muscle. As the tracer moves through your heart muscle it is absorbed into areas that have good blood flow. Areas that do not absorb tracer may not be getting enough blood or may have been previously damaged by a heart attack.

Results

Test results of your MPS scan will be sent to the Transplant Recipient Coordinators, who will contact you about the result. We will telephone you when they come in. If you have not heard from the Transplant Recipient Coordinator 2-3 weeks after your test, please call us.

Normal:	The radioactive tracer is evenly distributed throughout your heart muscle. Your heart muscle is receiving an adequate volume of blood.
Abnormal:	Some areas of heart muscle are not getting enough blood (ischaemia). This may mean that your heart has been damaged or coronary artery disease is present. Your heart is enlarged and the left pumping chamber (ventricle) is not working well.

■ Coronary angiogram

If your myocardial perfusion scintigraphy scan is abnormal, the cardiologist may want you to have an angiogram. A coronary angiogram can show whether your heart arteries are narrowed, to what degree, and where the problem is located.

During the angiography a thin flexible tube (catheter) is threaded through an artery in your arm or leg, up into your heart. A type of dye (contrast dye) is then injected into the catheter. The dye allows us to see if your coronary arteries are narrowed/blocked and how well your heart is pumping.

The results of any heart tests will be sent to the transplant surgeons. The Transplant Recipient Coordinator will contact you to discuss these results and tell you about any further tests you might need. If you have not heard from the Transplant Recipient Coordinator 2-3 weeks after your test, please call us.

Further tests

Other tests that you may need after your initial assessment are:

■ Magnetic resonance angiogram (MRA) or Computed Tomography(CT) of the pelvis and legs

This is a test which can be carried out in the radiology department at your local hospital or in Oxford. The test involves having a dye injected into your groin area and a series of pictures taken by a machine called an image intensifier, to look at the arteries in your legs. This will assess whether your arteries are narrowed or blocked. The surgeon needs to know if your arteries are good enough to be able to transplant the kidney without affecting the blood supply to your legs. The result of this test is sent to the transplant surgeon who will decide if any further treatment is required.

■ Doppler scan

Another test that you may need is a Doppler scan of your arteries and veins, to assess the flow of blood. You will have this test in the ultrasound department at your local hospital. The test involves having gel put onto your groin area and lower abdomen. The technician will then place a probe on your skin and move it around. The blood flow in your arteries and veins will be shown on a monitor. The results of the scan will be shown to the transplant surgeon.

7. How long will I wait for a transplant?

How do I get onto on the waiting list?

If all of your test results are within normal limits then the Consultant Surgeon will put your name forward to be placed on the transplant waiting list. Whether you are suitable for a pancreas transplant will be discussed at a weekly meeting of surgeons, heart specialists, anaesthetists and Specialist Nurses. If it is agreed that you are suitable, you will be added onto the transplant list.

The Transplant Recipient Coordinator will contact you after this meeting and advise you of the outcome.

Occasionally some people are felt to be too high risk or not suitable to receive a transplant and are declined the option of a pancreas transplant. In this situation, your care would be referred back to your original Consultant. The reason for this decision would be fully explained to you.

How long will I be on the waiting list?

Once you and the Transplant team decide that a pancreas transplant alone or a combined kidney and pancreas transplant is an acceptable option for you, the next step will be waiting for the organs to become available. Your name will be added to the National Transplant waiting list.

It is not possible to predict how long you will have to wait, but as a guide, the average waiting time in 2014 was 14 months. It may be shorter or longer than this, depending on your individual circumstances.

When the Consultant Surgeon On-call at the Transplant Centre is told of a potential pancreas (and kidney, if needed) becoming available, then the person who is the best match for that transplant will be called in. This person is selected based on a number of factors, including how long they have been on the waiting list. This process of matching the recipient to a suitable donor is carried out through a national allocation scheme.

What happens while I am on the waiting list?

Your local diabetes or renal specialist will continue to monitor your condition and kidney function. If there is any significant change in your medical condition this will be reported to the Transplant Unit in Oxford. Once a month, a blood sample must be sent to the Transplant Immunology (Tissue Typing) laboratory in Oxford. This sample will be needed when potentially suitable donor organs become available, as it is essential for final matching with the organ/s. It is extremely important that you have this blood sample taken and sent reliably because, if an up to date sample is not available in the laboratory, this may prevent you from receiving a transplant on that occasion.

We will offer you an appointment to be seen by us each year to confirm that you still want to receive a transplant and to assess your physical fitness. We will also organise an annual heart stress test for you locally or in Oxford. This is to check on how well your heart is working and your fitness for surgery. It is important to keep in touch with us and tell us about any changes to your health or medications, throughout your time on the waiting list.

While you are waiting for your transplant your local team will monitor your health as usual. They may request additional tests and procedures for you. If you are concerned about this, please contact us (see phone numbers at the end of the leaflet). We would also encourage you to keep an eye on your weight and, if you are a smoker, to seek help to stop.

8. What happens when I am called in?

When the Transplant Recipient Coordinator calls you (which often will be in the middle of the night), they will ask you 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 told whether you are the 'first choice patient' or the 'back up patient'. Due to the fragility of the organs, it is necessary for us to call more than one recipient, just in case there is a problem and the first choice patient cannot receive the transplant. This

will have been explained to you by the Transplant Recipient Coordinator at your clinic visit.

The Transplant Recipient Coordinator will give you advice about eating and drinking, in preparation for the surgery. You will be asked to come to the Wytham Transplant Ward in the Oxford Transplant Centre, at the Churchill Hospital. It is important that you arrive as soon as possible and by your own means of transport if possible.

The Transplant Recipient Coordinator has a very limited time in which to contact you. If you cannot be contacted quickly they will have to identify an alternative patient to offer the transplant to. This is why it is so vital that you remain contactable at all times.

There may be times when we call you in for your transplant and we are unable to go ahead with your operation. This can be because we have received new information about your donor, or the organ may be damaged and therefore not suitable for transplant. In order to give you the greatest opportunity to receive a transplant we will ask you to start your journey to Oxford once we have accepted the offer of an organ. If the Transplant Recipient Coordinator then receives new information about your donor which means your transplant cannot proceed, they will call you and ask you to return home. We do understand that this can be emotionally difficult and we will do our best to ensure you are kept informed at all times.

What happens on the ward?

When you arrive on the ward the nurse will show you to your bed. They will ask you some questions about your general health and dialysis. Occasionally there may not be a bed immediately available, however staff will do their best to make you feel comfortable within the ward environment and will find a bed as soon as possible.

The doctor and anaesthetist will come and examine you and ask more questions to make sure you are in good health for

the operation. You will have further blood samples taken. By the time you have arrived at the hospital, the crucial first test will usually be underway; this is called a cross-match. The cross-match test involves a recent sample of your blood and cells being checked for any antibody reaction to the blood and cells of the donor. Antibodies can react and attack the donor blood and cells as if they were germs trying to invade your body. This test is to see if there is compatibility and no reaction from your antibodies.

Usually this test is 'negative', meaning that there has been no reaction and that it is safe to go ahead with the transplant. If the result is positive this means that there has been a reaction and the organs are not suitable for you. This does not mean you will never have a transplant, but that you will need to wait for better matched organs.

While you are waiting for the cross-match the ward staff will carry out an ECG (a tracing of the electrical activity of your heart) to make sure that you have not developed any new heart problems. You will also be asked to sign a consent form for the operation. If there is anything you do not understand or would like further information about, please ask before signing the consent form.

You may need to have dialysis before you can have the operation. The ward nurses will arrange this for you.

9. What does the operation involve?

A pancreas and kidney (if required) from the same donor will be transplanted at the same time. A pancreas transplant alone operation takes 3-4 hours. A combined kidney and pancreas operation takes about 4-6 hours.

The surgeon will place the pancreas in one side (usually the right side) of your abdomen and the kidney (if required) on the opposite side (usually the left). Your own pancreas and kidneys will remain in place. The operation involves connecting the

blood supply of the organs to the vessels that take blood to your legs. In addition to connecting these blood vessels, another connection has to be made into your small intestine or to your bladder to drain the digestive juices that the pancreas produces. All this is performed through one cut (incision) in your abdomen, from below your breastbone to below your bellybutton.

If you have a diabetic complication called gastroparesis (where you have difficulty absorbing food and medications), the Consultant Surgeon may insert a special tube called a jejunostomy directly into your small intestine at the same time as the transplant. 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.

If you receive a pancreas transplant alone, the surgeon may connect your new pancreas to your bladder at the time of your operation. This is called "bladder drainage". Your new pancreas will produce juices that, if bladder drained, will drain into your bladder and be passed out of your body in your urine. This enables us to analyse your urine to check the level of amylase, in order to see how well the graft is functioning. Bladder drainage appears to be associated with improved graft survival outcomes, however it can cause a number of side-effects, which include irritation of your bladder lining (called chemical cystitis) and dehydration. To prevent and treat these symptoms you will be advised to drink plenty of fluids after your surgery and to take additional medications (sodium bicarbonate tablets).

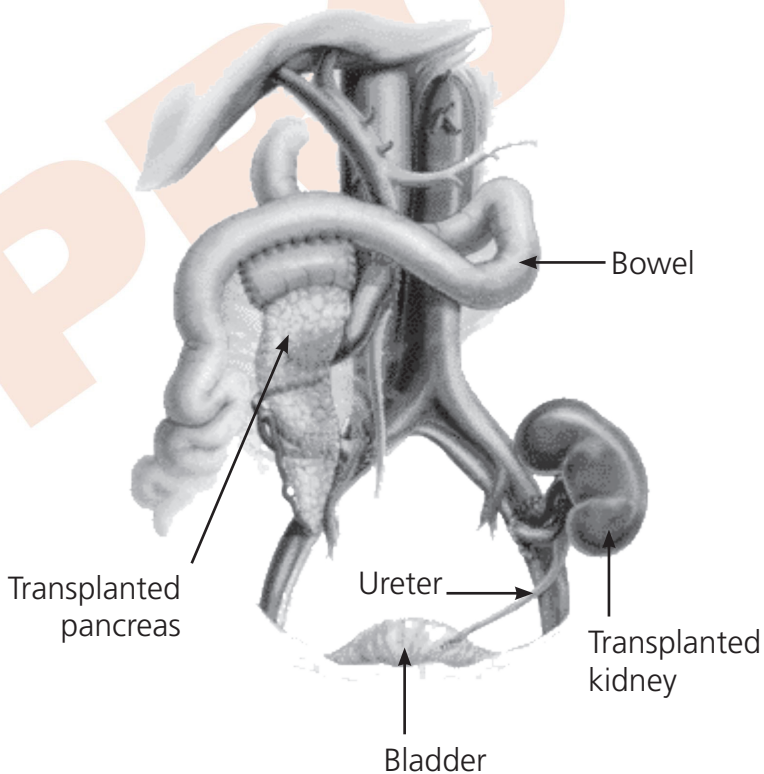
This procedure enables the Transplant team to closely monitor the function of your new pancreas using a urine test, and to detect and treat signs of possible rejection early. This will help prolong the life of your new transplant.

If the side-effects are affecting the quality of your life, the transplant surgeon may advise we change the connection from your bladder to your bowel. This would require a further smaller

operation in Oxford. The procedure and timing of this will be explained to you by the Transplant team.

We may not carry out bladder drainage if you have existing bladder emptying problems caused by your diabetes, or your kidney function is at a level where bowel drainage will be a better option for you. This will have all been explained to you at your first consultation.

The following picture shows you where the pancreas and kidney are placed in the abdomen during a transplant.



10. Where will I be cared for after my transplant?

The operation is carried out at the Churchill Hospital. You will spend the first 12-24 hours in the Intensive Care Unit (ICU) or High Dependency Unit (HDU). This is because of the length of time you are under the anaesthetic and the need to monitor you closely after your surgery. You will then be transferred to the Transplant Ward.

Waking up in the Intensive Care Unit (ICU) or the High Dependency Unit (HDU)

After your surgery you will wake up in the ICU or HDU. These are some of things you can expect.

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. This is called a **PCA** and stands for 'patient controlled analgesia'. 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.

You will have an **intravenous line** (a sterile plastic tube inserted into a vein) in both your arm and your neck. This will be used to give you fluids and drugs for the first few days after your surgery. You will also have a **urinary catheter** in place so we can measure the volume of urine you are passing. You will need to have this in place for about 5 days.

You will have a **nasogastric tube**, which is a thin tube that is passed into your nose and down into your stomach. It helps to keep your stomach empty or 'decompressed', to protect the area where your new pancreas is attached to your small intestine. You may also have one or more **abdominal drains** in place, to help remove any excess fluid from your abdomen.

You will need physiotherapy to help you to clear your chest and

cough effectively following your surgery. This helps to prevent you from developing chest infections. You will also have an oxygen mask on your face after your surgery, to ease your breathing. You will need to wear this for 24 to 48 hours, or until the medical team caring for you tell you that you no longer need it.

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

On the Transplant Ward

On the day after your surgery, or when we feel you have recovered enough, you will be transferred back to the Transplant Ward. You will be monitored very closely by the nurses and surgeons. Nursing staff will regularly measure how much urine you are passing and your blood sugar levels. They will also check your blood pressure, pulse and temperature 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 will be attached to a monitor that will measure your blood pressure, pulse and oxygen level. You will continue to have an intravenous line in your neck and/or arm for fluids and drugs, as well as the patient controlled analgesia (PCA) for pain control. This will be removed when you can take your painkillers by mouth. You will also continue to have your catheter, nasogastric tube and abdominal drains in place. These tubes and lines will gradually be removed as your recovery progresses.

Your blood sugar levels will be checked at regular intervals, so that we can monitor how well your new pancreas is working. You may receive some insulin in the early days after your operation. The insulin can be given through your intravenous line.

Whilst you are an inpatient on the Transplant Ward we will carry out a special ultrasound called a Duplex or CT scan. This scan

looks specifically at the blood flow of your new pancreas (and kidney, if required). The scan will show up any narrowing or blockages of the blood vessels.

11. How long will I stay in hospital?

How long you need to stay in hospital will depend on your progress following the transplant. The usual length of stay is 2-3 weeks. During this time the function of your new transplant will be monitored very closely.

Day by day you will feel stronger, become more able to move around, and be encouraged to start taking care of yourself little by little. As you feel better, you will be given time to learn about your new medications and how to take care of yourself and your new transplant when you are discharged home.

12. Delayed graft function

Sometimes the transplanted kidney does not work immediately. This is called **delayed graft function**. During this period we will closely monitor you. If you were previously on haemodialysis, you will need to continue with this until the new kidney starts to work properly; this may take a few days. If you were on peritoneal dialysis you may need temporary haemodialysis, as you will not be able to have peritoneal dialysis after your transplant surgery. During this time tests will be done to try and find out the cause of the delayed function.

13. 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 immunosuppressant drugs. Although these drugs protect your new transplant from rejection, they also reduce your ability to fight some infections. This means that you will also need to take other medicines that will protect you from the infections to which you are vulnerable.

The dosage of the immunosuppressant medications will be reduced over the next few months, following your transplant, however you will still need to take these medications for life, or as long as your transplant is functioning. **You should never stop taking these medications.** 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 and for one day afterward, 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 drugs, tacrolimus (Adoport) and mycophenolate. As with all medications, these drugs have some side-effects. However, it is important to remember that you may not experience all or any of these. Please speak to a member of the Transplant team if you are having problems with side-effects, as there may be an easy solution. Common side-effects of these medications are listed below.

Tacrolimus (Adoport)

- shaky hands
- upset stomach (usually when first taking this medicine)
- sleep disturbances
- increase in blood pressure
- an increase in blood sugar (diabetes); this will be monitored by us, using blood or urine tests

- hair loss
- mood changes
- headaches.

Mycophenolate

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

Research is on-going into new anti-rejection medicine, with the aim of reducing the side-effects and prolonging the life of the transplant. We will let you know if there are any new medicines that become available.

Self-medication training

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, and the nursing staff are happy that you are taking them correctly, 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.

Long-term immunosuppression medication

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

Research into new anti-rejection medicine continues, with the aim of reducing the side-effects and prolonging the life of the transplanted kidney.

Infections

As the anti-rejection medications suppress your immune system, you will be at greater risk of infections. These infections can be more serious 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.

Chicken pox may cause a serious illness while you are taking the immunosuppression tablets. 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.

Even if you do have immunity, you will still need to avoid close contact with anyone who has chicken pox or shingles.

14. What are the risks of transplant surgery?

With all transplant operations there are associated risks and potential for problems to occur during the operation and afterwards. The most common problems are listed below.

- **Bleeding**

As with all operations, there is a risk of excessive bleeding. This is more likely in pancreas transplantation, as a number of medications and infusions are given after the operation to keep the blood thin and prevent thrombosis (clotting) in the pancreas graft. Approximately 10% of patients (10 in 100) have some bleeding after transplantation that requires a return to the operating room, to check on the pancreas and control any bleeding.

- **Thrombosis**

There is a risk of a blood clot forming in the blood vessels to the transplant. This is called a thrombosis and can occur in 2 out of every 10 patients (20%). It can lead to the failure of the pancreas (or kidney). This is most likely to happen 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 measure how effectively your blood is clotting. You will be given various drugs to minimise the risk of a blood clot forming. However, these drugs can increase the risk of bleeding.

- **Pancreatitis**

Pancreatitis is inflammation of the pancreas and can make you very sick. This occurs because of damage to the pancreas during the process of re-warming it with your blood, after it has been stored on ice before the transplantation. If you develop graft pancreatitis 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. Pancreatitis of the transplanted pancreas usually

gets better on its own, but approximately 5-10% of people (5 to 10 in 100) who develop this problem will need the transplanted pancreas to be removed.

- **Further operations**

Approximately 1 out of every 5 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, should they arise. This may be followed by a further stay on Intensive Care or the High Dependency Unit.

- **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 immunosuppressant 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, by using white blood cells to attack it. Immunosuppressant medications help to control this response. However, rejection will still occur in about 1 in 4 transplants. Rejection can affect the pancreas or kidney, or both organs at the same time. In order to find out whether your body is rejecting the organ you may need a biopsy. This is a sample of the organ that is collected using a long needle. This is carried out using local anaesthetic to numb the area where the needle is to be inserted. Rejection can usually be treated successfully with additional immunosuppressant medications.

• **Patient and transplant survival**

The Oxford Transplant Centre has been carrying out pancreas transplants since 2004. The unit has now carried out this type of transplant over 700 times.

As with any major abdominal surgery and anaesthetic, there are risks to life. Your Consultant Transplant Surgeon will discuss the balance of risks and benefits with you at your assessment. This will include any specific risks that may apply to you.

The National Blood and Transplant Service statistics (2014) show that 1 year after a pancreas transplant 96% of patients (96 out of 100) are still alive and at 5 years 90% of patients are still alive (90 out of 100).

The National Blood and Transplant Service statistics show that in Simultaneous Pancreas Kidney (SPK) transplants the transplanted pancreas remains working after 1 year in 85% of people (85 out of 100). After 5 years this figure falls to 77% (77 out of 100 people).

In pancreas alone transplant (where there is no kidney transplanted), the data from the Oxford Transplant Centre shows the transplanted pancreas remains working after 1 year in 85% of people (85 out of 100). After 5 years this figure falls to 58% (58 out of 100 people).

15. What happens to the transplanted kidney if the pancreas has to be removed?

In the majority of cases the kidney will not be affected and will continue to function. If you and your Consultant decide that you want to be considered for a further transplant then we will refer you back to the Oxford Transplant team. We will then discuss with you the risks and benefits of a further pancreas transplant.

16. What happens when I am discharged from the hospital?

Once you have been discharged from the hospital you will still be monitored very closely. This is because changes in your condition can develop very quickly in the first few months after your transplant. For this reason you will need to visit the outpatient department three times a week after your transplant, to begin with. The frequency of your visits will gradually be reduced and adjusted, depending on your condition.

Your post-operative care will be shared between Oxford and your local centre. You will be told where your local centre is. How often you need to come to an outpatient appointment in Oxford will depend on which part of the country you come from. The doctors in Oxford will work very closely with your local centre.

If you have had a combined kidney and pancreas transplant then you will have had a stent placed in the ureter (between the kidney and the bladder). This will need to be removed under local anaesthetic 4-6 weeks after your transplant. If you are being followed up in Oxford then you will be asked to come to Wytham Transplant ward as an outpatient to have the stent removed under local anaesthetic. If you are being followed up at one of our local centres your nephrologist will need to arrange for you to have this procedure carried out there.

If possible, we recommend that you buy a blood pressure monitor, thermometer and weighing scales before you are called in for transplant, as you will need these after you are discharged, so that you can monitor your own health at home. Unfortunately they are not supplied on the NHS. Please ask a friend/relative to bring these into hospital before you go home, so they can be calibrated (set correctly).

17. 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 **Post-transplant Nurse Practitioners** can be contacted from Monday to Friday, during the hours of 9.00am to 4.00pm:

Tel: **01865 225 375**

Or you can bleep them through the main hospital switchboard:

Tel: **01865 741 841** – ask for bleep **5167**

If you have a problem outside of these hours (between 4.00pm and 9.00am) you can speak to a qualified nurse on the Transplant Ward.

Tel: **01865 235 011**

18. Who can I call for advice?

Being in hospital for any amount of time can sometimes cause other problems, at home or at work. There are patient support workers within the Renal Unit who can provide a confidential counselling service for you and your family members on a wide variety of personal matters. Please ask the nursing or medical staff if you wish to speak to them, or call the Patient Support Line:

Tel: **01865 225 781**

(24 hour)

19. Important points to remember

Change of circumstances: When you are listed on the transplant waiting list, please tell the Transplant Recipient Coordinator immediately of any change in your circumstances, such as holidays, change of address, telephone number, or if you are admitted to any hospital.

Tel: **01865 228 658** or **01865 228 659**

There is an answerphone available if we are unable to take your call. We will call you back by the end of the next working day. Leave a message with your name, contact number and your reason for calling.

Dialysis

If you are not on dialysis when you are first assessed in the clinic, but you then start haemodialysis or peritoneal dialysis, please telephone Transplant Recipient Coordinator to let them know. Changes are being made to the criteria for organ allocation, which means that you may be more likely to be considered for a transplant if you are already established on dialysis.

If you are on haemodialysis you need to inform your dialysis centre when you have 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, as it involves you having a small amount of a radioactive tracer put into your bloodstream. Please also avoid routine blood tests for 24 hours after you have had a myocardial perfusion scintigraphy scan.

If you are having peritoneal dialysis, please bring enough peritoneal dialysis supplies (such as caps) and a bag warmer to all hospital appointments, in case there is a delay.

Monthly blood samples for antibody screening

Once you are on the transplant list it is essential that you have monthly blood samples, so that we have up to date information about your antibody levels. You will be informed when you are activated 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, by first class post to the 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.

Blood transfusions

Once you are active on the transplant list you must tell us immediately about any blood transfusions that you receive. We will ask you to send us additional monthly blood samples to check for antibodies that you may have acquired from the blood transfusion. If you need additional supplies at any point, call the Transplant Immunology (Tissue Typing) Laboratory, who will post these to you.

Tel: **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 you might be at any time. Please do not have your answer machines on, especially at night, as we may be trying to call you for a transplant and we will not leave a message. The Transplant Recipient Coordinator has a limited amount of time in which to call you in for the transplant when a donor organ becomes available. If we cannot get hold of you we will call the next suitable person on the list.

If you change your mind

If you decide a transplant is not for you, please let your Transplant Recipient Coordinator know immediately so we can take you off the waiting list.

Transport arrangements for your transplant

In the event of you being called in for a transplant, it is important that 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. You will need to make your own transport arrangements to get to and from the Churchill Hospital. If you think you might have problems arranging transport, please discuss this with us.

20. Useful contact telephone numbers and addresses

The Oxford Transplant Centre

Churchill Hospital
Old Road
Headington
Oxford OX3 7LE

Tel: 01865 225 355/56

Churchill Hospital Switchboard

Tel: 01865 741 841

Transplant Recipient Coordinator (Kidney/Pancreas Programme)

(to be completed by Coordinator)

E-mail: @ouh.nhs.uk

Tel: 01865 228 658

Transplant Recipient Coordinator (Kidney/Pancreas Programme)

(to be completed by Coordinator)

E-mail: @ouh.nhs.uk

Tel: 01865 228 659

Transplant Ward

Tel: 01865 235 011

Renal and Transplant Outpatients (Appointments)

Tel: 01865 225 355

Tel: 01865 225 356

Renal and Transplant Nurse Practitioners

Tel: 01865 228 662

Secretary to Consultant Transplant Surgeons

Tel: 01865 228 675

Patient Transport Service

Tel: 0300 100 0015

Monday to Friday, 7.00am - 7.00pm (Oxfordshire patients only)

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21. Further information

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.

Tel: **01865 221 429**

(Monday to Friday, 9.00am to 5.00pm)

Email: hereforhealth@ouh.nhs.uk

Website: www.ouh.nhs.uk/HereforHealth



Oxford Kidney Unit

Information about the Oxford University Hospitals Kidney Unit, which provides a regional service for Oxfordshire, Buckinghamshire and Swindon.

Website: www.ouh.nhs.uk/oku/

Oxford Transplant Centre

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

Website: ouh.nhs.uk/services/departments/renal/transplant/default.aspx

Oxford Transplant Foundation

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

Website: oxfordtransplant.org.uk/oxford-transplant-centre/consultant-medical-teams.html

National Kidney Federation (United Kingdom)

This charity has a patient advocacy service and can be contacted through the National Patients Helpline.

Website: www.kidney.org.uk

Tel: 0845 601 0209 (calls are free from a UK landline)

British Kidney Patient Association

Website: www.britishkidney-pa.co.uk/

This charity has a telephone counselling service for patients and families who do not have access to a counselling service at their local hospital.

Tel: 01420 541 424

Disability Action Alliance

A UK based organisation providing advice and support for people with disability.

Website: <http://disabilityactionalliance.org.uk/>

Tel: 0207 247 8783

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.nacab.org.uk

or www.adviceguide.org.uk

Government advice and information on benefits and financial matters

Website: www.dh.gov.uk

Benefit Enquiry Helpline (DWP)

For information on healthcare entitlements and charges.

Tel: 0800 882200

Carers UK

Information and support for carers.

Tel: 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/

NHS Choices – Find an NHS Dentist

Information on finding a local NHS dentist.

Website: www.nhs.uk/NHSEngland/AboutNHSservices/dentists/Pages/find-an-NHS-dentist.aspx

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If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

Mr James Gilbert, Consultant Transplant & Vascular Access Surgeon
Shirley Lockhart, ANP Pancreas Transplant Programme
The Oxford Transplant Centre
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Review: July 2018
Oxford University Hospitals NHS Trust
Oxford OX3 9DU
www.ouh.nhs.uk/information

