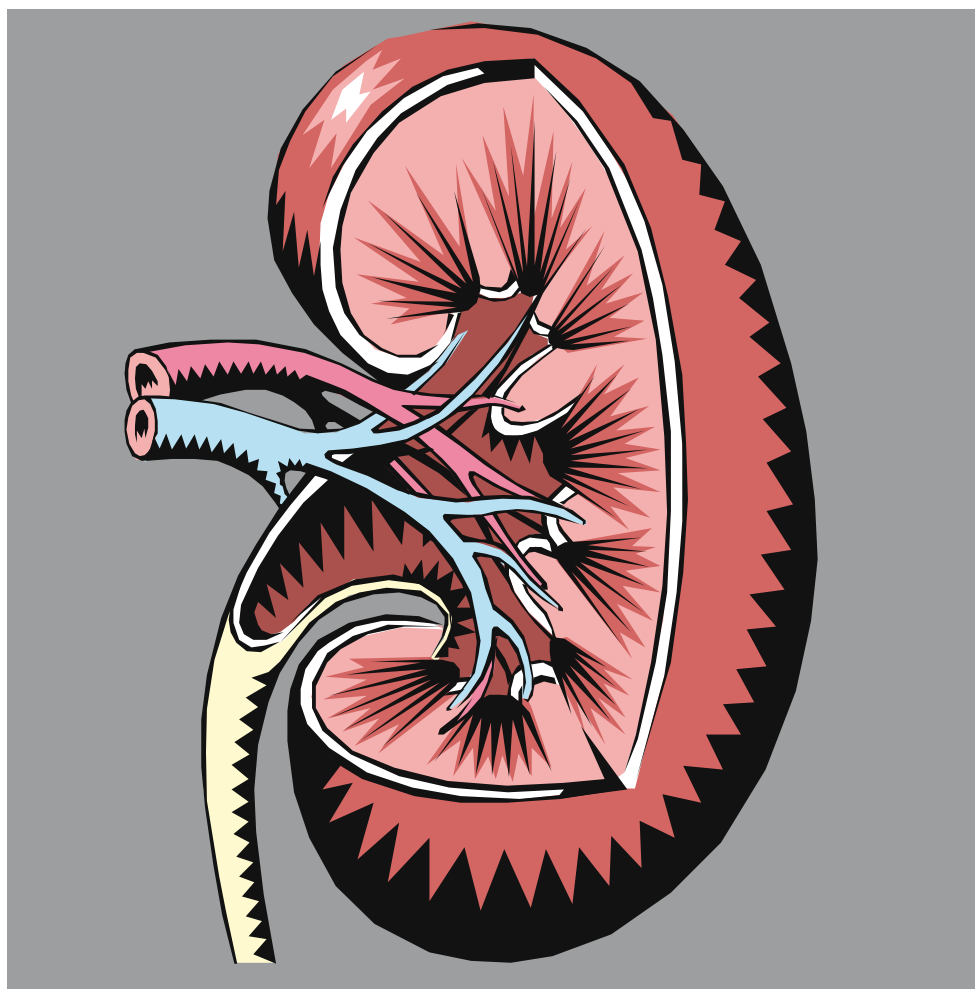


The Oxford Transplant Centre

Your Kidney Transplant

Information for patients



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Introduction

This booklet is for you to take home after your assessment appointment with the transplant surgeon and the Transplant Recipient Coordinator.

This booklet has been written to give you information about the risks and benefits of a kidney transplant. It will cover the information you will have discussed with your renal doctor, transplant surgeon and Transplant Recipient Coordinator. It is important that you fully understand this information, so please read this booklet thoroughly. If you have any questions, please speak to the nurse at your assessment appointment before you sign the consent form.

Kidney transplant

Kidney transplantation is the ideal treatment for people who have kidney failure. A successful transplant can achieve normal kidney function and frees people from needing dialysis. It can also have beneficial effects on the other complications of kidney failure and dialysis, including damage to the heart and blood vessels. A kidney transplant increases your life expectancy considerably, compared with dialysis.

Kidney transplants have been available through the NHS since the mid 1960s. Improved techniques have led to higher success rates over the years. These days, kidney transplant recipients can look forward to many years with an improved quality of life, which the freedom from dialysis brings.

Oxford Transplant Centre

The Oxford Transplant Centre is one of twenty-four transplant centres within the UK. It serves a large geographical area including Oxfordshire, Buckinghamshire, Berkshire and parts of Wiltshire, Gloucestershire and Northamptonshire.

Important points to remember

Change of circumstances

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

Tel: **01865 228660/228661/227370/228671**

(Monday to Friday, 8.00am to 6.00pm)

For all appointments

If you are on peritoneal dialysis, please bring enough peritoneal dialysis fluid and a fluid warmer to all hospital appointments, in case there is a delay.

Dialysis

If you are not on dialysis when we see you in the assessment clinic, but you then start haemodialysis or peritoneal dialysis, please tell us. Organ allocation criteria take account of dialysis status, 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 let your dialysis centre know if 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 a myocardial perfusion scintigraphy scan.

Blood transfusions

Once you are on the transplant list you must tell us immediately about any blood transfusions that you receive.

Monthly blood samples

Once you are on the transplant list it is essential that you have monthly blood samples. It is important that our Transplant Immunology (tissue typing) Laboratory have a monthly blood sample from you, so that they can monitor the levels of antibodies in your blood. You will be sent a letter once you are

put on the transplant waiting list, which will tell you what you need to do to make sure we receive these bloods.

If you are already on haemodialysis, these will automatically be sent off by the dialysis staff.

If you are not on dialysis or are waiting to start and have questions about blood samples, you can contact the laboratory staff who will advise you of what you need to do. The telephone number will be on the letter you receive confirming that you are active on the transplant list. They may send you a pack with the blood bottles for you to take to your GP or usual clinic to have your blood taken. Please return these to the hospital by first class post in the envelope provided. Please make sure you use the correct postage for the weight of the package. Please post samples back on a Monday, Tuesday or Wednesday. If you aren't able to send them on one of these days, please store the samples at room temperature until you are able to post them.

It is very important that we always have a current blood sample for you, as we may not be able to proceed with a transplant without this. Without a current blood sample, your transplant may be delayed, which will increase the time the kidney will be 'on ice'. The longer the kidney is 'on ice', the higher the chance of it taking longer to start working once implanted.

24 hour availability

Please make sure that your mobile phone is always switched on and that you have given us all phone numbers for where you might be at any time. Please do not have your answer-machine 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, the kidney will be offered to the next suitable person on the National Waiting List.

If you change your mind

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

Types of transplant

Cadaveric kidney transplants

The term 'deceased donor (or cadaveric) transplant' is used to describe a transplant kidney that has been removed from someone who has died or who has irreversible brain damage and is being kept alive by life support equipment. More than 60% of transplant kidneys in the UK come from this source. Consent is always sought from the donor's relatives before the kidney is used, even if the donor's wishes were already known. There are two types of cadaveric donors:

- **Heart beating donors (Standard Criteria Donor – SCD)**

'Heart beating' donors are patients who have suffered permanent and irreversible brain injury. 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 kidneys and other organs for donation can be removed whilst their heart is still beating.

- **Non-heart beating donors (Donation after Cardiac Death – DCD)**

'Non-heart beating' donors are patients whose organs are removed soon after cardiac arrest, when their heart has stopped beating and death has been certified. These patients would have had an extremely poor prognosis and it would have been agreed to withdraw any treatment that could help keep them alive. Consent is given by the family to remove the organs for organ donation soon after cardiac arrest, before irreversible damage has occurred.

The most recent survey of UK data by NHSBT (National Health Service Blood and Transplant) indicates that success rates for non-heart beating donor transplants at 1 year are very similar to those achieved for heart beating donor transplants. However, delayed graft function (see page 20) is more common with non-heart beating transplants.

You have the right to refuse a kidney that has been offered to you for transplant. This will not have any affect on your care or your position on the transplant waiting list.

Expanded criteria deceased donor kidney (ECD)

These are kidneys from heart beating donors either:

1. aged over 60 years
2. aged over 50 years with a history of high blood pressure, stroke as cause of death or with a known kidney impairment.

Approximately 25% of donors in the UK come from this category. By accepting one of these kidneys, you may receive a transplant sooner. These kidneys work well but may not work as well as kidneys from other categories.

High risk donors

Occasionally organs are used from donors with a history of intravenous drug abuse (injecting drugs), high risk activity for sexual disease, or certain cancers.

There are guidelines from the Advisory Committee on the Safety of Blood, Tissues and Organs (SABTO) for the use of organs from such donors. These organs are usually from young donors and work very well.

Dual adult donor kidneys

If the kidney function of a donor is less than 80% of normal, or a biopsy of the donor kidney shows evidence of kidney disease, good results may be achieved by using both kidneys from the donor and leaving your kidneys in place.

Paediatric donor kidneys

These kidneys are from a heart beating donor under 6 years old. There is a small risk of surgical complications due to the size of the kidney, blood vessels and urine drainage tube. These kidneys usually grow to adult size in 3 months. Both kidneys may be transplanted if the donor is under 2 years old.

The transplant surgeon will discuss these with you at the time of transplant.

Living kidney donation

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.

Clinical trials

Oxford is a Transplant Unit with a strong interest in research. You may be asked to join in a study or clinical trial when you are called for a transplant. You may also be sent information about research or clinical trials while you are on the waiting list.

You do not have to participate in any of these research trials and can withdraw from them at any time. Not taking part in these studies will not affect your care or your position on the waiting list.

What does a kidney do?

Most people have two kidneys, each about the size of a fist, located on either side of the spine at the bottom of the rib cage.

The kidneys are responsible for a number of functions. The most important function is removing waste products and balancing fluid levels in the body. Other functions include regulating your blood pressure, production of the hormone 'erythropoetin' which controls the production of red blood cells, and converting vitamin D from sunlight, which helps to make strong and healthy bones.

Why have a transplant?

The main purpose of having a kidney transplant is to improve not only the quality of your life but also the length of your life. Transplantation offers freedom from dialysis, as well as relief from many of the other symptoms of chronic kidney disease. If your diet or fluid intake has previously been restricted, having a kidney transplant should help you to be able to eat and drink more normally. Sexual function often returns to normal and women wanting to expand their family may be able to become pregnant, although this is not recommended within the first year.

Long term dialysis can cause cardiovascular complications (problems with your heart and blood circulation). These complications may be reduced or halted altogether as a result of having a kidney transplant. A successful kidney transplant has been shown to improve life expectancy substantially.

Who can have a transplant?

There is no upper age limit for having a kidney transplant, although it is important that whenever a kidney transplant is considered, the potential benefits outweigh any disadvantages. The transplant operation and treatment afterwards are both relatively demanding and therefore you will need to be fit enough to withstand the entire process. If you are very frail, or have multiple medical problems, the risks of undergoing a transplant may be too great and it may be decided that transplantation is not the best option.

The decision about whether transplantation is the best option will have been made by you, after discussing all the risks and benefits with your surgeon and nephrologist (kidney doctor).

Weight is an important factor for any surgery. Having a higher percentage of body fat increases the complexity and risks of surgery. It also increases the chance of complications afterwards. We will calculate your Body Mass Index (BMI) in order to assess the risks associated with surgery.

Will my kidneys be removed?

It is not usually necessary to remove your own kidneys before a transplant. If your kidneys are very large or cause lots of infections, the transplant surgeon will discuss this with you in more detail at your assessment.

How long will I wait for a transplant?

This question is always difficult to answer, as waiting time can depend on several factors, including your blood group, age, ethnicity, etc. On average, people who are listed for a deceased (cadaveric) donor transplant wait approximately two to three years, but this time frame can vary a great deal.

More information about allocation and centre specific outcomes can be found at:

www.kidney.org.uk/organ-donation

Relevant investigations

At your initial consultation, your transplant surgeon will go through a thorough medical assessment. You will also have a detailed discussion with the Transplant Recipient Coordinator. During the visit you will have a number of blood tests, as well as an ECG (electrocardiogram) and chest X-ray if you have not had these done in the past 6 months.

You will also be asked to arrange a dental review, if you have not visited the dentist recently. If you are not currently registered with an NHS dentist, you can call NHS 111 for advice on finding an NHS dentist. 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 50 years of age

and cervical smear tests every 3 to 5 years between the age 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. If required, you may then be referred for some additional tests. Not everyone will need these tests. The Transplant Recipient Coordinator will let you know at your assessment if you need any of these 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. If you need this test, an appointment will be sent to you following your initial consultation. You need to allow three to five hours for the MPS appointment.

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). It can also 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 takes 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.

How it feels

The MPS test is painless, however:

- You may feel a brief stinging or burning sensation when the needle is inserted into the vein in your arm.
- You may be uncomfortable lying still for half an hour, while you are on the table during the scans.
- If medicine to stress your heart is used, you may have symptoms of mild sickness, headache, dizziness, hot flushes, or chest pain (angina). These symptoms will only last a few minutes.
- If you are asked to exercise, you may experience chest pain, breathlessness, lightheadedness, aching in your leg muscles and fatigue. If you do, please report these to the technician. If the symptoms are severe, the exercise part of the test may be stopped.

Results

Test results of your MPS scan will be sent to the Transplant Recipient Coordinator, who will contact you about the result. We will telephone you when they come in.

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 test you will need to wear a hospital gown and lie on your back on an X-ray table. You may want to ask for a pad or blanket to make yourself more comfortable before the test begins. A lead shield or apron may be placed under your genital and pelvic areas, to protect them from X-ray exposure.

A round cylinder or rectangular box called a fluoroscope will be moved above and below you during the test. This captures the images of your arteries.

During angiography a thin flexible tube (catheter) is threaded through an artery of your arm or leg and up into your heart. A 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.

Before the procedure, the place where the catheter will be inserted (in your groin or above your elbow) will be shaved and cleaned. A local anaesthetic will be injected to numb this area. When the area is numb a needle will be inserted into the artery. A guide wire will be inserted into the artery through the needle, and the needle removed. The catheter will then be placed over the guide wire and inserted into the artery. It is then guided through the artery until the catheter tip is in the area to be studied. The catheter location will be checked using the fluoroscope. You may also need to have a small intravenous cannula (IV) inserted into your arm in case we need to give you any medications.

When the catheter is in place, the special dye is injected through it. During the injection you may be asked to take a breath and hold it for several seconds. A rapid series of X-ray pictures will be taken, developed, and brought up on the screen for the cardiologist to see immediately. You will be asked to lie very still to avoid blurring the pictures. We may need to inject more special dye, depending on the results of the images seen on screen.

An angiogram usually takes between one and three hours. This depends on how long it takes to position the catheter and how many X-ray pictures are needed.

When the test is over, the catheter is removed and pressure is applied for 10 to 15 minutes to the place where the needle was put in, to stop any bleeding. You will have a dressing put over the site and we can give you medicine for pain if you feel you need it. You will need to rest in bed after the test for several hours.

If the catheter was inserted into your arm, you should not have any blood taken from that arm or your blood pressure measured in that arm for several days. This is to help prevent any bleeding from the place where the needle was put in.

You will be given specific instructions for things to look out for after the test. You can apply an ice pack to the place where the needle was put in, to help relieve any pain and swelling you might have.

How it feels

You may feel nothing at all when the IV needle or the angiogram needle is put in, or you may feel a brief sting or pinch as the needle goes through your skin. Some people feel a stinging pain while the needle is in the artery. However, many people do not feel any pain (or have only minor discomfort) once the IV or catheter is in position.

The injection of local anaesthetic may sting briefly. You may also feel pressure within your artery as the catheter is moved. Do let your doctor know if you are uncomfortable, so you can be given extra local anaesthetic.

When the special dye is injected you will probably feel warmth near the area of your heart. This sensation lasts only a few seconds. For some people the sensation of heat is strong and for others it is very mild. You may also have a brief headache, flushing of your face, or a salty or metallic taste in your mouth.

These sensations will also pass quickly. Some people may feel nauseated or may vomit, but this is uncommon.

After the test, you may notice some tenderness and bruising where the catheter or IV was inserted.

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.

Other tests

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

■ Magnetic resonance angiogram (MRA) 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.

What happens when I am called in?

When the Transplant Recipient Coordinator calls you it could be at any time, day or night. The Transplant Recipient Coordinator has a limited time in which to contact you, therefore it is very important that we can contact you at all times. Please make sure we always have your correct contact details.

The Transplant Recipient Coordinator 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. The Transplant Recipient Coordinator may ask you not to eat or drink anything and to come to the Transplant Centre. You must arrive as soon as possible. You will need to make sure that you have transport available to bring you to hospital at any time of the day or night.

Occasionally, we may call you to tell you about the possibility of a transplant, but will ask you to remain at home. In this circumstance the Transplant Recipient Coordinator will keep in regular contact with you at home. They will let you know if we would like you to come in to the ward or whether the kidney is no longer available.

The transplant operation and hospital stay

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 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 may have further blood samples taken, so that tests can be performed to confirm the kidney is a good match for you. This is called the 'crossmatch'.

When the crossmatch result is available, you will be told that it is either 'negative' or 'positive'. If the result is negative, this means there was no reaction to the donor's tissue type (blood) and the transplant is a good match and can go ahead.

If the cross match result is 'positive' this means there was a reaction between the donor blood and your blood and it would be unsuitable to go ahead with the transplant. This does not mean you will never be able to have a transplant, it means you will need to wait for another occasion.

While you are waiting for the crossmatch you will have an ECG (a tracing of the electrical activity of your heart) and a chest X-ray. If you are on dialysis, you may also need to have dialysis before the operation. The ward nurses will arrange this for you.

There may also be other times when we call you in for your transplant and we are then unable to go ahead with your operation. This could be because we have received new information about your donor or we may find that the organ is damaged and therefore not suitable for transplant.

What does the operation involve?

A kidney transplant operation takes two to three hours. You will be given a general anaesthetic to make you go to sleep.

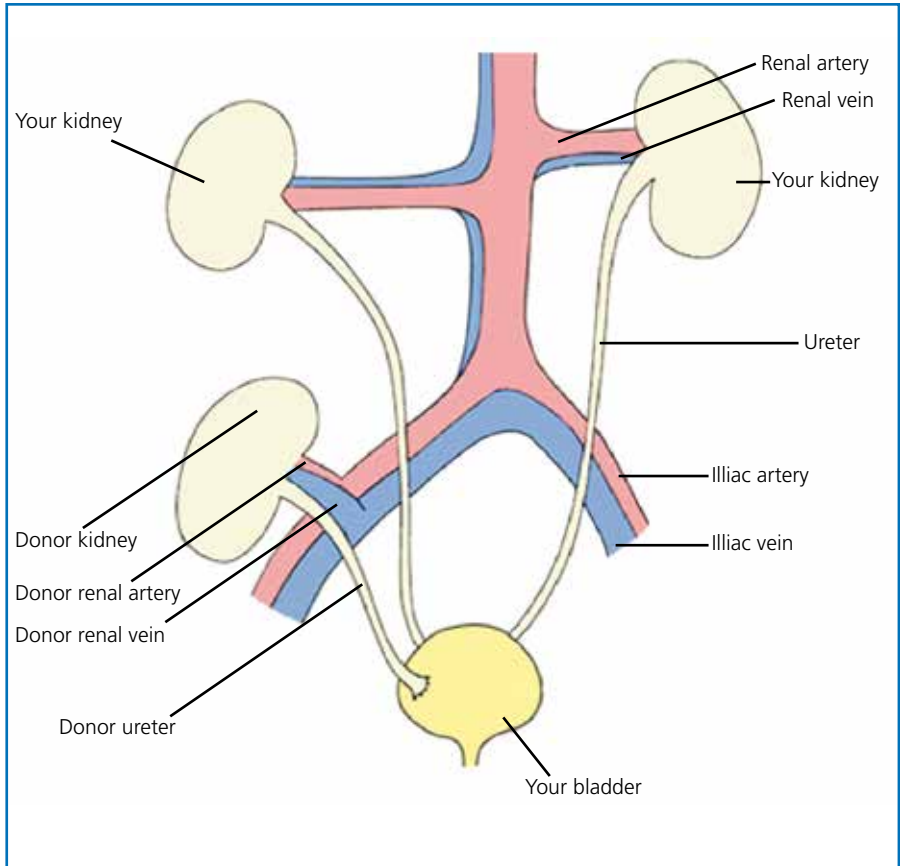
The surgeon will place the donated kidney in one side of your lower abdomen. The operation involves connecting the blood supply (artery and vein) of the new kidney to your own blood vessels. The new kidney's vein is joined to your own iliac vein (which takes blood from your leg back to your heart), and the kidney's artery is joined onto the iliac artery (which supplies your leg with blood).

The kidney outflow tube (ureter) is then joined to your bladder. This step of the operation will also involve the placement of a stent. The stent is a thin hollow tube which is placed inside the ureter to keep it open and allow the connection to your bladder to heal. All this is performed through one incision (cut) on your abdomen.

The stent will be removed 4 weeks after the transplant operation. This is done as a day case procedure under a local anaesthetic.

The following picture shows you where the donated kidney is placed in your abdomen during a transplant.

Placement of kidney transplant in the abdomen



Reproduced with the kind permission of www.ivy-rose.co.uk

What happens after the transplant operation?

After the transplant operation you will spend some time in the theatre while you come round from the anaesthetic. You will then be able to return to the transplant ward.

Pain

You may experience some pain and discomfort after the operation. This can be eased by the pain relief drip that you will have in one of the veins in your arm/hand. This is called a PCA (Patient Controlled Analgesia). This means you can control your discomfort by pressing a button when you experience pain. The pump then delivers a programmed dose of painkiller, which will ease your discomfort. The pump is specially programmed, so you cannot give yourself too much of the drug.

Additional tubes/drips

You will have an intravenous line in your arm (IV) and neck (central line), which will be used to give you fluids and drugs for the first few days after your surgery. You will also have a catheter placed in your bladder, so that the amount of urine you pass can be measured accurately. This is a way of checking how well your new kidney is working. You may have a drain (tube) coming out through the skin near your new kidney. This is to drain off any excess fluid from your abdomen. This will be removed within a few days.

You may also have an oxygen mask over your mouth and nose following your surgery. This will help to get rid of the remaining anaesthetic in your body.

The next few days

Over the following days you will be monitored very closely by the nurses and doctors.

You will be attached to a machine that will monitor your blood pressure, pulse and oxygen level.

You will continue to have a small plastic tube (central line) in your neck for fluids and drugs, as well as the PCA for pain control.

This can be removed when you are able to take painkillers by mouth. You will also continue to have your catheter in place for four days after the operation.

You may have an ultrasound scan of the transplanted kidney within the first few days. This is to look at the blood flow in the new kidney.

How long will I stay in hospital?

How long you stay in hospital will depend on how well you recover after the transplant. The usual length of stay is four to seven days. During this time, the function of your new kidney will be monitored very closely. Nursing staff will regularly monitor how much urine you are passing. 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 the function of your new kidney.

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

Delayed graft function

Sometimes the transplanted kidney does not work immediately. This is called **delayed graft function**. During this period we will 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 to start low volume PD or you may need haemodialysis. During this time tests will be done to try and find out the cause of the delayed function.

What drugs do I need to take?

In order to protect your transplanted kidney from rejection by your immune system you will need to take powerful medicines called immunosuppressants or anti-rejection medicines. Although these medicines protect your new organs from rejection, they also reduce your ability to fight infections. This means that you will need to take other medicines which will protect you from the infections to which you are vulnerable.

The dosage of the immunosuppressant medicines will be reduced with time following your transplant, but you will still need to take these medicines for the life of the transplant. If you were to stop taking the immunosuppressant medicines the new kidney could stop working and may be rejected by your body.

The common immunosuppressant/anti-rejection medicines used following kidney transplantation are tacrolimus (Adoport), prednisolone and azathioprine or mycophenolate. These medicines are used in a combination specific to your needs. Prednisolone tablets will be reduced and in some cases can be stopped after about three months.

At the time of the transplant we also use medicines referred to as **Induction Agents**. The two agents used in Oxford are basiliximab (Simulect) and alemtuzumab (Campath). These medicines help prevent your body from rejecting the donated kidney.

Alemtuzumab does not currently have a UK product license for use in transplant patients, but it is licensed for other medical conditions. It is available for individual transplant patients and is used in many transplant centres in the country. Please ask for our leaflet 'Unlicensed and off-label medicines' for more information.

As with all medicines, these immunosuppressant medicines 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 for immunosuppressant medicines are listed on the next page.

Tacrolimus (Adoport/Advagraf)

- hair loss
- headaches
- increase in blood pressure
- increased blood sugar levels (diabetes).
This will be closely monitored by blood and urine testing.
- mood changes
- shakiness of hands
- sleep disturbances
- upset stomach for a brief period.

Prednisolone

- facial puffiness – this usually become less of a problem when the dose is reduced
- increased appetite, weight gain
- increased blood sugar levels (diabetes). This will be closely monitored by blood and urine testing.
- increased hair growth
- rashes, bruising
- stomach irritation, indigestion.

Azathioprine and mycophenolate

- the most common side effect is a drop in white blood cell count. This puts you at risk of infection, as white blood cells normally help your body's immune system to fight bacteria/ viruses. Your blood count will be monitored and medication adjusted accordingly.
- hair loss (azathioprine)
- rash
- upset stomach, including diarrhoea, nausea and vomiting.

Self-medication training

Once you are comfortable after the operation you will begin to learn about your new medicines. 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 medicines yourself, closely supervised by the nursing staff.

Once you are confident with taking your new medicines, and the nursing staff are happy that you are taking them correctly, you will be able to take your medicines unsupervised, as you would do at home. This training aims to help you become familiar and confident with taking all your new medicines before you go home.

Long-term immunosuppressant medicines

These medicines put 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 medicines continues, with the aim of reducing the side effects and prolonging the life of the transplanted kidney.

Fertility and pregnancy

Fertility often returns after transplantation, so it is important that you use reliable contraception after your transplant.

We recommend to wait one to two years before trying for a baby and that you discuss this with the transplant team first, as your anti-rejection medicines may need to be changed. Mycophenolate especially must not be taken during pregnancy.

Infections

As the anti-rejection medicines 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. You should avoid close contact with anyone who has chicken pox or shingles. If you have never had chicken pox and come into contact with anyone with these infections, or children who develop chicken pox two to three days after you have had contact with them, you must contact the transplant unit immediately. You can be given some medication to help protect against this viral infection.

If you are unsure whether you have had chicken pox, please get in touch with us, so we can do a simple blood test and find out.

What are the risks of transplant surgery?

With all transplant operations there are associated risks and potential for problems to occur, both during the operation and afterwards. Some of these risks are highlighted below.

- As with all operations, there is a risk of excessive bleeding – this occurs in approximately 1% of people (1 in 100).
- There is a risk of a blood clot forming in the blood vessels to the transplanted kidney. This is called a thrombosis and occurs in 5% of cases (5 in 100). It can lead to the failure of the transplanted kidney. This can happen during the first week after the transplant and often results in the kidney being removed.
- In the early days following a transplant, the surgery and the immunosuppressant medicines may make your body more vulnerable to chest, urinary or other infections. You will be given antibiotics and anti-viral medicines to help prevent and treat any active infection.

- 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 medicines help to control this response. However, rejection will still occur in 15% (15 in 100) of all transplants within the first year. If your body does start to reject the transplant we can usually treat this successfully with additional immunosuppressant medicines.
- Other less common risks include pneumonia, reduced blood circulation to the leg, leaking of urine and narrowing of the ureter, deep vein thrombosis (DVT), transmission of a disease from the donor, return of the original kidney disease to the transplanted kidney, failure of the transplant to work, cancer and heart attack.

Blood transfusion

You may need a blood transfusion either during or after the transplant. Risks of receiving a blood transfusion include infection and allergic reactions. Blood transfusions can also lead to an increase in antibodies, which may make finding a suitable donor kidney more difficult if another is needed in the future. You will only be given a blood transfusion if it is essential.

Wound healing

After the transplant you may have a small amount of fluid leaking from the wound. This is usually managed with dressings. Approximately 5% of people (5 in 100) may have bleeding, infection, urine leakage or a hernia that may require an additional operation.

Pain

You are likely to have some pain at the operation site after your transplant. This usually gets better within a few weeks. Occasionally the pain may take longer to go. To help with this we will give you some extra painkillers. You may find you also have a small area of numbness around the scar, but this should get better.

Other risks

There have been very rare reports of an infection or cancer being present in a donor kidney which was not being diagnosed before transplant. All donor organs, including those from living donors 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.

Oxford Transplant Centre statistics¹ show that the survival rate (at one year after the operation) of a person undergoing a kidney transplant from a deceased donor is 98% (98 in 100). The survival rate of a transplanted kidney after one year is 95% and after five years is 89%.

Oxford Transplant Centre statistics¹ show that the survival rate after one year of a person undergoing a kidney transplant from a living donor is 99% (99 out of 100). The survival rate of the transplanted kidney after one year is 96% and after five years is 94%.

What happens when I am discharged from hospital?

When you have been discharged from hospital you will be monitored very closely, as changes in your condition can develop very quickly in the first few months after your transplant. For this reason you will initially need to visit the outpatient department three times a week following your discharge. The frequency of your visits will be reduced, depending on how well you continue to recover.

Below is the likely schedule of follow up visits after your transplant, although these may be changed according to your personal medical health.

Guide to follow up visits

<i>Post-op day/week</i>	<i>Frequency of visit</i>
Day 0-7	Inpatient
Week 2-4	Twice a week
Week 4-8	Once a week
Week 9-12	Fortnightly
Week 13-36	Fortnightly
Week 37-52	Once a month

You will be followed up by the Oxford Transplant team for six to twelve months after your transplant. After this time, you will be transferred back under the care of your referring kidney doctor (nephrologist).

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

What happens if I feel unwell at home?

The Oxford Transplant Centre is open 24 hours a day.

- The **renal post transplant nurse practitioners** can be contacted Monday to Friday during the hours of 8.00am to 4.00pm.
Tel: **01865 228 662** or **01865 228 663**
Or bleep through the hospital switchboard:
Tel: 0300 304 7777 – ask for bleep 5167
- If you have a problem **outside these hours** (from 4.00pm to 8.00am) you can speak to a qualified nurse on the ward, who will seek advice for you.
Telephone the **Transplant Ward**:
Tel: **01865 235 010** or **01865 235 011**

Who can I call for advice?

After the transplant operation, you may experience feelings of anxiety, depression and guilt. These feelings may interfere with your relationships with your family or friends. They may also cause problems with returning to work, obtaining future employment and getting insurance.

Sometimes these symptoms require treatment with medications or counselling. Please do talk to the Transplant Practitioners if you have any of these feelings, and they will refer you to the most appropriate person who can help.

Useful contact telephone numbers and addresses

Oxford Transplant Centre, Outpatients

Churchill Hospital
Old Road, Headington
Oxford OX3 7LE
Tel: 01865 225 355/56

Churchill Hospital Switchboard

Tel: 0300 304 7777

Transplant Recipient Coordinators

Tel: 01865 228 660
01865 228 661
01865 227 370

Living Donor Team

Tel: 01865 228 675

Transplant Ward

Tel: 01865 235 010

Post Transplant Nurse Practitioners

Tel: 01865 228 662

Secretary to the Consultant Transplant Surgeons

Tel: 01865 228 675

Useful websites to explore

www.ouh.nhs.uk

Oxford University Hospitals Trust website.

www.kidney.org.uk

The website of the National Kidney Federation in the United Kingdom.

www.globaldialysis.com

Gives details of holidays and travel information for people on dialysis.

www.transplantliving.org

Transplant information and resources.

www.nhsbt.nhs.uk

Facts and figures on transplantation in the UK.

www.nhs.uk/Pages/HomePage.aspx

NHS Choices website with information on many topics.

References

¹ 1 year data: Includes transplants performed between 1 April 2012 - 31 March 2016

5 year data: Includes transplants performed between 1 April 2008 - 31 March 2012

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**

Clare Snelgrove, Transplant Recipient Co-ordinators
Professor Peter J Friend, Professor of Transplantation,
University of Oxford. Director of Oxford Transplant Centre.
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Oxford University Hospitals NHS Foundation Trust
Oxford OX3 9DU
www.ouh.nhs.uk/information

