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NHS Foundation Trust

Pre-transplant Renal Education Programme

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Index

Helping you make the most of your kidney transplant at the Queen Elizabeth Hospital Birmingham, Renal Transplant Unit

Within this booklet we provide information for people waiting for a kidney transplant. This information is a basic guide only. Please contact us if you require any more information.

We are one of the biggest kidney transplant centres in the UK; performing approximately 150 transplants a year. We transplant patients from a number of hospitals, which include:

- Birmingham Heartlands Hospital
- New Cross Hospital, Wolverhampton
- North Staffordshire Royal Infirmary, Stoke
- Queen Elizabeth Hospital Birmingham
- Birmingham Children's Hospital (these transplants take place in that hospital)
- Royal Shrewsbury Hospital
- Russells Hall Hospital, Dudley

The kidneys that are used for transplantation are allocated to people on the national kidney transplant waiting list by an organisation called Organ Donation and Transplantation (ODT), or donated from living donors, who are usually known to the person receiving the kidney.

Currently kidney transplants occur on ward 305, which is a 36-bedded ward situated on Level 3 in the Queen Elizabeth Hospital Birmingham. Post discharge, extensive assessment and monitoring is required. This may be inconvenient but due to the nature of the operation it is essential. All patients except for Stoke patients will be required to attend Renal Outpatients Department 2-3 times a week, where you will remain under the care of a surgical consultant for the first three months. During your clinic appointment you may be seen either by a doctor, renal transplant coordinator or nurse.

Who can have a transplant?

Although renal transplantation is the preferred choice of treatment for many patients with End Stage Renal Failure (ESRF), only 20-30% are suitable. There are several reasons why an individual may fit into this category, if you do the renal transplant surgeon will refer you back to your consultant nephrologists to discuss with you further.

Is a transplant right for me?

For many people with kidney disease having a transplant is the right choice. However you need to decide if it is right for you.

Potential benefits of a transplant:

- Better long-term health compared to receiving dialysis
- Freedom from dialysis
- Freedom from dietary and fluid restrictions
- Improved energy levels
- Improved fertility
- Ability to work and travel more freely
- Preservation of access options
- Improved quality of life

Potential disadvantages of a transplant:

- Risk of failure
- Risk of loss of life
- Risk of bleeding or clotting
- Risk of chest infection
- Risk of reoccurrence of original kidney disease
- Delayed wound healing or hernia
- Risk of infections (CMV)
- You may experience some side-effects from anti-rejection medications

Where do kidneys come from?

Kidneys can be donated in several ways:

Living donor kidneys

1. Live

This is a direct donation generally from a relative, friend, spouse, sibling or altruistic donor, who donates one of their healthy kidneys to you.

2. Live Unrelated

A live donated kidney does not have to be blood group compatible. Incompatible live donors can be used if a willing compatible donor cannot be found. This can occur if the donor/recipient is blood-group incompatible (ABOI). 95% that are straight forward living donor kidneys, will be working after one year.

3. Deceased (Cadaveric Kidney)

This is from someone who has died and during their life expressed a wish to become an organ donor at the time of their death. Ideally with consent from their next of kin.

Most deceased donors die in an intensive care unit. There are two types of donor kidneys:

1. Donation After Brain Death (DBD) known previously as heart beating donors

The outcome of donors is better because the heart continues to beat allowing good blood flow up until the point of donation. The outcome of these donor types show that 60-70% of kidneys will work straight away. The remaining 9 out of 10 kidneys will be working after 1 year.

2. Donation After Cardiac Death (DCD) known previously as non-heart beating donors

These kidneys are from individuals whose heart has stopped for a period of time before the organs are donated, so there is a spell where there is no blood flow to the kidney.

Only 10-20% of these kidneys work straight away, of the remaining kidneys most will ultimately work in the next few weeks. 87-88% out of 100 will be working after 1 year.

Marginal kidneys

Some donor card kidneys will come from an individual who has suffered with health problems that may have affected their kidneys. If it is felt that a donor kidney is available for you and would have a decreased chance of working, this is something that will be discussed with you prior to the operation.

How do I get a kidney?

There is no age restriction to receive a kidney transplant as each person is assessed individually. However in order to receive a transplant kidney we need to ensure you are fit enough for the operation. You will need various cardiac (heart) investigations to be carried out to assess your suitability. You should ideally have a body mass index (BMI) of less than 35 and you will be advised to stop smoking as this can damage your blood vessels, making the operation more risky.

Once the surgeon has agreed your suitability for receiving a transplant you will have some bloods taken for testing.

To receive a deceased donor kidney you are registered with ODT on the transplant waiting list. Kidney donation is based on a best match with your blood group, tissue type, age and duration on list. Therefore the time on the waiting list is like a lottery ticket; it could be anything from one week to ten years, with the average waiting time for a transplant being three to four years. As tissue matching is more difficult for people of non-white ethnicity, patients from these groups may wait longer for a kidney. Informed and written consent is required to go on the transplant waiting list.

To receive a live donor transplant, we need to assess those individuals willing to donate a kidney to you. This will be discussed with you when being assessed you for the deceased (cadaveric) waiting list. The live donor team either at QEHB or at your local hospital will arrange some tests on any potential live donors. The donor will be given a health questionnaire to complete and contacted at a later stage with further information.

The blood tests

Blood group	This should be compatible with the donor blood group
Tissue type	A more detailed blood test to enable us to find you a better matched kidney
Antibodies	Antibody levels may change while you are on the waiting list, so they are checked every three months
Hepatitis	You will be tested for this while you are on the list. You may need treatment if positive
HIV	This will be discussed with you before the test
CMV	A common virus that you may already have had, or may come from the transplant. It occasionally flares up after the transplant but can be treated
Chicken pox	To check if you have had the disease in the past
EBV	To check if you have been exposed in the past
Syphillis	To check if you have had the disease in the past
Additional Information	
TB	If a patient has a history of TB a careful history assessment and cxr will be required to provide adequate preventative measures.

Waiting for a kidney

It is very difficult to predict how long you may wait for a new kidney. Therefore it is important that during this time you remain as healthy as possible. This means making sure you take regular exercise if you can, stop smoking, take your medication correctly, and maintain a healthy weight.

As you may be waiting for some time it is essential that you keep the transplant coordinators informed of any changes to your telephone numbers, your address, your mode of dialysis and dialysis days. **Do not rely on your dialysis unit to inform the transplant coordinators of these changes, it is your responsibility.**

During your waiting time it is important not to restrict your lifestyle. You will still be able to go on holiday but again, you need to let the transplant coordinators know when you are going and where you are going to. If necessary you can be suspended from the waiting list whilst you are on holiday.

Remember if we cannot contact you, you will not be able to receive your transplant.

Whilst you are on the waiting list it may at times be necessary to temporarily suspend you due to ill health. Your doctor will discuss this with you. If you are admitted to hospital please remember to ask the doctors or nurses to inform the transplant coordinators.

The phone call

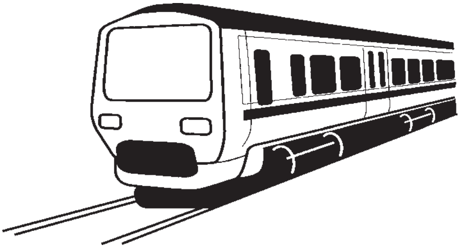
A transplant coordinator will call you as soon as a suitable kidney has been found for you. Remember this call can come at any time day or night, so its important to keep your mobile phone switched on at all times, and please ensure you can hear your landline phone at night. **If you are hard of hearing or profoundly deaf, please discuss your options with the transplant coordinator.**

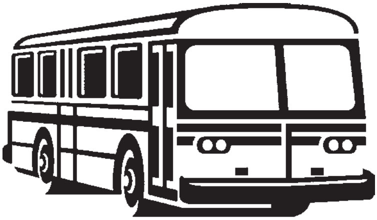
You may be asked the following:

- What form of dialysis are you on (if any)?
- When did you last have dialysis?
- How am I going to get to the hospital?
- How long will it take you to travel to the hospital
- What will I need whilst in hospital?
- To bring a list of medications to the ward
- To have nothing to eat or drink (nil by mouth)
- Have you had any blood transfusions in the last year?
- Are you on Warfarin or Clopidogrel?

When you receive the phone call the transplant coordinator will ask you to come into hospital straight away and will advise you not to eat or drink at this stage. Please tell the transplant coordinator if you are currently unwell, have had any recent hospital admissions or if you suffer from any allergies.

Occasionally you can be called into hospital and the transplant may not go ahead. This may be due to several reasons and will be discussed with you further by the renal transplant surgeon.





What happens when I get to hospital?

You will need to make your way to the transplant ward 305. A nurse will meet you there. You will need to have several tests carried out, e.g. ECG, chest X-ray, and blood tests, and you will be examined by a doctor to check you are well enough for the transplant.

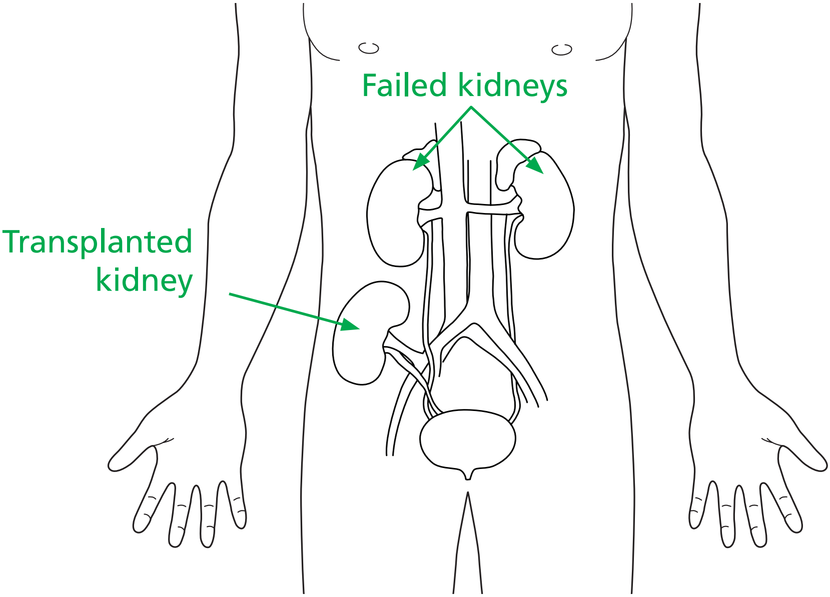
You may need to be dialysed, or if you are on CAPD (Continuous Ambulatory Peritoneal Dialysis), carry out some quick bag exchanges. You will need to drain out before the operation.

You may be asked to participate in a clinical drug trial. This is usually to trial new medication for transplant patients or may involve new ways of taking existing medicines. The drugs being trialled are often medicines that we will use in the future. Your doctor will explain these trials to you. You **do not** need to take part in these trials if you feel unhappy to do so; this will not affect the care you receive.

Sometimes it is necessary to call you into hospital before a final blood test called a cross match is carried out. This may be because your antibody test is out of date. It is important whilst you are on the waiting list an antibody test is taken every three months. Please ask your dialysis nurses about this blood test when you are in clinic. If this test is positive you may be sent home.

The operation

The operation takes about 2-3 hours. The transplanted kidney is put into your right or left groin. It is placed here as it is close to your bladder, the surgeon will join up your blood vessels, to the new kidney, and the tube from the kidney (ureter) to your bladder. Your own kidneys will not be removed.



Whilst you are anaesthetised you will have several tubes placed in your body. You will have a tube placed into your bladder called a urinary catheter. This will drain out all the urine your new kidney will produce into a bag so it can be measured. This will be in place for 3-5 days.

You will have a tube from the operation site, called a redivac drain. This will remove blood or fluid after the operation and will be in for approximately 3 days.

You will have a central line put into one of the blood vessels in your neck. This is so the nursing staff can measure your fluid balance very accurately after the operation. It can also be used to attach pain killing drugs and a fluid drip.

You will be given a pain control device (PCA or patient controlled analgesia). This is a hand held device with which you can deliver a dose of painkillers yourself as required.

Sometimes a small tube (stent) will be inserted into the ureter of the new kidney. This is to help the kidney drain and prevent kinking of the ureter. This stent is removed approximately 6 weeks after your transplant.

Complications

Rejection

Rejection can occur at any time even though you are taking your anti-rejection medication to stop your body fighting your new transplant kidney. Most often rejection occurs in the first few weeks after the transplant but can also occur months or years later. 15% of all patients experience some form of rejection which is treated with extra anti-rejection medication.

Delayed Graft Function

This is when the transplanted kidney does not work straight away despite having a good blood flow. This is common in 4 out of 10 donor card kidneys but uncommon in live donor kidneys.

If a kidney does not work straight away, it usually recovers after a few weeks from the transplant date and the individual may require additional dialysis support during this time.

Hypertension (High Blood Pressure)

This is common post transplant and medication will be prescribed to control this.

Infections

All anti-rejection medicines will reduce your body’s natural defence mechanism to fight infection. There is a virus called

CMV (Cytomegalovirus) which displays its symptoms as flu-like. So if you have been in contact with anyone with flu or displaying flu-like symptoms, it is important you contact the transplant team to do a blood test to check. You also need to be particularly careful to avoid contact with anyone with chickenpox especially if you have not had it yourself. Contact us straight away if this happens so that you can be assessed in the transplant follow-up clinic promptly.

Surgical Implications

Thrombosis

A thrombosis is when one of the blood vessels clots either and artery or a vein. This would require a further operation to rectify.

Urinary leak and lymphocele

Sometimes there is a leak between the kidney drainage tube (ureter) and the bladder. You may need a small operation to insert a catheter or drain temporarily to resolve the problem. Or a cyst of fluid (called lymphocele) may collect around the transplant. This may need to be drained.

Complications anti-rejection treatment

There is an increased risk of getting cancer because of the effect the anti-rejection medication has on your immune system. It is important to tell the doctor or transplant team about any changes you find on your skin such as moles or lesions and if theses have altered in shape, colour and appearance.

There is a 15% chance of developing steroid induced diabetes post transplant. If two or more blood results show a high blood glucose level you may require to start anti-diabetes tablets. Approximately 50% of patients diagnosed with steroid induced diabetes are only diabetic temporarily and once steroids are reduced the body self regulates.

After the operation

When you return to the ward your doctors and nurses will monitor you closely. You may experience some pain, so it is important that you tell your nurse if your pain is not controlled.

You will be encouraged to get out of bed the day after your transplant. This is to help prevent blood clots. It is advisable to bring in some loose clothing so that you can get dressed during your stay in hospital. You will usually be in hospital for about 7-10 days.

Whilst you are in hospital you will have blood taken every day to check your kidney function, full blood count and also to check that you are taking the right amount of anti-rejection medication. You will be given lots of new tablets and your nurse will explain what they are for and how and when to take them.

If your new kidney does not work straight away you may need an ultrasound scan or a biopsy. This will allow the doctors to be able to find out what is happening to it. A biopsy will show if there is any rejection in your transplanted kidney.

Follow-up care

You will need to come back to the Queen Elizabeth Hospital Birmingham frequently in the early stages. This will be 2-3 times per week when you first go home. If you do not usually attend the Queen Elizabeth Hospital Birmingham you will be able to return to your regular hospital for further appointments about 3-4 months following your transplant.

Hospital transport is not provided after your transplant unless you have a medical problem that prevents you from using private or public transport. If you think you meet the eligibility criteria you will need to fill in a Transport Booking Form. You can obtain a form by contacting the Hospital Transport Department and asking the staff to post you a booking form

or downloading a form from
www.uhb.nhs.uk/patient-transport.htm.

The first few months following a transplant can be very difficult. This can be due to the frequency of clinic visits, new medicines, side effects of the medicines and changes to your lifestyle. Please discuss any problems you have when you come to clinic so that the team can provide any available help.

You will be given further information following your transplant. If you would like to see a copy of this before your transplant please call the department.

Pregnancy

Although women with advanced kidney disease or those on dialysis have reduced fertility, it is still possible to become pregnant. The success of pregnancy in women on dialysis is relatively poor and is generally felt to be not advised. Some of the drugs used to prevent rejection can cause developmental problems and birth defects with a growing baby.

As you are waiting for a transplant you should be using contraception. This can be discussed with your nephrologists or family planning clinic or dialysis nurse.

The following contraceptive methods are recommended these include; condoms, the mini pill or the Mirena Coil (Intra uterine contraceptive device). We would generally advice against the combined (oestrogen containing) pill as it can increase your blood pressure and may cause an increase risks of clots in some dialysis patients.

If you are planning a family please discuss this with your nephrologists. You can then be referred to the combined kidney/Obstetric clinic for advice with your partner.

Menstrual bleeding

Menstrual problems is common amongst women with end stage renal failure (ERSF) who usually suffer from absence of their menstrual cycle (Amenorrhea) and experience irregular periods with scanty flow by the time they start dialysis.

Although a kidney transplant can restore and greatly improve the menstrual pattern in 49% of women, however irregular bleeding is still a major concern amongst those with a transplanted kidney.

Contacts

The Transplant Team

Renal Transplant coordinators 0121 371 4433
or fax 0121 371 4432

Renal Transplant Ward 305, 0121 371 3050

Renal Transplant Clinic 0121 371 4428 or 0121 371 4427 the renal transplant surgeons: Mr Andrew Ready, Mr Steve Mellor, Mr Ahmed Hamsho, Mr Nicholas Inston.

Renal Transplants Surgeons can be contacted via their secretaries through main hospital switchboard number: 0121 627 2000.

The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit www.uhb.nhs.uk or call 0121 627 7803

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PI15_0892_03 UHB/PI/0892 (Edition 3)
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Date: April 2015 Review Date: April 2017