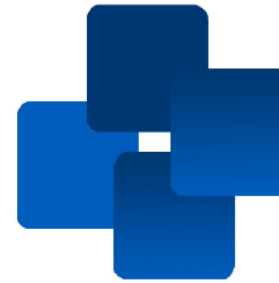
East and North Hertfordshire
NHS Trust

Patient Information

A Recipient's Guide to Kidney Transplantation

Renal Transplant Department



Introduction

This booklet has been written for patients with decreasing kidney function who are either on dialysis or approaching the need for it. One of the options for renal replacement therapy is that of kidney transplantation.

The aim of this booklet is to give you an initial introduction into transplantation and what you need to do to be activated on the kidney transplant waiting list. It is important to realise that a successful kidney transplant depends on your health and wellbeing.

Kidney Transplantation

Kidney transplantation can be a good treatment for kidney failure and has many benefits that can greatly improve quality of life. For example, freedom from dialysis, relaxing of diet and fluid restrictions, as well as an increase in life expectancy. However, a kidney transplant is a big operation with its own risks and it is possible that transplantation may not be the best treatment for you.

After a transplant operation you will need to take anti-rejection medication to prevent your body from rejecting the kidney. It is important to understand that a transplanted kidney will not last forever.

The Lister Hospital is not a transplant centre but has a dedicated renal team who are able to refer people to other specialist hospitals where the transplant operations are carried out.

Your ‘work up’ for transplantation will take place predominantly at the Lister Hospital, and will be managed by the renal transplant co-ordinators. However, the actual transplant operation will be carried out at the centre to which you have been referred. This will be discussed with you by a nephrologist (kidney doctor).

Renal Transplant Clinical Nurse Specialist

The renal transplant co-ordinators are a team of specialist nurses who are responsible for 'working up' recipients for transplantation. They are not however, the transplant team. The transplant team is the group of doctors, surgeons and nurses at the centre where the operation will take place.

Receiving a Transplanted Kidney

The Renal Association estimates that each year in the UK an average of 6,000 people would benefit from a kidney transplant, however, demand for kidneys in the UK is far higher than the available supply of donors, both living and deceased.

Ideally, a kidney transplant should be performed when testing shows that the extent of the damage to your kidney is such that you will require dialysis within six months. Realistically, for a variety of reasons, only one transplant in ten is performed on people who are not on dialysis. Most people with kidney failure need dialysis while they wait for a donated kidney to become available.

Most people are able to have a kidney transplant, regardless of their age. However, a number of factors could mean that it is not safe to have one.

You can receive a kidney from either a deceased donor or a live donor.

Deceased Donor

A deceased donor is someone who has died, usually following a stroke or irreversible damage to their brain. Together with the medical team, the donor's family has agreed that this person's organs can be given to help others.

Living Donor

It is recognised that a healthy person can live a completely normal life with only one kidney.

A living donor can be a friend or relative who is unconditionally willing to give you one of their kidneys. They do not have to be related to you but they will need to undergo certain blood tests to make sure they are a good match.

The Work Up Process

You will be assessed by a nephrologist at your usual clinic appointment. They will decide if you are healthy enough to receive a new kidney and the benefits of transplant outweigh the risks. They will consider the following:

- that you do not have certain medical conditions which can make the transplant too high a risk
- that you adhere to your medications, diet, fluids and clinic attendances

The nephrologist will then refer you to the relevant transplant centre for assessment and the Lister renal transplant co-ordinators for work up.

The renal transplant co-ordinators will arrange an appointment with you to discuss transplantation in detail. Following this appointment, they will arrange for you to have the relevant tests and for you to be seen in a clinic at the Lister Hospital by the appropriate transplant team.

On attending the transplant clinic, please be prepared to wait to be seen. We try to ensure that everyone is seen as close to their appointment time as possible but some individuals may take longer than others.

Please be aware that if you do not wish to have a transplant, you can withdraw from the work up process at any time.

Consent

You may be required to sign a centre specific consent form. Further information regarding this will be given at your transplant clinic appointment.

Weight

It is important to be aware that most transplant centres will take into account your current weight when assessing your suitability for transplantation. Your height and weight will be used to calculate your body mass index (BMI). If your BMI is too high then you may not be considered for transplantation as the associated risks of post-operative complications are too great.

Dental Checks

It is important that you take care of your teeth and gums. You must ensure that you visit your dentist every six months for a routine check up. Your dentist will be able to detect any dental health problems that may arise, particularly when you are taking anti-rejection medication.

Screening Tests and Investigations

For women between the ages of 25 and 64, regular cervical smear tests are essential and it is recommended you have them annually. If you are over the age of 50, you will need a mammogram every three years as part of the national screening programme.

Men over the age of 50 will need to have prostate-specific antigen (PSA) levels checked. This is a protein produced by the cells of the prostate gland. PSA is present in small amounts in the blood of men with healthy prostates, but is often raised in the presence of prostate cancer and in other prostate disorders.

Both men and women over the age of 60 will be required to have bowel screening. This is a national screening programme and requires three separate small stool samples to identify faecal occult blood (FOB).

Specific Transplant Blood Tests

You will be required to have blood tests specifically for transplantation. We will screen you for the presence of certain viruses, these are:

- Human immunodeficiency virus (HIV)
- Hepatitis B
- Hepatitis C
- Cytomegalo virus (CMV) which has symptoms similar to a bad cold
- Epstein Barr virus (EBV) also known as glandular fever
- Varicella zoster Virus (VZV) which is chicken pox
- Toxoplasmosis which is a parasite usually picked up from cat litter
- Syphillis which is a sexual transmitted disease

The presence of any of these viruses would not usually prevent you from being activated on the transplant waiting list however, the transplant team may need to specifically tailor your care post-transplant.

Blood Group

There are four main groups: O; A; B and AB. You need to be the same blood group as a deceased donor but not necessarily for a live donor, depending on your antibody levels.

Tissue Type

This test determines your individual make up of cells. Before transplantation, the tissue type of the donor and recipient is matched to minimise the chance of rejection. This information is held by the tissue typing department at the transplant centre.

Crossmatch

Your blood is mixed with the donor's blood to see if there is any reaction. If the test is negative, antibodies that would attack the donated organ are not present and the transplant can safely proceed. A positive result indicates a high chance of rejection and therefore the transplant would not go ahead.

For those recipients who have potential live kidney donors with a different blood group, please ask your renal transplant co-ordinator for information on antibody removal.

Serum Sample Screening

Once you have been tissue typed, you will need to have a three monthly blood test. Dependent upon which transplant centre you are under, this testing may not start until you are ready to be activated onto the transplant waiting list.

This test enables the transplant centre to observe your antibody levels so that when a kidney becomes available they can perform an initial crossmatch test.

If you are on haemodialysis, this test will be performed by the dialysis staff. If you are dialysing at home, the Home Therapies department will inform you when the sample is due. For pre-dialysis patients, a letter will be sent informing you of when these tests are due. You need to inform the Advanced Kidney Care team that you have had these samples taken.

It is extremely important that you have this test. If you do not, it could result in you being suspended from the transplant waiting list.

Transplant Link Nurses

There is a link nurse in each clinical area who will be able to provide you with information regarding the serum sample dates. They will also have access to information regarding your transplant status.

The Transplant Team

At the initial meeting with the transplant team, they will decide whether you are suitable to be considered for transplantation at their centre. They will evaluate your medical condition thoroughly and request that you have certain tests and investigations. These will often be dependent on your past medical history.

Specific Transplant Investigation Requests

To evaluate your heart the tests may include one or some of the following:

- Echocardiogram (ECHO) - an ultrasound scan of the heart
- Stress ECHO - an ultrasound scan of the heart following an injection that speeds up the pulse
- Exercise Tolerance Test - a treadmill test
- Coronary Angiography - contrast is injected through a blood vessel, usually in the groin to show any narrowing of the heart blood vessels on X-ray.

These heart tests are carried out in the cardiology department.

You may need to have images taken of your abdomen to show the size, whereabouts and condition of your organs in your body. This is often by done by ultrasound scan.

It may also be necessary to have your blood vessels examined, particularly to your legs and feet. This is done by a Doppler ultrasound scan.

The transplant team may request further tests and investigations and may want to see you again once the results are available.

Please be aware that you may not be considered fit enough to receive a kidney transplant. The reasons will be explained to you in detail.

You will need to have a recent chest X-ray and ECG prior to your appointment with the transplant team.

Transplant List Activation

Once you have had the necessary work up, your results will be discussed at a transplant team meeting. If the team are satisfied that transplantation is a safe option for you, they will approve your activation. However, they may also request further tests.

You will receive a phone call informing you of your activation onto the kidney transplant waiting list. A letter and leaflet with further information will follow.

Keep well on the waiting list by attending all clinic appointments, taking your medication as prescribed and complying with your renal replacement therapy as advised by the medical team.

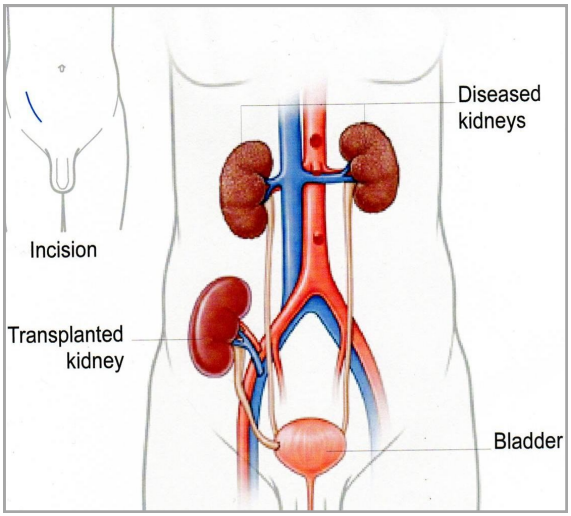
If you become unwell you may be suspended.

The Operation Process

The operation usually takes about 3-4 hours to complete.

The hospital stay is about 7-10 days however, this will depend on your health and how well the new kidney is working. In around 70% of people who have a kidney transplant, their new kidney begins working immediately after surgery. However, transplanted kidneys sometimes take up to 6 weeks to start working. If this is the case, you will need dialysis during this time. In some cases, the kidney may not work at all.

Where does the kidney go?



The new kidney is placed in your lower abdomen, near your bladder, on either the left or the right side. Sometimes two kidneys are transplanted. Your own kidneys are not usually removed.

Medication

After the operation, you will immediately begin treatment with medication, which is designed to prevent your immune system from rejecting your new kidney. These types of medication are known as immunosuppressants.

Immunosuppressants prevent your body's immune system from attacking the transplanted kidney, which would cause the kidney to be rejected.

Immunosuppressants are usually taken by mouth (orally) at a dose that is high enough to 'dampen' the immune system sufficiently to stop rejection, but not so high that the body is unable to fight off infection.

Finding this optimal dose is often a difficult balancing act. It may take several months to find the most effective dose that causes the least amount of side effects.

Because your body will not 'forget' that the transplanted kidney once belonged to someone else, you will have to take immunosuppressive medication for as long as you have a functioning transplant.

You will lose your transplanted kidney if you do not take these medicines. You must attend clinic regularly for monitoring, even if you feel well.

For more information on transplant medications, please speak with your nephrologist or arrange to see your hospital pharmacist.

Helping You Stay Well After the Kidney Transplant

It is imperative after your kidney transplant to keep yourself healthy. Once you have been discharged from hospital you will need to do the following:

- Make regular visits to the transplant centre and keep all of your appointments. At first this may seem no better than going to the dialysis unit, but these frequent visits will only last for the first few months. You may be transferred back to the Lister Hospital after the first 3-6 months if all is well.
- Take your medicines properly - **This is extremely important.**
- If you are experiencing any problems in regard to keeping your clinic appointments or taking your medicines, please contact the renal transplant co-ordinators.

If you feel unwell, we would like you to be seen by a doctor as soon as possible. If the renal transplant co-ordinators are not available, please contact Ward 6B.

Why You Need to Keep Your Appointments

At your clinic appointments the medical team will watch you very closely for signs of kidney rejection and for side effects of the medication that you are taking.

They will only be able to tell whether your kidney is being rejected by examining you and taking blood tests.

Should your body begin to reject your transplanted kidney, irreparable damage may have occurred before you feel unwell.

Risks

Due to the introduction of more effective immunosuppressant medications, the rates of serious complications that arise after a kidney transplant have fallen sharply. However, transplants are not risk free and potentially serious complications can arise from a kidney transplant.

Specific Surgical Risks

Any surgery is not without risk however, the surgical risks associated with this operation are:

- There is a 2% risk of death in the first year.
- Blood clots can develop in the arteries that have been connected to the donated kidney. They are estimated to develop in around 1-4% of kidney transplant cases.
- Renal artery stenosis occurs in an estimated 4% of cases, the arteries that are connected to the donated kidney become narrowed.
- Ureteral obstruction is a common complication after a kidney transplant. It develops when the ureter (the tube that carries urine from the kidney to the bladder) becomes blocked from clots of tissue or fluid that form during or after the operation.
- Urinary leakage from any part of the urinary system (the kidney, bladder, ureter and urethra) as a result of damage or disruption caused during surgery. This would usually occur during the first month after surgery.

Rejection

Acute rejection is where the immune system suddenly begins to attack the donated kidney because it mistakes it for a foreign object. This is a common complication in the first year after a transplant, affecting an estimated 30% of people.

The risk of rejection never goes away. You will always need to stay on your immunosuppressant medication.

The doses of the medication may be decreased by the doctors in the

The dose of the medication may be decreased by the doctors in the transplant clinic, but **you should never skip or stop your medication of your own will as you may risk losing your new kidney.**

Infection

After a transplant, minor infections are common. They affect an estimated 1 in 2 people. These infections usually take the form of:

- Urinary Tract Infection (UTI)
- Colds
- Influenza ('flu)

More serious infections, such as pneumonia (inflammation of the tissues in one or both lungs) and cytomegalovirus (a viral infection that can be severe in people with weakened immune systems) can occur and may require aggressive treatment and admission to hospital.

You will need to look out for fevers, unusual pains, or any other new symptoms.

Side Effects of Immunosuppression

Not all patients will experience side effects from their medication. Common side effects are:

- High blood pressure
- Diabetes
- High cholesterol
- Bone weakening, osteoporosis
- Acne
- Gingival hyperplasia (overgrowth of gums)
- Cancer - immunosuppressant medication may increase the risk of certain cancers, particularly skin cancer. You are advised to use a sunscreen whenever exposed to the sun; a high SPF sunscreen in summer and any SPF sunscreen during the rest of the year. Sunbeds should be avoided

Reappearance of Kidney Disease

Some forms of kidney disease can come back in the transplanted kidney. Your doctor and transplant staff will monitor your blood and urine for signs of this problem. If all is well it is expected that on average 85% of transplants will still be functioning at one year, reducing to 50% at ten years.

Details of the Donor

If you have received a kidney from a deceased donor there is only a limited amount of information that can be given to you. This is to protect the identity of the donor and their family.

Once you have recovered from the transplant operation and the kidney is working well, you can write to the donors family if you wish. Please discuss this with the transplant co-ordinators.

Renal Patient*View*

You, or anyone you authorise, can view your blood results, medications and some of your medical history on the internet using the renal Patient*View* site. You will need to sign a consent form in the presence of a member of staff to enable you to access the system. Please ask a renal transplant co-ordinator or a doctor in the clinic for further information.

Useful Resources and Further Information

National Kidney Foundation - www.kidney.org

The Renal Association - www.renal.org

Kidney Research UK - www.nkrf.org.uk

Transplant Support Network - www.transplantsupportnetwork.org.uk

British Transplant Society - www.bts.org.uk

Human Tissue Authority - www.hta.gov.uk
Email: enquiries@hta.gov.uk

Renal Patient*View* - www.renalpatientview.org

Booklets

A Patient's Guide to Kidney Transplantation - Roche

Kidney Transplant Guide - Addenbrookes Hospital

Additional patient information leaflets are also available on our Trust website: https://www.enherts-tr.nhs.uk/patient-information/

What if I have any questions?

If you have any concerns or questions, please speak to a member of the nursing team on the renal dialysis unit.

Please use this space to write down any questions you wish to ask:

Contact details

Lister Renal Transplant Co-ordinators	01438 285466 or 286363
Renal Transplant Administrator	01438 286367
Post Transplant Co-ordinators	01438 286363
Renal Counsellors	01438 285450
Renal Care Practitioner	01438 284957
Ward 6B, Nephrology (Renal) Ward, Lister Hospital	01438 284068

Transplant Co-ordinators' email address

Transplantcoordinators.enh-tr@nhs.net

Livedonorcoordinator.enh-tr@nhs.net

Acknowledgements

This booklet has been written with the help and advice from the transplant team at Addenbrookes Hospital, as well as members of the Lister Hospital Renal team, living donors, renal patients and their families.

www.enherts-tr.nhs.uk

You can request this information in a different format or another language.

Date of publication: January 2012
Author: Transplant Team
Reference: Version: 3 (Mar 2020)
Review Date: March 2023

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