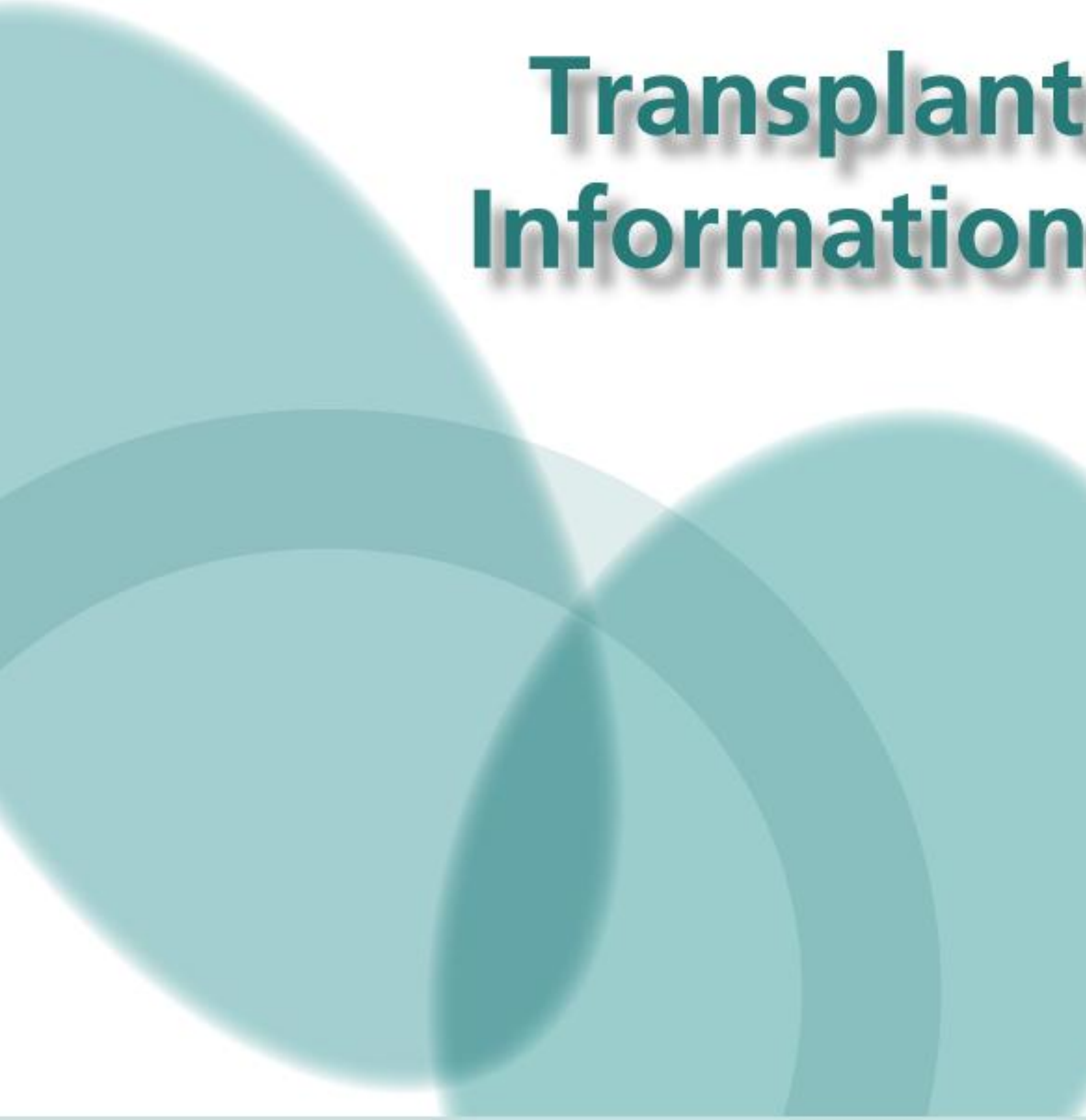
University Hospitals of North Midlands NHS
NHS Trust

Transplant Information



Patient Information Booklet

Transplant Information

Why is a kidney transplant being considered?

The doctors looking after you have referred you to the Transplant Team because you have kidney failure. You may already be having treatment for this in the form of dialysis, or you may be planning treatment for the future. The best form of treatment varies from person to person but in general, a successful kidney transplant can give you a better quality of life than dialysis treatment. However, a transplant operation is a major undertaking and not everybody is suitable for a transplant. This may be because there are medical problems, which make the risks of a transplant too great, or because you decide that you do not wish to have a transplant.

How do I know if I am suitable?

The Transplant Team will see you in a pre-transplant assessment clinic to give you more information and to find out if you are suitable for placement on the transplant waiting list.

What will happen at the clinic?

- You will be given information about transplantation in general, and any particular issues which relate to yourself. You will be given the opportunity to ask questions and discuss this further.
- The doctor will see you to ensure that you are medically fit for a transplant operation. This will involve a thorough physical examination and going through your medical history.
- Further tests will be necessary and will be arranged at this clinic visit.

What are these tests?

  - Blood group.
  - A series of blood tests to check if you have ever been in contact with certain viruses or infections. These include HIV (the virus that causes AIDS), Hepatitis B, Hepatitis C, Cytomegalovirus (known as CMV), Epstein Barr Virus (known as EBV or glandular fever) and TPHA (the test for syphilis). It is important to test for these viruses because they may be dormant (sleeping, causing no symptoms) in your body. Following a transplant they could be 'woken up' and cause illness. You will need to give us permission to take these tests, particularly the HIV test. If you feel that you require further counselling before going ahead with the test, we can arrange that for you.
  - These tests will be repeated annually when you are waiting for a transplant. We will not usually seek your consent each time, so you should let us know if you change your mind.
  - ECG – an electronic recording of the heart beat
  - Echocardiogram – a sound wave picture of the heart
  - Chest x-ray
  - You may require other tests and the doctor will explain these to you.

- Some of these tests can be done on the day but for some, there is a waiting list of a few weeks to a few months. It is important that you keep any appointments for tests and that if you are unable to attend, you inform the hospital, so that they can be used for other patients.
- If these test results are satisfactory, you will be referred to the Transplant Surgeons at the Queen Elizabeth Hospital in Birmingham or the Manchester Royal Infirmary.

- In some cases after this assessment we feel that you are not suitable for a transplant because the risk would be too great. This will be explained to you and you will be offered an appointment with the Transplant Surgeons to discuss this further if you would like to.
- Sometimes the tests show abnormalities which would not have been found otherwise. In that case, we may refer you to another specialist, for example a heart specialist for further tests or treatment if needed. We would normally inform you by telephone or letter. If you have any queries or would like to see the doctor again please contact the Transplant Team.

What happens when I see the Surgeon?

- The surgeon will talk to you again about transplantation and answer any questions that you have. He/she will go through your medical history including the tests that you have had already and will perform a short physical examination.
- You will meet one of the Transplant Co-ordinators who will explain the process of going on to the transplant waiting list. They will take more details, such as how to contact you.
- You will have further blood tests to establish your ‘tissue type’. Each individual has a different ‘tissue type’. Your body is more likely to accept a kidney if the ‘tissue type’ is similar to your own (i.e. is a better match). This information is needed before you can go on to the list.
- If all is well, you will become ‘active’ on the waiting list a few weeks after your appointment. This means that if a kidney becomes available you could be called up at any time for a transplant.
- At times you may need to be ‘suspended’ from the waiting list, for example if you are on holiday or unwell (further information is given below).

What happens while I am on the waiting list?

How long will I have to wait for a kidney?

The average wait for a kidney transplant is two to three years but this varies widely. It could be within the first month of being active on the waiting list or as long as ten years or more.

Kidneys are allocated depending on who is the best ‘tissue type’ match. If two or more people have a similar match then other factors are taken in to account, such as the length of time that has been waited. There is not a top or bottom of the list. This is a national scheme, which has been designed to be as fair as possible. More information is available from UK Transplant.

www.uktranslant.org.uk

UK Transplant
Fox Den Road
Stoke Gifford
Bristol
BS34 8RR

Tel: 0117 975 7575
Fax: 0117 975 7577

General enquiries: enquiries@uktransplant.nhs.uk

Where does the kidney come from?

There are two possible types of kidney transplants called cadaveric transplants and living donor transplants.

Cadaveric Transplants

These come from a previously healthy person who has died in hospital, perhaps following a car accident, head injury or stroke. Their relatives have agreed for their kidneys and other organs to be used to help others. With improvements in transplantation it has become possible to use kidneys which would have been considered unsuitable in the past (marginal kidneys). This includes kidneys from people whose heart has stopped while they were not on a life-support machine (non-heart beating donors). Kidneys from non-heart beating donors do not usually work straight away after a transplant. This delayed function can last for days or weeks. You would need to continue dialysis until the kidney starts working. There is also a small increased risk of the kidney never working. However, you are still likely to benefit from receiving a non-heart beating donor kidney rather than staying on dialysis. You will be asked to indicate in advance whether you would accept a kidney from a non-heart beating donor. If the Transplant Surgeon feels that the kidney offered to you is marginal or is from a non-heart beating donor, this will also be discussed with you at the time of the transplant.

Living Donor Transplants

In many cases a member of the family, husband, wife, or close friend may wish to donate a kidney. This can be a very fulfilling experience for the kidney donor. In addition, kidneys from living donors tend to do better than those from cadaveric donors. One advantage is that the transplant can be planned to take place before dialysis in some cases. If anyone has offered you a kidney please let the Transplant Team know.

If you would like advice on how to discuss this with your family and friends, please ask the Transplant Team for further information.

Outcome of different types of kidney transplants

	Never functioning	Delayed function	Working after 1 year	Working after 5 years
Live Related	0%	1%	98%	85%
'Normal' Cadaveric	2%	20%	90%	75%
Non-heart beating donor	3%	80%	85%	70%

What do I need to do?

It is very important that you inform the Transplant Nurses if you change address or telephone numbers.

Inform the Transplant Nurses if you are going on holiday and provide contact numbers. You will be temporarily suspended from the transplant list for the duration of a holiday if you are uncontactable or unable to get back in time (e.g. abroad, Northern Ireland or Channel Islands etc).

Whilst waiting for a kidney transplant to become available, keep yourself as fit and active as possible and if you smoke – **STOP!**

Keep your teeth and gums healthy. Have regular dental check-ups.

It can be difficult at first when you know you may be called but it is important to continue with your normal routine e.g. see friends, make plans and enjoy yourself as much as possible.

What will the Transplant Team do?

We may need to suspend you from the transplant list if you become unwell.

You will be reviewed in the dialysis clinic, or by the Transplant Consultant either every six months or annually to ensure that you are medically fit to remain on the transplant list.

From time to time you may need to have further tests, either if your medical condition changes, or if a long time has elapsed since your previous tests and they have gone 'out-of-date'.

Having the transplant operation

What will happen when a kidney becomes available?

You will be contacted by one of the Transplant Co-ordinators to inform you that a kidney is available for you. They will ask if you are well and tell you to have nothing else to eat or drink and to make your way to the Queen Elizabeth Hospital in Birmingham or Manchester Royal Infirmary. If you are a diabetic you will be informed of what to do.

If you are on peritoneal dialysis (CAPD or APD), you will need to take a supply of equipment and fluid with you. Please discuss this with the co-ordinator.

You will be seen and examined by a doctor to ensure that you are still medically fit for a transplant. You will also have the opportunity to ask questions again and to give your consent indicating that you would like the transplant to go ahead.

Where does the new kidney go?

The kidney is placed in your lower abdomen close to your bladder and just above your groin. It can be either on the left or the right hand side where it rests behind your hip bone.

How long does the operation take?

The operation usually takes around two to three hours.

What happens when I get back to the ward?

You will have several drips and tubes attached to your body. There will be a catheter to drain urine from your bladder, a drip to give you fluids and drugs, and a wound drain near the operation site. These will be removed over the next three to five days.

You will be given regular pain relief to keep you comfortable.

You will be closely monitored for heart rate, blood pressure and quantity of urine produced. Frequent blood tests will be carried out and you will be examined regularly to determine how the new kidney is functioning.

Most patients start to drink fluids within twelve hours of the operation and can eat by the next day.

Your medication will be changed and you will be given medication to stop your body from rejecting the new kidney. You will also be given other medication for example, ‘prophylactic’ medication to protect you from infections. Your new drugs will be explained to you.

What if the kidney does not start working straight away?

In most cases the kidney starts working straight away but it can take longer. When this happens it is usual for the kidney to start working after two to three weeks but it can take up to three months, in which case you would need to continue dialysis during this time. In a very few cases the kidney never works properly.

How long will I be in hospital?

Usually about two weeks, but it could be longer depending on circumstances. You will be discharged home from hospital when it is safe to do so.

What arrangements will be made for my care after I am discharged from hospital?

- After your discharge from the University Hospital Birmingham, you will be seen within a few days at the University Hospital of North Staffordshire (Stoke-on-Trent) by a member of the Transplant Team.
- Alternatively, after your discharge from the Manchester Royal Infirmary you will continue to be seen as an outpatient at Manchester Royal Infirmary for 3-6 months. Your care will then be transferred back to the University Hospital of North Staffordshire.
- At first you will be seen two or three times a week. You will have regular check-ups in the outpatient department and/or on Ward 26.
- Over time you will still have to attend, but not as frequently.
- Eventually you will be seen every 3-4 months.

What happens at the clinic?

- You will need to bring a 24 hour urine collection and mid stream urine (MSU) to each clinic appointment.
- You will be weighed.
- Your blood pressure will be checked.
- You will have blood samples taken. **DO NOT** take your Neoral or Prograf on the morning of your appointment until your blood has been taken.
- You will see a nurse or doctor who may need to examine you.
- The purpose of those visits is to ensure that you are well and that your kidney is working well. Your medication will also need to be adjusted from time to time. If there are problems with your kidney they will need to be investigated.

What happens if there is a problem with my kidney?

Things you should look out for

In the period after your operation it is important that you get back to normal but you also need to know when to contact the Transplant Team if there are problems. Please contact us if:

- There is new or increasing pain over the kidney or operation site
- You have a temperature, fever, shivers or hot sweats
- You pass less urine than normal
- Passing urine is more difficult than normal or you have discomfort or burning
- Your urine become cloudy or smelly
- You feel breathless or unwell in any other way that is concerning you

Please do not hesitate to contact the Transplant Nurses or the Renal Unit (Ward 29) if you have any of the above symptoms. Remember to tell them you have just had a transplant operation.

What is rejection?

'Rejection' is a medical term that means your body has recognised the kidney is not your own and tries to reject it. It can occur at any time but is more common in the first few months, particularly in the first few weeks, after a transplant. It is diagnosed on a biopsy. It is very common, about 30% of people experience rejection in the first three months after a transplant. If rejection occurs then your doctor will consider a number of treatments, the type of which will depend on your own special circumstances. Rejection does not necessarily mean that you are going to lose your kidney – most get better.

What happens if I lose my kidney?

By the end of the first year following a transplant about nine out of ten patients have a working kidney. This is very good, but it does mean that about one out of ten patients have lost their kidney or it never worked. This can be a very difficult time and a great disappointment. If this happens you will need to go back on to dialysis treatment and when you feel ready you will be reassessed to see if you are able to go back on to the transplant list. Many people have had successful second and even third transplants.

How soon could I get back to normal after a transplant operation?

- We usually advise four to six weeks before driving and you should inform your insurance company.
- When you return to work will depend on your job and how you feel. In general, we advise that it may take up to three months before you feel fully fit.
- As with any operation it is advisable to wait about four weeks before having intercourse. Fertility may return to normal after a transplant for both men and women. You should therefore start to use contraception immediately. It is not recommended that women get pregnant in the first year after a transplant. It is better for the transplant to 'get settled in' before getting pregnant. Please ask for advice if you want to try and conceive at any time. We can advise you about what to expect and the situation is different for each patient. We may also need to change your medication, as some of your medication may be unsafe for use in pregnancy. Make sure you have had the Rubella vaccine before your transplant as this is a live vaccine and cannot be given afterwards.
- Many people find their sex drive increases and sexual function may improve or return. If you have any problems please feel free to discuss them with the doctor or nurse.

Your feelings

- In the early months you may experience mixed feelings and may not know whether to laugh or cry. Talking will help and your doctors, nurses, relatives and friends are there to help you with any problems. You may wish to write to your donors family. Contact the Transplant Nurses for further information.

Going on holiday

- It is not advisable to go abroad in the first six months. Always check with the Transplant Team before you book your holiday, in case vaccinations are required. They can advise you about whether you need to take special precautions or whether travel would be inadvisable. If vaccinations or drugs are required, they can inform you whether they are safe in your case. Live vaccines should never be given to transplant patients.

What drugs will I have to take?

Everyone who has a working kidney transplant has to take anti-rejection drugs (immunosuppressants). You may also have other medication prescribed. You may experience some side effects, but it is important to keep taking them. One of the commonest causes of transplant failure is when the patient stops taking their medication properly.

A combination of any of the following may be used:

- **Neoral –** also called Ciclosporin
- **Azathioprine –** also called Imuran
- **Prednisolone –** also called steroids
- **Prograf** – also called Tacrolimus
- **Cellcept –** also called Mycophenolate Mofetil
- **Myfortic –** also called Mycophenolic acid
- **Simulect –** also called Basiliximab
- **Sirolimus –** also called Rapamycin

It is important that you tell anyone supplying or prescribing drugs (e.g. pharmacists or GPs) that you have a transplant and are taking medications.

Side effects of Immunosuppressant drugs

All these drugs damp down your body's immune system and therefore have similar side effects. All the drugs will make you more prone to infections. This is most likely in the early stages when you are on higher doses of the drugs and also when your treatment has been increased, for example if you have had rejection. During this time you will be given other medication to try and prevent the most common or serious infections. If you are concerned that you may have an infection please let the Transplant Team know.

In the long term all immunosuppressant drugs cause an increased risk of some cancers, in particular skin cancers and cancers of the immune system (lymphomas). There is also a small risk of other cancers. However, it is important to remember that even taking in to account all these risks patients with a transplant tend to live, on average, longer than those without. So in most people the benefit of the transplant and the tablets outweigh the side effects.

In addition, each immunosuppressant has more specific side effects. The most common ones are listed here:

Neoral or Ciclosporin side effects:

- Trembling hands
- Increased hair growth
- Bleeding or swollen gums
- Increased blood pressure
- Fluid retention

Prednisolone side effects:

- Weight gain
- Stomach irritation and ulcers
- Skin changes (thinning and bruising)
- Bone thinning (osteoporosis)
- Bone fractures
- Increased blood sugar levels (diabetes)
- Swelling
- Mood swings

Azathioprine or Imuran side effects:

- Feeling sick and vomiting
- Increased risk of bleeding
- Mild hair loss

Tacrolimus or Prograf side effects:

- Trembling hands
- Hair loss
- Increased blood sugar levels (diabetes)

Cellcept or Mycophenolate Mofetil side effects:

- Diarrhoea
- Stomach cramps or discomfort
- Anaemia

Myfortic Mycophenolic acid side effects:

- Diarrhoea
- Stomach cramps or discomfort
- Anaemia

You will receive separate information on other medication you may be prescribed that is not listed here.

How can I keep myself healthy following my transplant?

Maintaining your weight

Your appetite will improve after your transplant. It is therefore important that you eat a healthy balanced diet, as it is easy to gain too much weight.

Oral hygiene

Keep your teeth and gums healthy by brushing regularly and visiting your dentist. Tell your dentist that you have had a transplant and what medication you are taking. You may need antibiotic cover for some treatments. Let us know if you have any gum swelling or a sore mouth.

Keeping fit

Keep active by taking exercise that suits you. Special precautions may be needed in contact sports (e.g. rugby, martial arts), so please discuss this with the Transplant Team. After about three months you can return to swimming and other activities.

If you would like to, you can join the Transplant Games Team and enjoy the gym and other activities at their weekly meeting.

Skin care

Your medication can make your skin more sensitive to the sun. You need to look for any changes in moles and new skin lumps or bumps. Cover up in the sun. Wear a hat and use sun screen (factor 25 or more). You may have more hair growth on your body or face. This will become less, as you need less medication. You can discuss any concerns with the skin care nurse who is present at the transplant clinic.

Keeping a healthy heart

Kidney patients and transplant patients have a higher than normal likelihood of developing heart disease and circulation problems (e.g. heart attacks, strokes and amputations). There are several things you can do to reduce your risk. These include stopping smoking, keeping your weight to normal levels and reducing your alcohol intake to recommended levels (14 units per week for women and 21 units per week for men). You should avoid added salt in your diet if you have high blood pressure. In addition, when you come to clinic the doctors and nurses will check your blood pressure and your cholesterol and may advise you on treatment for that.

Screening for cancer

It is important to keep up-to-date with your smear tests. Follow normal guidelines for self examination of your breasts or testicles.

How long will the transplanted kidney last?

Over time the kidney could be damaged by several things including rejection, 'wear and tear', side effects of treatment or recurrence of your original kidney disease.

A kidney transplant does not last forever. The average life span of a transplant kidney is over ten years for a cadaveric kidney and fifteen years for a living related transplant.

The doctors at the transplant clinic will monitor your kidney function. If it is worsening, they may advise you on tests or changes in treatment.

Here are some general guidelines to help you keep your kidney working:

- Take the immunosuppressant drugs as prescribed
- Attend appointments as requested
- Seek advice from the Renal Unit as soon as a problem is experienced

We hope you have found this information useful. If you have any questions please do not hesitate to ask the Transplant Team. Contact details for the current team are enclosed separately.

Transplant team number	01782 676377/8
Ward 29 number	01782 676124/142

Patient websites that may be helpful

www.kidney.org.uk
(UK National Kidney Federation)

www.talktransplant.com

Addresses of Transplant units

Manchester Royal Infirmary
Oxford Road
Manchester
M139WL

Tel 0161 276 1234

University Hospital Birmingham
The Queen Elizabeth Hospital
Birmingham
B15 2TH

Tel 0121 472 1311

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