

Preparing to join the kidney transplant national register

Renal Medicine & Transplantation

Information for Patients

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What is a kidney transplant?

A kidney transplant is a surgery that places a kidney from another person into your body. It is the best form of treatment for patients with kidney failure. It is not a cure for the kidney disease. A working transplant helps you regain good health.

The transplant has to be maintained by daily medications and through follow-up by both the surgical and medical teams. Not all patients with end stage kidney (renal) failure (ESRF) are suitable to get a kidney transplant. We will talk to you about the reasons for this, backed by the multi-disciplinary team.

How successful are kidney transplants?

Around 95 (deceased donor) and 98 (live donor) out of 100 kidneys will be working 1 year after transplantation. At least 98 out of 100 patients will be alive 1 year after a transplant.

The success rate of transplantation depends on many factors including:

- the condition of the patient receiving the kidney.
- the type of donor.
- the condition of the donor.
- the condition of the kidney.
- the drugs used to prevent rejection.
- compliance of the recipient.

Transplant from a deceased donor

A deceased donor transplant is used to describe a transplant kidney that has been removed from someone who has died.

**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

More than half of the transplanted kidneys in the UK are from this source. We always get permission from the donor's relatives before the organs are used. This is even if the donor's wishes are already known. The average age of a donor is about 54 years. The death process and associated disease have an impact on the potential outcome of the transplant. Specialist nurses care for the donor. They run a number of tests as well as blood tests to check for infections and kidney function. They also find out a lot of information about the general health and behaviour of the donor. The surgeon will go over this information with you. This is to support you to decide whether you wish to move further or not.

The different types of donor

Donor after brain death (DBD):

These are donors that have suffered a permanent and irreversible brain injury. Once tests confirm that the brain injury will not recover and permission has been gained from their relatives, then donation can happen. The patient is taken to the operating theatre and the kidneys removed while the heart is still beating. 94 to 96 out of 100 transplants from a brain dead donor are working at 1 year.

Donor after circulatory death (DCD):

These are patients who have a very poor results and will not get better. Permission is asked from their relatives for the donation to take place. The kidneys are removed soon after the heart stops beating. 90 to 95 out of 100 transplants from a circulatory dead donor are working at 1 year.

The kidneys may take longer to start working. This is due to the impact of the death and retrieval process. This may mean you have to stay in hospital longer and you may need more scans and biopsies of the transplant. We call this delayed graft function or in simple terms the sleepy kidney. This is seen in about 40 out of 100 transplants.

Registry data suggests that in the UK, 86 out of 100 transplants will be working at 5 years. This is the same for kidneys from both DBD or DCD donor transplants.

If you are concerned about the type of kidney you may get, please ask your consultant or the transplant co-ordinator for more information.

Live donors:

This is usually from a relative or friend. More information about live donation is available on request. The results are best from live donors. 97 to 98 out of 100 transplants from a living donor are working at 1 year, and 93 out of 100 at 5 years.

How are kidneys allocated?

A central computer at NHS Blood and Transplant (NHSBT) is used to allocate kidneys. In general, the donor and recipient must have the same blood group. Points are given for the closeness of match according to tissue-type and how long a patient has been waiting.

We do not normally accept single kidneys from elderly donor patients or a donor with an underlying history of disease. This is unless they are given both for a better chance of success. The recipient will then get both kidneys and have a dual transplant.

Please make sure we always have your up-to-date contact details. This is so we can contact you when a kidney becomes available. To make sure that this process is fair it is guided by a set of nationally agreed rules. We as the local centre cannot influence this process.

How long do I have to wait for a transplant?

According to the NHSBT:

- 34% of people on the register are transplanted within 1 year (national data).
- 68% are transplanted within 3 years (national data) (66% for Leicester).
- the average wait is just over 2 years for a transplant.
- if you have a living donor your wait is much shorter.

Why do some people have to wait longer than others?

- Some people have unusual tissue types. For these people there are fewer donors with a good match compared to patients with common tissue types.
- Some people have antibodies (proteins) which work against certain tissue types. These antibodies can appear after pregnancy or blood transfusions. So not all donor kidneys will suit all patients.
- Ethnic minority recipients may have to wait longer due to match of tissue type (average 3 years).

How much will I be told about the donor?

You will be told about

- the type of donor the kidneys have been removed from.
- If there is an increase higher risk of complications related to the transplant.

You may also be told

- the age range of the donor,
- their gender and type of death, for example trauma or a stroke, and
- other disease the donor had (like, diabetes, high blood pressure, cancer etc). The surgeon will talk to you about this in full detail.

Please note there are unknowns which can potentially be transferred, like infection and cancer, which may pose a risk to you (1 in 2000 patients).

What is cross-matching?

Before a matched kidney can be given to you, a final test has to be done. This is the cross-match. A sample of your blood is mixed with the cells of the donor. If there are antibodies in your blood that kill the donor cells, your body will not be able to accept the kidney and transplant cannot be carried out. In simple terms if the cells are happy we are able to carry on with the transplant.

Once you are on the waiting register, we will need a sample of your blood at least every 3 months. This is to measure the antibody levels in your blood. These are called anti-HLA antibodies.

- **Virtual cross-match:** a crossmatch might be predicted using these antibodies. If it is negative for antibodies, the surgeon will move forward with the transplant. This saves critical time that the kidney is being held on ice (cold time).
- **Peripheral blood cross-match:** if the virtual cross-match does not turn out to be negative, then the lab will move forward with formal cross-match testing. To reduce the critical cold time, it might be possible to do the cross-match using blood drawn from the potential donor. This is before the organs are taken out.
- **Formal cross-match:** As soon as the kidney gets on site, the given cells are used to carry out a cross-match. This is done for all potential positive cross-matches and if it was not possible to do a peripheral blood cross-match.

It is important that you give us a blood sample every 3 months. This is so the lab has up-to-date information about your antibodies.

How are medications used to prevent rejection?

We give medication to patients who have had a transplant. This is to prevent their body rejecting the new kidney. To avoid rejection, a mix of some or all of the following immunosuppressive medications will be given to you. You will need to take them for the life of your donor kidney:

- Tacrolimus - also known as prograf or adoport or modigraf or advagraf. This is taken twice a day and the dose will change according to the drug concentration in your blood.
- Tacrolimus does not suit everybody. If you have a problem with tacrolimus - cyclosporine twice a day or sirolimus once a day may be used instead.
- Prednisolone - this is taken daily and will be reduced every 2 weeks. After that, you remain on a very small dose of 5mg.
- Mycophenolate mofetil - also known as MMF or Myfortic. This is taken twice a day.
- Basiliximab - also known as Simulect. This is given only twice. Once before you go down to theatre and then 4 days later.

Are there any side effects from these medications?

These immunosuppressive medications are very powerful. They stop you rejecting the kidney by weakening your immune response. You become more at risk to some infections and cancers as a result. The most common being skin cancer and lymphoma. The infections tend to be viruses or other infectious agents that are already in your body at the time of the transplant.

They may also be in the transplanted kidney, rather than infections that you catch from other people. The most common virus to cause problems is called cytomegalovirus. Some patients are given a drug called valganciclovir to prevent infection (see next page).

Transplant patients are more likely to get skin cancer. They need to protect themselves from the sun. 1 out of every 100 patients transplanted will get a cancer of the blood called lymphoma.

The link to the videos is: <http://tinyurl.com/2htjppx7> and, the transplant medication information QR code to scan



Most common potential side effects of tacrolimus:

- shaking hands (tremor).
- hot flushes and tingling in the hands and feet.
- increase in blood pressure.
- increase in blood cholesterol.
- diabetes in 10 out of every 100 patients transplanted.
- nightmares (first 2 weeks).
- constipation and pain from wind (first 2 weeks).

Most common potential side effects of prednisolone:

- weight gain due to increased appetite.
- temporary rounder appearance to your face which can change how you look.
- increase in blood pressure.
- increase in blood cholesterol.
- diabetes in 10 out of every 100 patients transplanted.
- personality change - very rarely.
- thinning of the bones (osteoporosis).

Most common potential side effects of mycophenolate mofetil:

- tummy (abdominal) cramps and/ or diarrhoea.
- abnormality of bone marrow function. This may make you an easy target to infection or bleeding. You may become anaemic. This is having a problem of not having enough healthy red blood cells or haemoglobin to carry oxygen to the body's tissues.

The side effects are linked to the dose of the medication. These are reduced slowly over the first 3 months. They may be treatable, for example tablets for high blood pressure. Many of the side effects will usually go away within a few days or weeks after the transplant. This is without the need for any treatment.

What about other medication?

You may likely need to keep taking some of your current medication, such as your blood pressure medication. Some patients may have to start taking medication to lower blood cholesterol. Also, you have to take medication to prevent infections. This is because you are more at risk of getting infections after a transplant.

You will have to take:

- Co-trimoxazole (also known as Septrin) for 6 months to prevent a rare type of chest infection.
- Valganciclovir for 3 months to prevent a common viral infection.
- Aspirin to reduce renal vein thrombosis.
- Lansoprazole to reduce gastritis.

What happens when there is a kidney for me?

You need to keep your contact details current and up-to-date. Make sure to tell us if you are going away on holiday or your health changes. You can update your details by calling our recipient co-ordinator on **0116 258 8266**.

When a kidney becomes available for you, the transplant doctor at Leicester General Hospital will call you. This could be at any time of the day, more commonly at night.

The person calling you will

- confirm your details with you,
- ask if you are well, and
- check when you last had dialysis (if needed). **This is to prepare you for theatre.**

You must come to the hospital as soon as you are told that there is a kidney for you. When you get the call it is important that you:

- **keep calm** - they will ask you a few questions and give you clear instructions about what you need to do. You will have enough time to decide.
- **listen** to the information being given to you.

They will tell you

- when you need to stop eating and drinking in preparation for the surgery.
- where and when you have to report to: at ward 37 Glenfield General Hospital, Leicester.
- **be prepared** - think about what you want to bring into hospital. It is important you do not spend too long at home packing.
- **think ahead** - make sure you have thought about how you will get to Leicester General Hospital.
- **plan** this well in advance. Since the kidney offer is not a planned visit, you cannot use the hospital transport service. You will need to arrange your own transport to get to the hospital.
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- You can **only use the** hospital transport to go home when discharged and for up to 6 weeks after the transplant to the clinic, after this is dependent on individual eligibility.
- **arrive** safely as soon as you can, but do not drive dangerously or break the speed limit.

It may help to bring a relative or friend with you. You will need to check hospital visitor policy at the time, as visitors may not be allowed inside the hospital.

Checklist of essentials you need to bring into hospital for your transplant:

- Any medication or list of medications that you are taking.
- A wash bag.
- Some money to buy things from the shop.
- Some comfortable slippers.
- Do not bring any valuables in with you.

When you arrive you will have a quick Covid test. A clear result will be needed before admission to the ward.

What does the surgery involve?

It will take a few hours to make sure you are fit for surgery.

- You will have a blood test, a chest X-ray, cross-match and ECG (heart tracing) tests, and will get examined by a doctor. The transplant surgery will be explained to you.
- You will be given a chance to ask questions before you are asked to sign a consent form for surgery.
- Depending on your blood results, you may need to have a treatment to filter wastes and water from your blood (**dialysis**) before the transplant. Sometimes, the results of the cross-match test, or tests on the potential donor kidney, may show that it is not suitable for you. This is obviously very disappointing. It means that the transplant cannot take place and you will go home. This is safe practice and in your best interest.
- You will be put to sleep by a general anaesthetic before surgery.
- You get 1 kidney which is placed above the groin on either the left or the right side.
- Surgery takes between 2 to 4 hours. You will be away from the ward for about 5 to 6 hours. This includes the time taken to put you to sleep (anaesthetic time) and also to monitor you in the recovery room after surgery (recovery time).

What happens after surgery?

When you wake up, there will be some plastic tubes emerging from your body. These can include:

- a thin tube (catheter) placed in your bladder. This is to drain away your pee (urine).
- a thin plastic tube in your neck (a central line). This is used to give you fluids and medication. This is not used often.

- a line to a vein in your arm. This is used to give you fluids and medication, such as painkillers.
- a plastic drain tube by the side of the surgical wound to drain any blood or fluid from the site of the surgery.
- you will have a morphine or fentanyl infusion which you control for pain relief.

We have put these tubes so that we can give you better care. Usually, they are taken out 2 to 5 days after your transplant. Most patients stay in hospital for 5 to 10 days.

After leaving hospital you may be seen in the transplant clinic 3 times a week at first. You will need to come less often as your new kidney settles into your body. You will always have to come for regular check ups. This is even many years after the transplant and for as long as it continues to work.

It is very important that you take your medication when prescribed and do not miss any tablets. Please check that you have got the same make or brand of the tablets as before. Missing medication will result in your body rejecting the kidney and cause the transplant to fail.

What tests will I need after the transplant?

- At first, you will have a blood test every day. This is to check that the kidney is working properly.
- After surgery while you are waking up, an ultrasound scan is done. This is to check the kidney is getting a good blood supply.
- During your recovery other types of scans may also be done. This is to check how well the kidney is working.

What if my body tries to reject the new kidney?

To find out whether your body may be rejecting the new kidney. We will check your blood, your pee (urine) and your temperature. If we suspect this, we will take a sample (biopsy) of the kidney tissue for checking to confirm this. You will be given a local anaesthetic before this procedure so that you will not feel any pain. Using scan imaging, a little piece of the kidney is removed using a needle. Next, this is looked at under a microscope in the laboratory.

If we suspect rejection we will take action with treatment straight away. This is before it is confirmed. This involves having an injection of another steroid called methylprednisolone each day for 3 days. You would usually have this as an outpatient. It is unusual to lose a kidney through rejection as the immunosuppressive medications are very powerful. Rejection can sometimes be treated by other medication.

Will I need dialysis after the transplant (sleepy kidney)?

Up to 40 out of 100 patients may need dialysis after a deceased donor transplant. The donor kidney may be slow to start working (sleepy kidney). It may take a few days or weeks before some kidneys start to work properly.

You should not worry if you need to have dialysis after a transplant. If your kidney is slow to start working, you may need to have more scans and biopsies. This is to make sure that the kidney is well and that there is no rejection. You do not usually have to stay in hospital until the kidney starts to work. A sleepy kidney is seen in up to 40 out of 100 deceased donor transplants and 5 out of 100 live donor transplants.

What are the possible risks and side effects of surgery?

There are risks linked with all big and small operations. This can lead to serious complications or even death. The transplant surgery and the days shortly after it carry the same risks. During your work up tests done before your transplant and the transplant information programme (TIP), the transplant coordinators, surgeon, and the nephrologist will go over the risks with you. At the time of your transplant, before you sign the consent form, they will go over them with you again.

The risks for patients having a kidney transplant:

Kidney failing in the first year:	5 to 7 out of 100
Bleeding:	5 out of 100
Problem with the join between the kidney and the bladder:	7 out of 100
Blockage of the blood vessels supplying the kidney:	2 to 5 out of 100
Narrowing of the blood vessels supplying the kidney:	5 out of 100
Wound infection:	5 out of 100
Collection of fluid around the kidney:	7 out of 100
Blood clots in the legs:	1 out of 100
Acute rejection of the donor kidney:	15 out of 100
Kidney function that is delayed and needs dialysis:	40 out of 100
Risks of getting infections from the donor:	1 out of 1000*
Risks of getting transmissible cancers from the donor:	1 out of 2000*
Risks of immunosuppression:	see page 5
Certain underlying conditions or diseases coming back again (recurrence)	

*About 1 in 2000 donors have a hidden cancer, or 1 in 1000 an infection that we do not know about. Even though the tests are quite strong and viruses are checked for, we cannot know beforehand which donors have these hidden infections or cancers. You can catch certain infections without knowing from such donors. In such case you might need ongoing care, like antiviral medication.

*About 2 in 100 donors have died from a cancer in the brain or other cancers treated in the past. We make every effort to get all the details of these cancers and treatments before deciding whether the organ is safe to use. Yet, there is a small chance this may be passed to you.

Your consultant may feel that it is in your best interest to have a blood transfusion during or after the transplant for various reasons. This will be discussed with you before surgery. The risks of blood transfusion are low and you will be given a leaflet about this.

You may start having other conditions linked to having a kidney transplant. The risks are very small. The consultant will go over these with you before you sign your consent form.

What happens if I decide that I do not want a transplant?

Your current treatment for kidney failure will continue. If you are on the UK national register you will be removed. Transplantation is encouraged. This is because, you will be free from most food and drink limitations and dialysis. It may also improve your quality of life and your life expectancy.

Can I be removed or suspended from the transplant waiting register?

Yes, if you are not well or you have had to have surgery. That means that you would not be fit enough to have a kidney transplant. Your kidney doctor will talk to you about this.

You will be able to get back on the waiting list and keep the points you earned once you have fully recovered. You will also be suspended from the register temporarily if you travel for any length of time, including going abroad for a holiday.

Further decisions to make

If we have given you this information, it means you may be suitable and have decided to have a kidney transplant. There are 2 more decisions we would like you to make before your transplant:

- Are you against getting any type of deceased donor kidney?

If you are not happy to get a particular type of deceased kidney. Please speak to your consultant for further information and so we can record your wishes. Please note the results are no different between DBD or DCD organs. Also, the match score is not so important. Immunosuppressive medications have improved over time and patients do better with a transplant than staying on dialysis.

- Taking part in clinical studies of new drugs or new drug combinations.

We are constantly trying out new ways to improve the results of transplantation. 1 important way is to do clinical studies comparing new drugs or new combinations of drugs against the ones we use at the moment. In these studies, patients are randomly selected to receive either the established drug combination or the new ones. We would have some evidence that the new drugs may be better or the same as the established drugs. You would not be given medications or a combination of medication that we thought would not be as effective. You need to decide whether you want to take part in a clinical study at the time of your transplant. Whichever decisions you make, will have no influence on your care.

Any questions?

If you have any questions about kidney transplants or the decisions that you need to make, please contact the renal recipient transplant coordinator team on **0116 258 8266/4736**.

You should also tell the co-ordinator if you change your mind about any decisions. Arrangements can be made to discuss your queries in clinic if needed.

You will be reviewed in clinic on a yearly basis whilst awaiting for your kidney transplant. This is to check that you remain suitable to be active on the UK transplant register.

Further information

National Kidney Federation: www.kidney.org.uk

Kidney care UK: kidneycareuk.org/

NHS Blood and Transplant: www.nhsbt.nhs.uk/organ-transplantation/kidney

If you have any questions, write them down here. This is to remind you what to ask when you speak to your nurse or consultant:

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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