Department of Renal Medicine and Transplantation

Your forthcoming Deceased Donor Transplant

This information is for patients who are considering whether to have a kidney transplant. It explains what happens before, during and after a transplant. It also tells you about any risks and side effects involved.

You will already have been a given a copy of the booklet: Kidney Transplantation, A Guide for Patients and Relatives. This covers much of the following information in more detail.

How successful are kidney transplants?

Kidney transplantation is very successful. Over 90 out of 100 kidney transplants are working at the end of the year. At St George's Hospital over 85 out of 100 kidney transplants are still working after five years. The reason why some kidneys fail soon after the transplant can be related to the kidney, technical issues related to surgery or health issues which the patient might have. If there is anything specific to you that may increase the risk of failure of the transplant, this will be discussed in detail at the time of your activation on the transplant waiting list.

There is a small risk to your life (two to five percent) in the first year after the transplant. This may depend on other health conditions and your age at the time of the transplant. After a year the risk to your life decreases with a functioning kidney, compared with remaining on dialysis.

The success rate of transplantation depends on many factors including the following:

- 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.

The deceased donor

A deceased donor transplant is used to describe a transplant kidney that has been removed from someone who has died. More than half of the transplanted kidneys in the UK are from this source. Permission is always gained from the donor's relatives before the organs are used, even if the donor's wishes are already known.

Specialist nurses attend the donor and carry out numerous special tests including blood tests for infections and kidney function. They also find out a lot of information regarding the general health and behaviours of the donor. This information will be discussed with your surgeon who will decide whether the kidney would be suitable for you.

The types of deceased donor

Donor following Brain Death - DBD (Heart beating donor)

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. 95 out of 100 transplants from a brain dead donor are working after one year.

Donor following Circulatory Death - DCD (Non heart beating donors)

These are patients who have a very poor prognosis and will not recover. Permission is sought from their relatives for the donation to take place. The kidneys are removed soon after the heart stops beating.

90 out of 100 transplants from a circulatory dead donor are working at one year. These types of kidneys may take longer to start working. This may mean you have to stay in hospital longer and you may need more scans and biopsies of the transplant.

It has been calculated that in the UK 70 out of 100 transplants will be working at 10 years. This is the same for kidneys from both brain dead and circulatory dead donors.

If you are concerned about the type of kidney you may be offered, please ask your consultant or transplant sister for more information.

Dual deceased donor kidney transplant

There are some cases where one kidney from a deceased donor may not have enough function to provide long term benefits and therefore both kidneys from the same donor are transplanted into one patient. More information will be discussed during clinic visit.

Live donors

This is usually from a relative or friend. More information regarding live donation is available on request.

97 out of 100 transplants from a living donor are working after one year. The operation is very similar and the antirejection medication required is the same. However, the surgical complications rates are lower than quoted in this leaflet.

How are kidneys allocated?

A central computer at NHS Blood and Transplant is used to allocate kidneys. Usually, the donor and recipient must have the same blood group. Points are given for the closeness of match according to tissue type, how long a patient has been waiting and to some extend how long someone is on dialysis. The waiting time starts when someone is cleared by the transplant team to go onto the national waiting list.

Please make sure we always have your up-to-date contact details so we can contact you when a kidney becomes available.

How much will I be told about the donor?

You will be told about the type of donor from whom the kidneys have been removed. If there is an increased risk of complications related to the transplant this will be discussed with you.

You may also be told the age range of the donor, their gender and type of death, for example trauma or a stroke. These will be discussed with you by the surgeon. It is important to note that every effort is made by the national organ retrieval team to get maximum information about the donor and their previous health. On rare occasions some information may come to light after the transplant has been performed. In rare cases this can have a significant impact on your health. All this and further information is discussed in detail at the time of transplant listing, transplant surgery and follow up period.

What is cross matching?

Before a kidney can be given to you, a final test must 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. Once you are on the waiting list, we need a sample of your blood at least every three months to measure the antibody levels in your blood. These are called anti-HLA antibodies. We also do a virtual crossmatch at St George's to minimise the waiting time before a transplant can be carried out.

How are drugs used to prevent rejection?

We give drugs (medicines) to patients who have had a transplant to prevent their body rejecting the new kidney. We plan which drug treatments are needed by dividing our patients into two categories:

- Low Immunological Risk. This covers patients who are having their first transplant **and** who do not have high levels of anti-HLA antibody.
- High Immunological Risk. This describes the group of patients having their second or subsequent transplant **or** who have high levels of anti-HLA antibody.

Depending on under which group you come, you will receive a combination of some or all the following drugs to prevent rejection. The drugs are:

- **Tacrolimus** - also known as Adoport or Advagraf. Adoport is taken twice a day whilst Advagraf is once a day. The dose will change according to the drug concentration in your blood.
- **Prednisolone** - this is taken daily and may be stopped after a week unless you have a high immunological risk.
- **Mycophenolate Mofetil** - also known as MMF. This is taken twice a day.
- **Basiliximab** - also known as Simulect. This is given only twice, once during the operation and then four days later.

Are there any side effects?

These drugs are very powerful and common side effects include the following:

General side effects of taking immunosuppressive drugs
The drugs stop you rejecting the kidney by weakening your immune response. A consequence of this is that you are more susceptible to some infections and cancers. 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 below).

Transplant patients are more likely to get skin cancer and it is important to take precautions to avoid sun exposure. One out of every 100 patients transplanted will get a rare cancer called lymphoma. This is often treatable if found early.

Side effects of specific drugs

Tacrolimus
Tremor of your hands
Hot flushes and tingling in the hands and feet
Increase in blood pressure
Increase in blood cholesterol
Diabetes in 10 of every 100 patients transplanted
Nightmares (first two weeks)
Constipation and wind pains (first two weeks).

Prednisolone
Weight gain due to increased appetite
Round (“moon”-shaped) face which can change how you look

Increase in blood pressure
Increase in blood cholesterol
Diabetes
Personality change - very rarely
Osteoporosis (thinning of the bones).

Mycophenolate mofetil
Abdominal cramps and / or diarrhoea
Abnormality of bone marrow function. This may make you more susceptible to infection or bleeding. It may result in you becoming anaemic.
The side effects are related to the dose of the drugs, which is reduced gradually over the first three months. They may be treatable, for example with blood pressure tablets.
Many are self-limiting and they will usually go within a few days or weeks of the transplant. These do not need to be treated.

What about other drugs?

You will probably have to continue with some of the medications that you are currently taking, such as your blood pressure medications. Some patients may have to start taking blood cholesterol lowering medication.

In addition, you may 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 one of:

- Co-trimoxazole for three months to prevent a rare type of chest infection.
- Valganciclovir for six months to prevent a common viral infection.

As a result of these measures, hardly any of our patients acquire this type of chest infection or viral infection.

There may be other medications given to you depending on your individual needs and medical history.

What does the operation involve?

You must come to the hospital as soon as you are informed that there is a kidney for you. You will need to make your own way to the hospital as transport will not be provided.
It will take several hours to make sure you are fit for the operation. You will have a blood test, a chest x-ray and ECG (heart tracing) and be examined by a doctor. The operation will be explained to you and you will be given the opportunity to ask questions before you are asked to sign a form to consent for the operation. Depending on your blood results, you may need to have dialysis before the transplant.

Very occasionally the results of the final crossmatch, issues with the donor or tests on the kidney, show that it is not suitable for you. This is obviously very disappointing as it means that the transplant cannot take place and you will go home.

You will be put to sleep by a general anaesthetic before the operation. You get one kidney which is placed above the groin on either the left or the right side. Sometimes you may be offered two kidneys and this will be discussed with you at the time of the kidney offer.

The operation takes between two and four hours and you will be away from the ward for about five to six hours. This includes the time taken to put you to sleep and to monitor you in the recovery room after the operation.

If you have other health issues such as heart disease or previously have had a stroke, you may require admission to the High Dependency Unit (HDU) or Intensive Care Unit (ICU) after the operation.

What happens after the operation?

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

- A thin tube (catheter) placed in your bladder. This is a tube to drain away your urine.
- A line to a vein in your arm. This is used to give you fluids and medications, such as pain killers.
- A plastic drain tube by the side of wound. This is to drain any blood or fluid from the site of the operation.
- A thin tube (catheter) near the wound to give you a local anaesthetic directly into the wound site. This should help to minimise any pain.
- Occasionally patients have a plastic tube inserted into the vein at the base of the neck.

These tubes are placed so that we can look after you. They start to be removed after the second day after your transplant.

Most patients stay in hospital for five to ten days if their transplant is straightforward. After leaving hospital you will be seen in the transplant clinic twice 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, 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 that no tablets are missed. Please check the make or brand of the tablets are the same as you have previously received. Missing medication could result in you rejecting the kidney and the transplant failing.

What investigations will I need after the transplant?

You will initially have a blood test every day to check that the kidney is working properly. After the operation while you are waking up, an ultrasound scan is done to check the kidney is receiving a good blood supply. During your recovery other types of scans may also be carried out to check how well the kidney is working.

What if my body tries to reject the new kidney?

If we suspect that your body may be trying to reject the new kidney, we will take a biopsy of the kidney tissue for examination. A local anaesthetic is given before the procedure so that you will not feel any pain. A small piece of the kidney is taken through a needle and is then examined under a microscope.

You may require additional treatment if you have some rejection. This involves receiving an injection of another steroid called methylprednisolone each day for three days. You would usually receive this as an outpatient. It is unusual to lose a kidney through rejection as the new drugs are very powerful. Occasionally other drugs may be used to treat rejection.

A transplant biopsy may be advised at three months after the transplant to help choose the best long-term drug treatment.

Will I need dialysis after the transplant?

A few patients may require dialysis after their transplant, as the new kidney may be slow to start working. It may take several days to several 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 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.

What are the risks and side effects of the operation?

There are risks associated with all major and minor operations, which can lead to serious complications or even death. The transplant operation and the days immediately after it carry some risks. These will have been explained to you by the transplant sisters, kidney doctor (nephrologists) and surgeon during your pre-transplant assessments. They will be explained to you again at the time of your transplant before you sign the consent form.

The risks for patients undergoing kidney transplantation:

The kidney failing in the first year	10 out of 100
Bleeding	5 out of 100
Problem with the join between the kidney and the bladder	5 out of 100
Blockage of the blood vessels supplying or draining the kidney	4 out of 100

Narrowing of the blood vessels supplying the kidney	5 out of 100
Wound or urinary tract infection	5 out of 100
Collection of fluid around the kidney	5 out of 100
Blood clots in the legs	1 out of 100
Acute rejection of the new kidney	15 out of 100
Hernia of transplant wound	4 out of 100
Delayed kidney functioning requiring the need for dialysis	30 out of 100
Risks of acquiring blood borne infections or transmissible cancers from the donor	1 in 2,000
Risks of immunosuppression (see above)	

Your consultant may feel that it is in your best interest to receive a blood transfusion during or after the transplant. The reasons for a blood transfusion will be discussed with you before the operation. The risks of blood transfusion are low. If you would like further information, please ask as we can provide you with a leaflet.

You may develop other conditions related to receiving a kidney transplant. However, the risks are very small and the consultant will discuss these with you fully before the operation.

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

Your current treatment for kidney failure will continue. Transplantation is encouraged as you will be free from dialysis and most dietary and fluid restrictions. It may also improve your quality of life and your life expectancy.

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

Yes, if you are unwell or it has been necessary for you to have an operation that means that you would not be fit enough to undergo a renal transplant. This will be discussed with you by your kidney doctor. Once you have recovered then you can be reactivated on the waiting list. You will not go back to the beginning of the list and will return at the point on the list where you left.

You will also be suspended from the list temporarily if you travel abroad.

Two further decisions

If we have given you this information, it means you are suitable and have decided to have a kidney transplant. There are two more decisions we would like you to consider before your transplant.

A. Do you have objections to receiving any type of deceased donor kidney?

If you are not happy to receive one type of deceased donor kidney please speak to your consultant for further information and so we can record your wishes.

B. Clinical research studies on new drugs or new drug combinations
We are constantly trying out new ways to improve the results of transplantation. One 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 offered drugs or a combination of drugs 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.

Whatever the decisions you make, they will have **no** influence on your care at St George's.

Any questions?

If you have any questions about kidney transplants or the decisions that you need to make, please contact the Recipient Coordinator on telephone 020 8725 0107. You should also inform her if you change your mind about your decision.

Useful sources of information

National Kidney Federation: www.kidney.org.uk
Kidney Care UK: https://www.kidneycareuk.org/
NHSBT Organ donation: https://www.organdonation.nhs.uk/
NHSBT transplant activity reports:
https://www.odt.nhs.uk/statistics-and-reports/organ-specific-reports/

Please contact the transplant nurses if you would like another copy of the booklet: Kidney Transplantation, A Guide for Patients and Relatives.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:
Monday, Tuesday and Thursday between 10am and 4pm
Friday between 10am and 2pm.

Please contact PALS in advance to check if there are any changes to opening times.

The Walk-in and Advisory telephone services are closed on Wednesdays.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough Wing.

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS UK
The NHS provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. **Web:** www.nhs.uk

NHS 111
You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones. **Tel:** 111

AccessAble
You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.

This has been endorsed by the Patient Information Group
PInG

Reference: RTS_YDDT_02 **Published:** September 2024 **Review date:** September 2026