

Kidney Health Information

Kidney Transplantation

What is kidney transplantation?

If you are diagnosed with failing kidneys before you need dialysis, treatment can sometimes prevent (or certainly delay) their complete failure. But when your kidneys finally stop working effectively, then you will need either dialysis or a transplant.

While dialysis is able to get rid of waste products from your body, it does not replace all the functions of your own kidneys. A transplant does. These necessary functions include:

- continuous removal of waste products of metabolism
- continuous removal of excess fluid
- production of a natural hormone called erythropoietin, to prevent anaemia. (If you become very anaemic, exertion will leave you short of breath)
- conversion of vitamin D in food into an active compound, which helps to keep bones healthy. (All patients with kidney failure develop some bone disease)

- excretion of some drugs
- helping to control blood pressure

Your kidneys are normally undertaking these functions continuously, day and night, year in year out, without you even having to think about it.

It has been shown that kidney transplantation gives better quality and quantity of life than dialysis treatment, so it is in your best long-term interest, provided that you are fit enough to undergo it.

How am I assessed for kidney transplantation?

You will be referred for consideration of kidney transplantation once you are nearing (or have actually started) dialysis. Assessment does not depend on age or ethnic background but on whether you are fit enough to have the operation and to deal with the problems that can occur after surgery. So if you have evidence of heart disease, chest condition or other problems, special investigations will be undertaken to assess whether the risks are too great for transplantation. There will be discussion between the transplant surgeon, your kidney doctor (nephrologist), specialists in other disciplines if necessary (such as a cardiologist or chest physician) and your GP, as well as yourself, before making a decision.

If you are considered fit for transplantation, the benefits and risks have been explained to you and various tests have been undertaken, you will be put on

the transplant waiting list. The tests include checking your tissue type and whether you have had certain virus infections (Hepatitis B and C, HIV, Cytomegalovirus).

You will also be asked whether you have a relative or spouse who would consider being a live kidney donor. Most live donors come from within the family but, increasingly, more spouses are coming forward and even some close friends. Live donor transplantation gives the transplant kidney a better chance of long-term survival, compared to transplants from patients who have died (cadaveric transplants). You should think carefully before ignoring or rejecting this form of kidney donation since it is in your best interests to accept. While there are risks as well as benefits to live donor transplantation, these will be fully discussed with you and the donor, so that you can both make a decision on the basis of evidence and knowledge.

Inevitably emotion also plays a part in the decision-making, but rest assured that the transplant will only go ahead if your donor is fit and healthy.

How long will I wait for my new kidney?

Once you are accepted for transplantation, you will go on a local and a national waiting list. The national waiting list is held by UK Transplant (UKT), a government-funded body which co-ordinates transplantation in the UK and

holds the details of all patients on each local waiting list in every transplant centre in the UK. Whenever a kidney donation takes place, the donor tissue type is registered with UKT and a computer search is made to see which patients have the best match – so a kidney donor in Aberdeen may be best matched to a recipient in Plymouth or Liverpool, and the kidneys would be sent to these transplant centres for specifically identified individuals.

Your waiting time for a kidney will not depend on *when* you are placed on the transplant list but on *how well matched* you are to the donor. Some people have been very fortunate and received a transplant within a few weeks of joining the waiting list, whereas others have had to wait for a long time. If your origin is from outside the UK, or you have an unusual tissue type, the waiting time is likely to be longer because the chances of matching with the pool of UK donors will be less. Don't forget that for cadaveric transplantation someone has to die before he or she becomes a donor, so it is impossible for doctors to predict when a suitable matched kidney will become available. Also, there are always more people in need of a kidney transplant than the number of donors available.

Will my blood group and tissue type affect the wait?

Blood group:

In the first instance, your blood group determines whether you can receive a donor kidney. There are four blood groups: O, A, B and AB. The blood group has to be compatible (though not necessarily the same) as follows:

Donor Blood Group	Recipient Blood Group
O (47% donors) – universal donor	A, B, AB, O
A (40% of donors)	A, AB
B (9% of donors)	B, AB
AB (4% of donors)	AB – universal recipient

Kidneys from donors in blood group O (“universal donors”) can be given to anyone in other blood groups, and patients in blood group AB can receive kidneys from donors in any other blood group (“universal recipients”). Blood group B is uncommon in the UK (about 9% of donors) but is quite common (40%) in the Indian, Pakistani and Bangladeshi populations. Blood group and tissue matching differences are the main reasons for the difficulty in Asian dialysis patients receiving a kidney transplant from UK donors.

Tissue type:

We all inherit a set of chromosomes from our father and mother, making two sets of chromosomes altogether. Amongst these chromosomes there are so-called HLA genes (Human Leucocyte Antigen) which are within the genetic material of virtually all the cells which make up the body. There are three principle transplantation genes that are particularly important: HLA 'A', HLA 'B' and HLA 'DR'.

There are many different HLA 'A', 'B' and 'DR' genes and so it is difficult to get two people perfectly alike, but it is possible to achieve a good enough match for a successful transplant. The larger the group of patients and donors, the more chance there is of a good or perfect match between donor and recipient. That is why kidneys are shared throughout the UK. It has been shown in many studies that good matching between donor and recipient leads to longer kidney survival, and hence is in the best interests of everyone. In a situation where there is a shortage of donor organs, it makes sense to maximise the benefit in prolonging kidney survival.

Who would donate my new kidney?

There are three types of donor:

- **Heart-Beating Donor** This is the most common form of organ donor. Usually the donor has undergone a sudden, serious event such as a

brain haemorrhage, a head injury following a road accident, or another event which has led to them being placed on a ventilator (breathing machine), being unable to breathe unaided. Tests are carried out to establish whether or not the patient will ever recover adequate brain function, particularly a capacity to breathe independently again. If tests confirm that brain damage has been extensive and irretrievable, it is at this stage that the family are informed and the subject of organ donation is raised; in most cases, the relatives consent to organ donation. The donor is then transferred to the operating theatre where the respective organs are removed, whilst the heart is still beating and the ventilator is still providing oxygen to the tissues. In these circumstances, the kidneys remain perfused with blood until a special cold solution is infused into the kidneys to cool them down. The donor's heart remains beating until it is finally removed, if consent has been given for heart donation, and this is only done when the other organs (liver, kidneys, pancreas, etc) are ready to be perfused, cooled and removed.

- **Non-Heart beating Donor** This is quite a different situation from heart-beating donation. The donor has again usually had a sudden collapse following brain haemorrhage, heart attack or other event which results in the heart stopping (cardiac arrest). The patient may already be on a hospital ward or brought in by ambulance to the A&E

Department; he or she receives full resuscitation measures as normal but if this fails to restart the heart, then the patient is declared dead. If relatives are available, consent is requested for organ donation. If consent is given, a tube is placed into the main artery and the kidneys are cooled down with the special organ preservation fluid, so that they are not irretrievably damaged and can be removed for transplantation. Because the donor's heart has stopped beating before the kidneys are perfused with the cooling solution, some damage to the kidney will have taken place. However, they have a tremendous capacity to repair and will usually start working in the transplant recipient some weeks later. If you receive a kidney from a non-heart beating donor, you will be maintained on dialysis until such time as the kidney starts to work again.

- **Live Donor** In this situation, someone you know – usually a family member – offers you one of their kidneys. After they have undergone testing to make sure that they are suitable, the kidney is transplanted into you.

In this situation of course, the kidney is functioning very well before removal and the process for removal and transplanting into you is much shorter. Any damage caused by the removal process is therefore minimised, and usually the kidney starts working immediately. Studies have shown that in the long-term this type of transplant will result in

the best outcome.

The nature of live donor transplantation means that it is a daytime activity on a scheduled operating theatre list, whereas cadaver transplantation tends to be an emergency procedure.

What happens in the transplant operation?

The operation itself takes anywhere between one-and-a-half and three hours, although if there are difficulties it may take even longer. The key factor is not the length of the operation but the care with which it is performed. Technical factors within you and any anatomical abnormalities in the donor kidney will dictate the length of the procedure. The kidney is placed in the lower abdomen just above your thigh. The kidney's vein is joined to your own iliac vein (which drains the blood from your leg), and the kidney's artery is joined onto the iliac artery (which supplies your leg with blood). Once these blood vessels have been connected, the circulation to your kidney is released; the kidney becomes pink and may start to work more or less straight away. Indeed, urine may pass out of the ureter, the tube that joins the kidney to the bladder. The ureter is then joined to the bladder to complete the operation.

Often, a special drainage tube is left in, near the kidney, to drain out any blood or other fluid from the operation site. A catheter in your bladder drains the urine into a bag for monitoring. You will return to the ward with one or

two intravenous infusions, a drain, a catheter and a PCA (Patient Controlled Analgesia), which is a morphine infusion for pain control which you can adjust yourself.

After the operation, you and your kidney will be monitored carefully. Your kidney may be scanned by ultrasound to check on the circulation, and to make sure that the ureter does not become obstructed.

How will I be monitored after the operation?

Immediately following the transplant, you will start taking immunosuppressive medication to help prevent your body from rejecting the new kidney. The medicines that you are given to prevent rejection may not be entirely effective, and break-through “acute rejection” may occur, usually within the first six weeks after transplantation. Thereafter, the rejection episodes are much less common and are usually triggered by external factors and, most particularly, if you do not take your immunosuppressive drugs.

Once your kidney is working and is stable, you will be discharged home. Some transplant units have a policy of sending you home as soon as you have recovered from the operation, whether the kidney is working or not. In these units you will be monitored very closely as an outpatient until the kidney starts to function. In those that keep you in hospital until the kidney

starts to work, after you have been discharged from hospital you will also be monitored closely in the outpatient clinic, but probably less frequently. This monitoring will require you to go to the hospital or the transplant unit up to three times a week so that blood tests can be performed, and your immunosuppressive drug levels can be monitored. It is important to remember that deterioration in your kidney function does not necessarily imply acute rejection; there may be other factors such as obstruction to urine flow in your ureter or bladder, or excessive levels of immunosuppressive drugs. Follow-up clinic appointments are important to monitor your kidney function, your blood pressure and your general well-being. Many centres ask for you to monitor your own blood pressure at home as well as your urine output and temperature. Most often you will be given a book in which to record these measurements, and all your prescribed drugs will also be recorded in the book. It is vital that you bring this book with you every time you attend the hospital. The dosage of your drugs will be readjusted with time.

What long-term monitoring is needed?

If you are well and the kidney function is stable, you will usually be discharged home between one and two weeks after the transplant. After the first six to eight weeks following transplantation you will be monitored once

a week, and then in time less frequently. If you are several years post-transplantation, you will generally be seen on a three to six monthly basis – but you will never be discharged.

Despite many years of function, kidneys do deteriorate and the whole purpose of the outpatient appointment is to monitor the function of your kidney. In addition, there are many other factors that need to be monitored to improve the long-term survival of the kidney and your life. These include your weight, blood pressure, the lipids (fats) in your blood, bone disease, heart disease, prescribed drugs and so on. *Attendance at outpatient clinics is essential.* A lot has been invested in you, not only by your family and your transplant team but also the donor family who have given their loved one's kidney to you, and it is your responsibility to treasure that gift.

Not taking immunosuppressive drugs as prescribed (non-compliance) is a problem which is probably far more common than even doctors are aware of. Every transplant centre has patients who lose their transplant because of this completely avoidable factor. If the drugs that you are taking are causing some problems, talk to your doctors about changing them rather than stop taking them. Your doctor will not insist that you take a drug which you find unpalatable, or causes unacceptable side effects. Monitoring you after transplant is a partnership between you the patient, the transplant unit staff and your GP. If you feel depressed, or have other problems, then every transplant centre has an “open door” policy so that you can contact

transplant unit staff at any time to discuss your concerns. Most patients use this facility at some time or other.

Your GP is responsible for the overall care for you and your family, so he or she is very important in monitoring and managing your general health. Many patients and their GPs are happier for much of the care after transplant to be controlled by the transplant centre. However, there is a three-way partnership between you, your GP and the transplant centre staff to try and maintain your good health. The transplant centre should be in regular contact with your GP via your discharge letters and clinic letters, informing the GP of changes in drug prescription, your kidney function and general health.

High blood pressure is a common feature of kidney failure, both before and after transplantation, and the management of this is often a shared partnership between the GP and the hospital doctors. It is important that you participate in this by measuring your blood pressure yourself if you have a machine, or have your blood pressure checked by the nurse at the GP practice. Many GPs and hospital transplant centres run “healthy lifestyle” clinics which are there to monitor and advise you on improving your general health.

Some patients are more comfortable in attending the transplant centre clinic rather than going to their GP if they have a problem. This is understandable

and arrangements usually allow for this. However, your GP is the first port of call in an emergency situation. In some areas, GPs will prescribe your immunosuppressive drugs for you, but in other areas your drugs will be supplied by the hospital. Home delivery service of the immunosuppressive drugs has become more available in some areas, and this may be appropriate for you once you are stabilised on a settled dose of your medication.

What are the survival rates of kidney transplants?

Kidney survival time	% survival rates	
	Cadaver kidneys kidneys	Live donor kidneys
At 1 year	85 -90	90-95
At 5 years	70	80
At 15 years	50	60

Whilst your medical team would like your kidney to last forever – and some kidneys indeed survive for more than 30 years – unfortunately this does not usually happen. Therefore, transplantation plays only one part in the management of your kidney failure, with dialysis being the counterpart.

How am I notified when a transplant becomes available for me?

You will receive a telephone call, usually from the Transplant Co-ordinator or a nurse from the Transplant Unit, informing you that a kidney has been accepted for you, and asking you to come into hospital. Sometimes the kidney is already in your transplant unit but at other times it will be transported from another UK transplant centre. The telephone call may come at any time, including the middle of the night. There is clearly no way of predicting in advance when the call will come; in fact, most patients are easier to get hold of in the middle of the night than during the day!

Am I guaranteed to receive the kidney?

The first thing that will happen when you arrive at the hospital is a blood test which will be sent to the tissue typing laboratory for the "cross match" test. This test is absolutely essential to see whether your blood has any antibodies against the donor. The cross match test takes at least four hours to perform, and longer if more complex tests have to be undertaken, but during this time you will be "booked in" by a doctor who will assess whether you are fit enough to undertake the transplant, and you will have more blood tests (usually done at the same time as blood taken for cross match testing), an ECG and chest x-ray. Once the all-clear is given, the operating theatre will be contacted about proceeding with the transplant. Very occasionally a

combined discussion between the doctors on the transplant team and the anaesthetist will result in you not going ahead with the transplantation because of medical problems.

What are the risks involved in transplantation?

- ***Infection***

The anti-rejection immunosuppressive drugs partially suppress your immune system, which fights infection in the body, so you will be more prone to infection than you were on dialysis. Infections frequently involve the urinary tract and the transplant centre will undertake regular urine tests. Repeated urine infections can damage your kidney and, if they occur, you may be prescribed a regular low dose of antibiotic, which is changed every few months.

Virus infections such as flu or the common cold may last longer than normal. A virus you may not have heard of is cytomegalovirus, CMV for short. Half of the UK population has had CMV infection, and the virus then lives inside the body. Blood tests will detect whether you have had the virus infection or not. If you have not, and you receive a kidney from someone who has had the infection, then there is a 1 in 2 chance that the virus may be passed to you through the kidney. The virus can cause a variety of medical problems, some serious. However, virus

transmission can be detected early and effective drug treatment started to prevent serious disease. In some centres, doctors prefer to give you anti-viral drugs for three months.

- ***Death***

Unfortunately, there is a risk of death in a small percentage of people following transplantation, usually due to two main factors:

- a heart attack or other complication of the heart
- severe infection

These risks are increased in those with existing heart disease and infection problems. The older you are, the greater the risk. Your transplant surgeon and physician will balance the risk of transplantation with the benefits, and decide with you whether it is too great a risk. It is important to remember the risk of death is not just at the time of the transplant operation itself, but also the recovery period afterwards, during which time you may require intensive anti-rejection therapy.

- ***Cancer***

The immunosuppressive drugs can increase the risk of developing certain cancers, the most common being skin cancer. It is particularly important to avoid excessive exposure to the sun by avoiding sunbathing. Most skin cancer is treated by localised excision.

More serious is the risk of cancer of the immune system (lymphoma).

The risk of developing this form of cancer exists during the lifetime of the transplant whilst you are taking immunosuppressive drugs, but the overall risk is small.

- ***“Marginal” kidneys and donors***

The ideal donor is aged between 15 and 50. However, there are not enough donors in this age group to satisfy the need. Kidney donors who are less than ideal are called “marginal” donors. Some examples are:

- donors over 65
- donors who have had mild high blood pressure (hypertension)
- diabetic donors who do not have evidence of kidney disease
- also donor kidneys with anatomical problems (multiple arteries, etc)

and donor kidneys which have been stored for a long time after removal from the donor have higher risks of delayed kidney function.

These kidneys may have a higher failure rate in the long term, but the evidence is that you are better-off with a kidney transplant, even from a “marginal” donor, than staying on dialysis. Kidneys from non-heart beating donors often have delayed function but the outcome in the long-term is good.

What will happen if I live a long way from the Transplant Unit?

Many of you will live closer to your old dialysis unit than the transplant centre. The kidney doctor, who looked after you pre-transplant, will be kept up-to-date about your progress following transplantation. Increasingly, more of the kidney doctors in the dialysis units outside of the transplant centres are becoming more involved in taking care of transplant patients. In some areas, such kidney doctors will look after you following the first few months after transplantation and others some time later. However, the transplant centre and the kidney doctors will keep in touch with each other in order to monitor your progress.

If your kidney function starts to deteriorate, then further investigations, including transplant biopsy, may be done in the transplant centre rather than in the renal unit. However, this will vary depending on what arrangements have been made in your area.

How soon will I be mobile after a transplant?

It is important to get mobile as soon as possible after a transplant in order to reduce the risk of thrombosis in the veins in your legs. So the nursing staff will usually get you out of bed the day after the transplant, even if it is just sitting in a chair. Once the drain, catheter and intravenous drips have been

removed – generally within five days of your transplant – you should be walking around the ward comfortably.

In general, it is important for you to keep fit and healthy, and exercise is an essential component of your recovery. This exercise could merely be walking outside rather than any planned fitness activity. Exercise will aid your recovery as well as maintaining your health, and there is no reason why you could not get back to normal activity by six weeks after transplantation, provided your post-transplant recovery has not been difficult. In the long-term, even strenuous exercise should not cause you any harm. However contact sports such as rugby would best be avoided since there is more risk of injury to the transplanted kidney than to your own kidneys due to its position.

Do you have to remove my own kidneys to get the transplant in?

It is unlikely that your own kidneys will be removed at any time unless they are causing you problems or will interfere with the transplant. For example, if you are getting repeated water infections from diseased kidneys, or they are causing persistent high blood pressure despite taking many drugs, then your kidneys may be removed. The position of your own kidneys make transplantation at that site extremely difficult and even dangerous, therefore the transplanted kidney is actually placed in the lower abdomen just above

the thigh and close to the blood vessels supplying your legs. The kidney can be comfortably accommodated in this position. The kidney transplant is usually easy to feel on examining your abdomen compared to your own kidneys, which are well hidden underneath the rib cage.

How will I know if I am rejecting my new kidney?

Acute rejection usually occurs within the first three months after transplantation, and especially within the first six weeks. Your immune system will recognise the kidney as “foreign” and will react against it despite the immunosuppressive drugs given to you. Doctors can recognise this by the increase in serum creatinine and urea in the blood tests, and you will recognise it by the reduction in the amount of urine you pass and sometimes when the kidney feels tender. Most often acute rejection is confirmed by performing a kidney transplant biopsy.

When can I return to work?

The whole purpose of transplantation is to allow you to lead a normal life, which includes the ability to work and earn a living. The precise time at which you can return to (or search for) work depends on the type of job you have, the length of time you are in hospital or receive anti-rejection treatment and

how well you have coped with transplantation and its aftermath. If you have a desk job which does not involve heavy physical work, then you can return to work within six weeks to two months following transplantation. If you have a physical job, then you may need three months before returning to work. If you have a physically demanding job, employers will often be sympathetic and ease you back in with a less demanding job initially.

Am I restricted in my diet after a transplant?

If your kidney is working well, then you can eat any food you like. Indeed, one of the problems after transplantation is that you may put on a considerable amount of weight because the restrictions on your diet no longer apply. There are many instances of patients putting on 2–3 stone in weight! Clearly this has a very negative impact on health generally – blood pressure, blood lipids (fats which are related to increased heart and blood vessel disease), increased pressure on bones and other problems. Therefore, maintaining a healthy diet is important for you. If you need advice, the dietician who gave you information before your transplant will also give you further information afterwards.

Will my sex life be affected?

Sexual activity is often unsatisfactory when you are on dialysis. After transplantation, as you start to feel better, there may well be a steady improvement in your sex life. In women, menstrual periods may return and therefore the ability to have children. It is extremely rare to have children whilst on dialysis and so transplantation is certainly an avenue by which women are able to start or complete a family. However, conceiving a child within the first 12 months after transplantation is generally discouraged. You first need to recover from the transplant operation and any problems associated with it.

Can I go on holiday?

One of the benefits of transplantation is the fact that you do not need to dialyse when going away on holiday. Relaxing on holiday with your family either at home or abroad is certainly one of the exciting prospects following transplantation. Transplant centres generally do not like you to travel abroad in the first year following transplantation but thereafter, provided you take precautions, there is no reason why you cannot go abroad. The critical factor is whether you are exposing yourself to a risk of infection. Certainly dialysis patients and transplant patients who have gone abroad have contracted Hepatitis B and other infections, so if you are travelling outside the Western

European countries, it is advisable to use bottled water only (even to clean your teeth).

What happens if I lose my kidney?

Losing your kidney transplant means that you will need to go back onto dialysis and this will be discussed with you in the phase leading up to your needing dialysis, just as before when your own kidneys were failing. You will need to readjust to the more constricting requirements of dialysis in order to keep well. Your kidney doctor (nephrologist) will take over your management once again and will discuss your future dialysis options with you. Peritoneal dialysis will remain a possibility, although you may first need a period on haemodialysis to stabilise your condition. After a period of recovery, you will be re-evaluated for another kidney transplant. If you have lost your kidney abruptly soon after transplantation, or you were not well during the period you had your transplant, you may not feel that you want another. Generally speaking the survival of the first transplant is better than the second, the second is better than the third. But some patients even have the opportunity to have a fourth transplant.

There will be a reluctance to give you a second opportunity to have a transplant if you are the cause of your kidney loss by not taking your immunosuppressive medication or attending clinics. Don't forget, there are

not enough kidneys to meet the demand, and it is only fair to the donor and his or her family, to other patients on the transplant waiting list (some of whom will have been waiting for many years longer than you), and to the transplant team that the life of the kidney should be preserved for as long as possible. When a kidney transplant is given to you, a bargain is made between you and the transplant team. They will look after you to the best of their ability as their part of the bargain, and you must take your medication without fail for as long as your kidney works, as part of yours.

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Kidney Research UK, Kings Chambers, Priestgate, Peterborough PE1 1FG

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