

Living Donor Kidney Transplantation

Your questions answered

living-donor



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Contents

Introduction	2
Why do we need living donation?	3
Who can donate a kidney?	5
What does a potential living donor need to consider?	9
What makes a donor suitable?	10
How do I become a donor?	15
What are the risks and benefits for donors and recipients?	17
What further assessments are necessary?	22
What other practical aspects need considering?	26
Who are all the different people involved in the process?	29
Who makes the final decision?	32
What is actually involved once the decision is made?	35
How do donors feel afterwards?	39
Getting back into a routine	41
Where can I get more information?	43
Glossary	45
Acknowledgments	48

Introduction

If you have a relative with kidney failure, the treatment options are **dialysis*** and, for suitable patients, transplantation. Kidneys for transplantation come either from people who have donated those organs after their death, or from living relatives or close friends. This booklet has been written to give information to those considering living kidney donation.

There will be a lot of verbal information given to prospective donors, both before and during the long assessment period. This booklet has been prepared to make sure that all prospective living donors and their families can have the opportunity to read about the risks, benefits, investigations, procedure and follow-up associated with donating a kidney. Everything covered in this booklet will be discussed on a personal level by the medical staff.

This booklet is not a replacement for face-to-face meetings between the transplant team, the prospective donor, the **recipient** and their families. More information is always available from the doctor at your renal unit or transplant unit, or from the transplant coordinator.

* The terms in bold text are explained in the glossary at the end of this booklet.

Why do we need living donation?


A successful kidney **transplant** is the best treatment for many patients with **end-stage renal disease**, from a medical, psychological and social point of view.

In the UK, the majority of transplanted kidneys are from people who have died and have no brain activity. This occurs most frequently in hospital intensive care units and often as a result of road traffic accidents or brain haemorrhages (bleed). Despite the introduction of donor cards, there are still too few kidneys available to help all those who require a transplant, thereby producing a waiting list. In 2000, 1823 kidney transplants were performed in the UK. Most of these transplants were from people who had donated their organs after their death (**cadaveric donors**), although 336 were from living donors. However, there were over 6000 people who were on the waiting list to receive a transplant.

The 1994 King's Fund Report recommended that a programme to increase the number of living donor kidney donations would overcome the problem of too few kidneys being available and improve long-term outcomes. Some countries with the highest rates of transplantation rely more heavily on living donors than the UK. Whereas living kidney donation has previously accounted for only 18% of kidney transplants in the UK, 39% of all transplanted kidneys in the USA and 37% in Norway are from living donors.

For some patients with end-stage renal disease, transplantation may be the best option

As the make-up of the body within families can be similar, or more rarely – as in the case of identical twins – the same, the likelihood of the recipient's body rejecting the new kidney is



smaller. Therefore, there is a greater chance of a successful kidney transplant if the kidney is donated by a living relative. Non-related living donors, usually spouses or partners and sometimes close friends, may also be considered. Although it is less likely that they will be as good a match as a close relative, there is a good chance of a successful transplant. The advantage of living kidney donation is that living donor organs are in better condition, and the kidney will be without blood for a very short time, which increases the chances of a successful transplant.

Living donor transplants are more likely to be successful than cadaveric transplants

One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will hamper them in later life. A healthy person can live a completely normal life with only one kidney; indeed, some people are born with only one kidney. If one kidney is removed, the remaining kidney increases slightly in size and capacity, and can carry out the function of the two. The amount of urine passed is normal and the donor is unaware of any difference in kidney function. Lifestyle is not affected and normal work can continue.


Therefore, it is possible to remove one kidney from a healthy living person and transplant it into someone who needs it, with no ill effects on the donor other than the operation itself. Large studies have concluded that there does not appear to be any risk of serious problems from donating a kidney. There is sometimes a slight rise in blood pressure or increased loss of protein in the urine, but these do not have an adverse effect on health.

Who can donate a kidney?

Generally, a close relative of the person with kidney failure considers donation. Living organ donation is allowed under the Human Organ Transplants Act 1989 (HOT Act); this Act states that genetic confirmation of their relationship is required, while prohibiting certain practices such as offers of money or other gifts. Donors are usually brothers, sisters or parents of the individual. Less often, other close relatives, such as uncles, aunts, grandparents, sons or daughters become donors. Increasingly, non-related individuals, such as partners and close friends, are becoming organ donors. In 2000, a total of 336 living kidney donor transplants were performed in the UK and, as time progresses, this number is likely to increase.

Increasingly, non-related individuals, such as partners and close friends, are becoming organ donors





Whoever becomes a donor must be over 16 years of age; however, it is very unlikely that a person aged under 21 years would be considered for donation. There is no strict upper age limit in donating a kidney, but there is less chance that a much older person will pass the medical examination necessary before donation is judged to be safe. As with many things, progressing age can bring additional uncertainties. Size of the kidney is also a factor to be considered, and young children who require a transplant may be too small to take a full-size adult kidney.

Although, one might think that most family members would want to give a kidney, life is not nearly so simple. Donation between brothers and sisters can present some psychological problems. A large amount of emotional pressure can be brought to bear on individuals.*


The problems are usually less for the parents of children requiring a transplant, but even here loyalties may be divided between the desire to provide for one child, while inevitably depriving the other children of one parent for a period of time. This is not a trivial consideration, as the transplantation may come after a prolonged illness for the affected child, during which other children may have felt deprived of their share of parental love. Also, parents, as with all donors, must face up to the possibility that the kidney transplant may not function, and all will have been in vain. Finally, there may be conflict between the parents as to who should give a kidney.

* For this reason, although in the UK 16 years is the legal age for provision of informed consent, a donor under the age of 21 years is rarely used. Adult child-to-parent transplants have been undertaken, but are not encouraged generally.



In some cases, a potential donor is not genetically related to the proposed recipient. For example, a husband and wife or step-parents – although related legally – have no genetic link. There are also occasions when friends or long-standing ‘adopted’ family members may wish to be considered as a donor. Although there is less likelihood of them being a good genetic match than directly related family members, it does not mean that they will be excluded from consideration. In the UK, the number of genetically unrelated donations is increasing rapidly, together with the rate of successful outcomes.

In these circumstances, a further simple procedure has to be followed which takes the form of a discussion with an independent third party. A report is then submitted to the Unrelated Live Transplant Regulatory Authority (**ULTRA**), who must give approval before the transplant can go ahead.



The donor and recipient are required to provide evidence of their relationship such as photographs, letters and, if appropriate, a marriage certificate. The submission of this form ensures that there has been full and informed consent, and that no coercion or payment has been made to the donor.

The transplant team is fully aware of all the problems – psychological or otherwise – in volunteering as a potential living kidney donor. For that reason, they may appear to take a deliberately discouraging stance, pointing out to prospective donors all the physical hurdles and tests they must pass before being considered. They will also warn of the possible loss of the transplant in honest terms. It is very important that, before volunteering and throughout the assessment process, close members of the family fully understand the process and consider all the risks and implications. Every family thinking about a living donor transplant should discuss openly how they all feel so that they are prepared for any eventuality and consequences that may arise.

What does a potential living donor need to consider?

Someone who is thinking about donating one of their kidneys to help a loved one has many things to take into consideration. It is something that has to be thought about seriously from a personal point of view. The medical staff will also want to do tests, which may take quite a long period of time. This is to make sure that the donor is in good physical health and that the kidney would be a suitable organ for transplantation.

It's worth remembering that the operation to remove a healthy person's kidney is – as far as their own body is concerned – not of any direct benefit. Although all possible precautions are taken, there is always a small risk when undergoing surgery.

There are also practical issues that need to be considered, such as the time taken off from work for the investigations and after the operation, or the domestic responsibilities and arrangements, such as looking after the children or the family pet.

Donors need to think carefully about the practical aspects of donation

Pressure from other members of their family may arise and there may be pressure to continue with the donation from within the family, even if the donor is not entirely sure it is the right thing to do.

A number of investigations are performed that may uncover an unknown medical condition. Also, the donor will need to consider facing his or her future with only one kidney.

What makes a donor suitable?

Before the medical staff can agree to a person becoming a donor, they must be satisfied that the donated kidney is unlikely to be rejected by the recipient's body and that the person willing to be a donor is unlikely to suffer ill health as a result of making the donation.

Checking blood groups

Most people are familiar with the fact that red blood cells have a specific type or group – A, B, AB or O. In fact, for successful transplantation, the blood group of the potential donor must be compatible with that of the proposed recipient. So, before anything else, the blood group compatibility of the donor and recipient must be tested. The different pairs that can be considered are shown below.

Matching blood groups	
Recipient's blood type	Required blood type of potential donor
O	O
A	O or A
B	O or B
AB	O or A or B or AB

Being Rhesus-positive or -negative does not influence the outcome of a kidney transplant and is not taken into consideration during the matching process.

A suitable match of blood groups like this is necessary before any further assessment can be considered. Family members may have different (i.e. incompatible) blood groups, so it may not be possible for one person to give a kidney.




Making sure the donor is healthy

Although all transplant units will have their own procedures, another blood test that must be undertaken fairly early in the process is to check that the donor is not carrying any potentially harmful viruses. A potential donor's blood will be examined for the presence of antibodies to certain active viruses, such as:

- hepatitis B
- hepatitis C
- human immunodeficiency virus (HIV) – the virus that leads to acquired immune deficiency syndrome (AIDS)
- cytomegalovirus (CMV).

With the exception of CMV, if any of these viruses are detected, the transplantation cannot normally take place due to the risk of viral transmission. Although the donor may be quite healthy, because the recipient will be immunosuppressed to prevent rejection, he/she is at real risk of serious infection from these viruses. CMV is related to the chickenpox virus and over half the adult population carries this virus, which is harmless to them. CMV may be passed from the donor to the recipient with the kidney transplant. In immunosuppressed recipients, CMV infection may cause symptoms that range from a mild influenza-type illness to a more serious infection, particularly in patients who may not have previously encountered the virus. Modern antiviral drugs can help combat the infection.

The age of the potential donor is also important. Most frequently, donors are considered between the ages of 21



and 70 years, although donors outside this range have been considered in some circumstances.

To ensure that a potential donor will be able to offer an adequately functioning kidney to the recipient, and be fit enough to undergo the operation and live normally with only one kidney, he or she must be in excellent physical condition and have a clear medical history. During the course of the thorough pre-donation medical and psychological assessment, another previously undiagnosed medical condition may be detected. If tests show evidence of poor kidney function, or if investigations show the possibility of the donor being medically unsuitable, then the donation would be refused.

What is tissue-type compatibility?

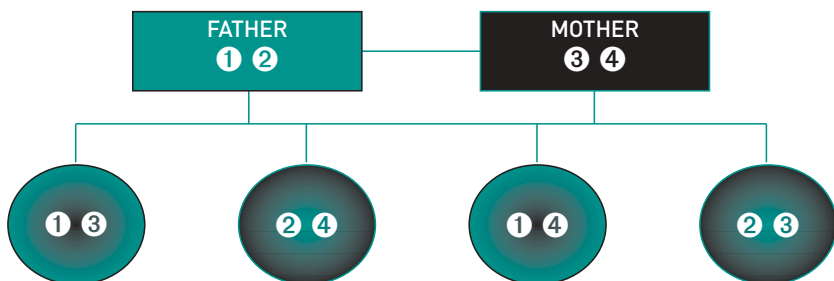
An issue that may influence the suitability of a potential donor is his or her tissue-type compatibility with the recipient. The tissue type of an individual is determined by 'marker' proteins on the surface of cells. These proteins can be very varied. The higher the percentage of these proteins that match, the greater the chance that transplantation will be successful in the long term. This compatibility is more frequently seen when people are related; however, more and more successful transplants are being performed in people who are not perfect **'tissue-type'** matches.

What do you mean by marker proteins?


Each of our body's cells contain DNA (deoxyribonucleic acid) – the 'genetic blueprint' for our entire body's make-up. One particular part of DNA carries information that determines the production of a series of 'recognition' or 'self' proteins

on the surfaces of cells known as human leucocyte antigens (**HLAs**). As all cells in the body have the same DNA, HLAs are present on most cells to a greater or lesser extent. Unlike blood groups, many different types of proteins make up the HLA system, so it is rare to find a perfect tissue-type match in the general population. This does not stop a transplant from being successful.

Individuals inherit two sets of DNA – one from their father, and one from their mother. The diagram below shows how different tissue types are inherited from each parent. Within a family, brothers and sisters might inherit the same two sets of DNA from their parents (there is a one in four chance of this happening), share half their tissue type (a one in two chance of this happening) or inherit completely different genetic information (a one in four chance). That is why a family member is more likely to be a good match than someone who is unrelated.



All of us inherit one set of DNA from our mother and one set of DNA from our father. In this diagram, each set of DNA is represented by the numbers **123** and **4**.



There is a group of patients for whom tissue-type matching is vital – individuals who have developed a large number of circulating antibodies directed against HLAs. This can result from prior blood transfusion, previous transplant or pregnancy.

A poorly matched kidney from a living donor, such as from a spouse, usually has a good chance of long-term survival. However, if it does fail in the future, it is more likely to cause antibodies to develop, which sometimes reduces the chances of finding a second suitable donor.

Why are so many tests needed?

Checking that a donor is both suitable and healthy is a long (3–6 months) and in-depth process. This is so that the medical team is as certain as possible that the transplantation will be successful for both recipient and donor. It also gives potential donors plenty of time to consider their options and be sure that they want to proceed.

Generally, to be able to donate, donors must:


- have a compatible blood group
- have no viral infections that would preclude a transplant
- be aged between 21 and 70 years
- be physically fit
- have a clear medical history
- have good kidney function.

How do I become a donor?

There are two possible situations. In the first, a donor may offer their kidney when a loved one is diagnosed with advanced renal failure. Transplantation before dialysis has begun is known as **pre-emptive transplantation**, and this approach is now becoming more frequent. It can avoid the problems and difficulties that can be experienced with dialysis.

In the second situation, the potential recipient has been on the transplant waiting list for some time, and the prospective donor has witnessed a decline in his or her condition. The donor may also see the disruption that dialysis can bring to the individual's and family's lifestyle.





Medical staff will also be aware of an individual's circumstances, such as the likelihood of a suitable cadaver kidney becoming available (whether the person has a common blood group and/or tissue type).

Whether the suggestion originates from the family member, spouse or the medical staff, there is never any substitute for talking the issue through. Direct personal communications are the key to making sure living kidney donation can be successful, both for donors and recipients. The most suitable person for the family member or spouse to approach is the transplant coordinator or nurse. He or she can often help to begin the long and complicated process involved with donating a kidney.

What are the risks and benefits for donors and recipients?


There are risks and benefits associated with living kidney donation. In this section, we will try to point out both of these aspects for the prospective donor and the recipient.

Potential donor disadvantages

One of the main issues a donor will face is the risk of major surgery. All surgery carries risks, no matter how small. The most common risks associated with a **nephrectomy** are usually relatively minor and can be treated appropriately. These include wound, urinary tract and chest infections, which occur in approximately one in three (33%) donors. More serious complications, such as bleeding that requires blood transfusion or blood clots, occur in approximately one in 50 (2%) donors and again the medical team is experienced in dealing with such situations quickly and appropriately. Rarely, one in 1600 to one in 3300 (0.03–0.06%) of donors may die as a result of the operation. However, the chance of this happening has been compared to carrying a similar risk as having a fatal road accident.

The rigorous assessment process and dedicated hospital care minimises these risks, but cannot remove them completely.

Another issue for the donor regarding the nephrectomy is that it is more difficult and uncomfortable than the recipient's operation. Post-operative pain can usually be controlled with painkillers, but 4% of donors still suffer from pain 1 year after the operation.



In the years after the operation, a small minority of donors may develop a slight rise in blood pressure and an increased amount of protein in their urine. This does not need to have an adverse effect on health and can be effectively treated by the donor's GP.

While the donor is undergoing suitability tests, an unexpected abnormality may show up. This can be a shock to the donor but the transplant team are always there for support and referral to the appropriate speciality will be organised.

After the operation the donor may experience a sense of anticlimax, in fact one study showed that 4% of donors regretted making the decision to donate.

Potential donors are free to change their minds at any time

Psychological issues play a big part in the decision to become a donor. Feeling under pressure to donate can be incredibly hard to deal with, especially if the recipient is a close family member. An important point to remember is that you are able to withdraw your consent at any time if you change your mind. Facing the future with only one kidney can also be difficult for the donor. However, the body can function normally with just one, as the remaining kidney performs the work of two. Another psychological issue is that of transplant rejection or failure, which can occur regardless of the amount of tests that are carried out. This can be devastating to both donor and recipient, and needs to be considered very carefully.



There are three practical issues that need to be considered.

- The donor will need to spend 7–10 days in hospital for the operation, and have a further 8–12 weeks off work, incurring possible loss of earnings or annual leave.
- Potential donors should alert their insurance company to determine any effect that donating a kidney may have on their life cover or other premiums. Insurance companies recognise that donors undergo a rigorous health check and usually do not alter their premiums as a result.
- Women who take the oral contraceptive pill must stop taking it 1 month before the operation and use alternative contraceptive methods until after the operation.

Donor advantages

The biggest advantage donors can enjoy is that they have given the gift of life. The feeling of satisfaction, which comes from donating a kidney to a loved one, is immense and cannot be overestimated. Seeing a loved one enjoy a better quality of life because of your gift is very rewarding. This very positive aspect of living donation often completely outweighs the physical disadvantages.

On a wider scale, donation to someone you know removes that person from the waiting list and helps another potential recipient gain a cadaveric kidney more quickly.

Giving the gift of life is both satisfying and rewarding



Recipient disadvantages

The risks associated with major surgery also apply to the recipient, although the operation to implant a kidney is not as disruptive as the one to remove the kidney from the donor. Complications after the transplant operation, such as poor blood supply to the kidney or severe rejection leading to failure of the organ, can cause great disappointment to everyone concerned. However, living donor kidney transplantation is a very successful procedure. Medical data show that 95% of kidney transplants are working well after 1 year and over 80% are still functioning after 10 years. Furthermore, many recipients remain fit and well more than 20 years after their transplant.

**Long-term transplant survival
can never be assured, but
is usually high**

Psychological problems can also affect the recipient. Sometimes he or she may have tremendous feelings of being indebted to the donor.

A positive relationship between prospective donor and intended recipient has been shown to improve the chances of a successful transplant.

Another issue the recipient has to face is the fear of transplant failure. This can lead to worries of restarting dialysis. If the transplant is unsuccessful, he or she may also feel guilty for all the trouble everyone has gone to and the sacrifices they have made. This fear can last for years, as long-term transplant survival can never be assured. It is best to discuss these fears with relatives or members of the transplant team.



To prevent the transplant being rejected, the recipient will receive medications to suppress his or her immune system. This can make him or her more susceptible to a variety of infections and to some types of cancer, especially of the skin. The recipient needs to take particularly good care of him- or herself to avoid this risk.

Recipient advantages

The main benefit to the recipient of a successful kidney transplant is freedom from dialysis. Some people who need dialysis continue to feel unwell after each session, or feel well for only 1 day before feeling unwell again. Also, patients having continuous ambulatory peritoneal dialysis may find it very time-consuming.

Most recipients manage to return to employment following the transplant. In fact, in Europe as a whole, 79% of those with functioning living donor transplants are working full-time, with the remainder either working part-time or capable of work but unemployed. This represents excellent rehabilitation.

**After the operation, recipients
are free from dialysis**

What further assessments are necessary?

There is a sequence of tests that is necessary to thoroughly examine the health of the potential donor as well as the well-being and anatomy of the kidney. This system of testing, and the order in which it is undertaken, may differ between transplant centres; however, this is an example of the types of tests that a potential donor can expect. These tests sometimes involve a short stay in hospital (1–2 days) for the potential donor. Throughout the period of assessment, potential donors should bear in mind that there may be a possible reason for the kidney donation being unacceptable.

Blood tests

Blood samples will be taken for routine analyses. Haematology tests can show **anaemia** or signs of infection, and blood chemistry tests can show kidney and liver function, or the suggestion of diabetes. Samples are also tested for hepatitis B and C, HIV, CMV and syphilis. Consent will be obtained before testing for HIV and counselling can be provided before and after the test.

Another blood sample will be taken from both the donor and recipient to check that the recipient does not have '**antibodies**' that may react against the donor. This is called **cross-matching**. It is sometimes carried out several times before the transplant takes place and is repeated just before the operation.



Urine analysis

Many underlying conditions (e.g. diabetes) can be identified by examining the urine for glucose, protein, blood or bacteria – so all these constituents will be assessed. You will be asked to provide a urine sample that will be sent away for analysis.

Blood pressure monitoring


As the kidneys can be a prime target of damage due to high blood pressure, the potential donor's blood pressure will be checked to exclude high levels, known as **hypertension**. Sometimes, if slightly higher levels than normal are found, the potential donor may be asked to attend a special assessment centre for numerous readings over a 24-hour period. This usually takes place in a quiet area of the transplant unit, where the daily noise and bustle of the hospital environment is kept to a minimum. Alternatively, you may be given a portable device that measures your blood pressure at home for 24 hours.

Kidney function tests

These tests are performed to ensure the donor has two good functioning kidneys, so that donation can go ahead.

Creatinine clearance

Creatinine is a substance that is produced naturally in our bodies and is normally removed by the kidneys continuously. If the kidneys are not functioning well the level of creatinine



in the blood rises. The level of creatinine in the blood, and the amount being excreted in the urine over a 24-hour period, are measured. An accurate assessment of kidney function can be made by measuring the levels of creatinine in this way.

Glomerular filtration rate

This is a test to assess the capability of the kidney to 'clear' the blood of a substance. A small amount of a harmless radioactive tracer is injected into a vein and blood samples are taken at hourly intervals for 3 hours to measure the individual's renal clearance of the radioactive tracer. It works by a similar principle to the creatinine clearance test, but gives even more precise results.

Electrocardiogram (ECG)

This test is used to check that the heart is healthy and functioning properly. An ECG involves having several small electro-sensitive pads placed at different points on your chest, arms and legs for a few minutes. You may wear your clothes or a hospital gown for the procedure. The pads monitor the electrical activity of your heart to produce a tracing. The pads will not cause any pain or give you an electric shock. If heart disease is present, an abnormal tracing would be seen, and this could increase the risks associated with anaesthesia during the nephrectomy.

X-rays

A series of X-rays, especially of the chest area, may be taken to ensure normal function.



Renal ultrasound

This is a non-invasive scan that checks the size and shape of the kidneys, and can exclude any anatomical abnormalities.

Renal angiogram

This is usually the final and most invasive of all the procedures, and involves an injection of dye into one of the large arteries. A special kind of X-ray is then used to reveal all the details of the kidneys and the vessels going to and from them. This is obviously very important, so the surgeons can have a clear idea of which kidney is the better one to remove, and which has the easier access for them. The anatomy of the donor's kidney must be normal before the donation can proceed. Some centres have adopted different approaches to performing this assessment. These include computerised tomography (CT) renal angiography or magnetic resonance angiography. CT angiography is a special kind of X-ray taken of the abdomen. Dye is then injected into a vein in the arm and the scan is repeated. The whole procedure takes about 30 minutes and can be performed on a day visit to the hospital. Magnetic resonance angiography is a similar technique using a powerful magnet rather than X-rays. Not all transplant centres will assess renal anatomy with these techniques.

What other practical aspects need considering?

The financial burden associated with donating a kidney frequently includes the cost of travel and accommodation (if the donor lives a considerable distance from the transplant unit), lost wages and other non-medical costs incurred during the recovery period. Due to the nature of the procedure, the donor will probably be in hospital for about 7–10 days, in addition to needing about 8–12 weeks away from work. This could present the problem of earning very little, or no, money.

Talk to your employer about paid sick leave

Whether or not a donor gets paid while off sick from work is dependent on his or her employer. Employers are not obliged to provide

paid sick leave. It is sensible for the donor to discuss the whole issue with his or her employer early in the living donor process. Most employers understand, so this should not present a problem.

If this is not the case, then it may be possible for the donor to claim social security benefit. Assuming the necessary contributions have been paid in the past, the Department of Social Security will pay incapacity benefit if the donor can provide a medical certificate. If the donor is already receiving Income Support, the amount received may increase at this time. In these circumstances, the best approach initially would be to contact the local social services or the hospital social worker for advice.

Regardless of who actually donates the kidney, all family members have the option of participating in the transplant experience, by offering practical and emotional support to those undergoing the surgery.



Although the 1989 HOT Act forbids any form of payment as a coercion to donation, it does allow reimbursement of legitimate expenses incurred by the donor. However, this is at the discretion of the local healthcare authority.


Another financial issue that may need to be considered is the cost of private health or life insurance after donation. The donor should be acceptable to most insurance companies as living a normal life with one kidney and insurance premiums should not change. However, this may vary depending on the insurance company.

Financial issues need to be considered

There are many other practical issues that need to be considered and appropriate plans that need to be made, in case the kidney donation is accepted and the associated stay in hospital becomes a reality. One such issue is that women taking the contraceptive pill should stop taking it 1 month before the operation as there is an increased risk of thrombosis. An alternative contraceptive method will therefore need to be used.

Once the date for the operation has been set, and it's time to go into hospital, it's worth making sure that the following arrangements have been made:

- employers know that several weeks will be required away from work from that date
- friends and family know what is happening

- 
- children have somewhere to stay and someone to look after them
 - pets are being looked after
 - the house is locked and secure, and electrical appliances in the home have been switched off
 - transport to the hospital is arranged.

The following checklist can also help in preparing items to be taken for the stay in hospital.

- ✓ Overnight bag, including washing products, towel, toothbrush and toothpaste
- ✓ Something to sleep in, dressing gown, slippers
- ✓ Any medication currently being taken
- ✓ Loose fitting underwear and clothing for after the operation
- ✓ Contact lenses and solutions, or glasses
- ✓ Book or magazine to read
- ✓ Coins for the telephone

Who are all the different people involved in the process?

There are many different people in the transplant team and each has a specific role.

Transplant coordinator

The transplant coordinator represents the hub of the team and is responsible for ensuring that the individual aspects of identifying a donor, all pre-donation assessments and the actual operations run smoothly. He or she will be aware of what stage has been reached and who is responsible for each part of the process. Simply put, he or she will coordinate every stage to make sure that everything proceeds as easily as possible.

Consultant transplant surgeon

The consultant transplant surgeon is the person who removes and/or transplants the kidney. In some centres, the same surgeon will perform the removal and transplantation of the kidney, while in other centres each operation will be performed by a different surgeon. The transplant surgeon has to be sure that all the results of the tests for matching the donor to the recipient point to a successful transplant. He or she must also be sure that both the donor and the recipient are fit to undergo surgery, with minimum risk. The surgeon who removes the kidney carries overall responsibility for ensuring the safety of the donor.



Consultant kidney specialist

The consultant kidney specialist is the person, together with the transplant surgeon, who has to be sure that the transplanted kidney will be likely to restore the health and reasonable lifestyle of the intended recipient, and that the donor's health will not suffer as a result.

Consultant anaesthetist

There will usually be two anaesthetists, one for the removal operation from the donor, and one for the operation to transplant the kidney to the recipient. It is their responsibility to ensure the health of both patients during the surgical procedures.

Transplant nurse practitioner

The transplant nurse practitioner cares for the donor and the recipient after their operations.

Physiotherapist

After any form of surgical procedure, returning to full activity can be a bit of an uphill struggle. The physiotherapist can frequently advise on methods to make rehabilitation easier.

Psychologist

As we have already pointed out, there can be important psychological effects in considering kidney donation. Whether it's family pressures or any other emotional discomfort, the psychologist is there to help.



Social worker

There may be many practical issues that present themselves as problems to potential kidney donors, and a social worker who has knowledge and experience in this particular field can offer a lot of sound advice and support.

GP

In the main, the potential donor's family doctor will be kept advised of all the events. Once the donor has been discharged from care by the hospital-based transplant team, it's then usual for his or her general health to be looked after by his or her GP. After giving a kidney, donors have an annual check-up with their GP to assess their blood pressure and test their urine to ensure everything is normal. Some transplant units run annual follow-up clinics for donors.

Who makes the final decision?

Before any donation is possible, both the recipient and the donor have to agree that they want the operation to proceed.


All the test results will be reviewed by the transplant surgeon(s), kidney specialist and, in some centres, an independent doctor.* The operation will not go ahead unless all these results are satisfactory.



The decision to become a donor must not be taken lightly as there are always risks when undergoing surgery. However, these risks are less than with other major surgery because donors must be in excellent health at the time of the operation.

Despite all the tests, there is a 5% risk that the recipient will reject and lose the transplanted kidney during the first year.

* If a potential donor and recipient are genetically unrelated, an independent assessment submitted to the ULTRA will be required.



The period of testing and matching, which can continue over several months, provides opportunities for private and confidential discussions with the transplant surgeon(s), transplant coordinator, consultant kidney specialist and other members of the transplant team.

At any time, potential donors are free to raise specific concerns with the transplant team that they may not wish to share with other family members or the intended recipient. It is essential that donors talk through any worries with the transplant team so that they are confident that they have made the right decision. The transplant team would much rather know of any concerns that the donor may have about proceeding, regardless of which stage the donor decides that he or she does not wish to go ahead. If the donor should decide to withdraw his or her consent, even at a late stage, then this will be kept confidential by the transplant team. Nothing will be held against someone who decides that they do not wish to become a donor.

Sometimes talking to someone else who has been a living donor can be helpful as they have personal experience of the donation process. Your transplant coordinator can arrange this for you. It is very important that throughout this process close family members can understand fully what is happening and consider carefully all the risks and implications. The support a donor receives from his or her family can sometimes make the decision making very complex or very easy.

Assessment period

Donor healthy and wants to donate; medical staff happy with donor's health

Recipient wants to receive organ

Date of transplant agreed, taking into consideration donor's commitments

Donor goes into hospital 1 day before transplant

Recipient goes into hospital 2-3 days before transplant

Final tests performed

Operation goes ahead; usually takes 2-2¹/₂ hours followed by recovery period

What is actually involved once the decision is made?

The nephrectomy (removal of a kidney)

Under a general anaesthetic, the kidney is removed by an operation in the same way as if the kidney had to be removed because it was diseased. Most surgeons remove the kidney through an incision in the side, sometimes removing the smallest rib (the twelfth or lowest rib) to gain access to the kidney. Some surgeons prefer to remove the kidney through an abdominal incision. The kidney is lifted out of the wound, flushed with a cold solution to wash out blood and slow the metabolism, after which it is carried into the adjacent operating theatre where the recipient is waiting.

The donor's incision is then sewn up in layers and he or she returns, via the recovery room, to the ward. The donor will have several temporary tubes or lines inserted during the operation. These may include a tube inserted into the bladder (called a catheter) and a drainage tube from the wound. Fluids can be administered through a drip and, because the incision can be painful afterwards, injections or infusions of pain-killing drugs can be added as needed. Tubes are usually removed after the first 2–3 days when the donor is encouraged to get out of bed and sit in a chair. That way, the risk of complications can be minimised.



How long does it take to recover?

A donor's stay in hospital is usually between 7 and 10 days. He or she can expect to be out of bed the day after the operation and home in less than 2 weeks. Some surgeons use stitches or clips to close the skin around the incision made during the operation. These are usually removed 10 days after the operation. Occasionally, a special kind of stitch is used; these stitches are not removed because they dissolve gradually by themselves.

The donor can be out of bed the day after the operation

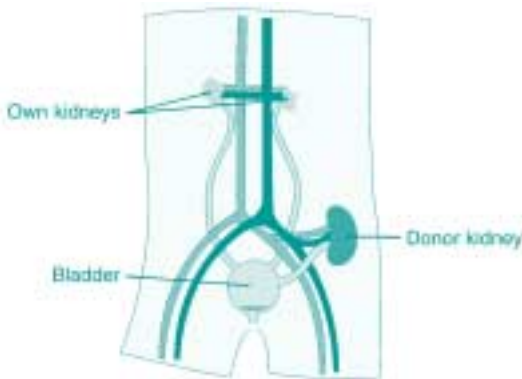
The wound can remain sensitive for several weeks. There may be 'twinges' or a 'drawing' sensation for up to 6 months. Sometimes a small area of numbness may be noticed on the skin of the tummy or abdomen, because small nerves have been cut by the incision at the side. However, the scar should be the only permanent reminder of the donor's operation. The donor usually has to take 8–12 weeks off from work to recuperate, depending on the individual and his or her occupation. Very occasionally, in less than one in 20 (5%) donors, a bulge may develop at the site of the scar as a result of muscle weakness.

Before leaving hospital, a clinic appointment will be made for the donor. This will probably be for between 4 and 6 weeks after discharge. An annual appointment with the transplant centre or the GP is advisable to ensure that there are no long-term side-effects.


A small number of transplant centres are now using 'key-hole' surgery to remove the donor kidney. This technique avoids many of the problems related to the wound site and donors are reported to recover quicker from their operation. One drawback is that it requires special expertise and some surgeons think that the donor kidney may be more likely to be damaged during removal. However, as experience of this newer technique grows, its use is likely to become more widespread.

The kidney transplant

The kidney is put into the recipient's outer pelvis – protected by the hip-bone – low down and to one side of the bladder (see figure). The blood vessels of the new kidney are then joined to the large blood vessels supplying the leg. The kidney lies snugly here away from the intestines and their covering, and the ureter can be sewn into the bladder more easily. The recipient's existing kidneys are not removed, so they can end up with three kidneys!



Position of the new kidney after the transplant.



The recipient should be out of bed within 1–2 days. After only a few days, most or all of the various tubes necessary for the operation will be removed. Sometimes before, but always during and after the transplant, medication to suppress the immune system will be necessary.

Antirejection medications are given to the recipient

Antirejection medications will help the recipient's body to tolerate a 'foreign' organ. In the early stages, the medication may be in the form of infusions; later this will change to tablets. Although the dosage may be reduced over time, this medication will have to be taken by the recipient for the entire life of the transplant.

The most anxious time for both the recipient and donor is the wait to see if the new kidney functions well. Depending on how successful the transplant has been, the recipient can usually expect to leave hospital 1–2 weeks after the transplant has been performed.

Recipients soon feel the benefit of their new kidney

By that time, he or she will probably already be feeling the benefit of the operation. Usually, recipients will have to visit the transplant outpatient clinic quite frequently to begin with, but this becomes less frequent as time progresses.

How do donors feel afterwards?

The donor will be asked to return to the hospital a few weeks after his or her operation so that the medical team can ensure that he or she has made a good recovery from the operation and that the wound has healed well.

It is recommended that the donor should receive annual check-ups to monitor blood pressure and kidney function using a simple blood test and examination of the urine. These annual check-ups may take place at the transplant centre where the donor's operation took place or at the GP's surgery.





Psychological effects

After donating a kidney, some people feel a sense of anti-climax; so much time has been spent thinking and worrying about the operation that life may seem a little empty afterwards. The donor may also feel sad and have an unconscious resentment towards the recipient if he or she feels unsupported by relatives and hospital staff after the operation, as attention is shifted to the recipient.

This kind of feeling can be more pronounced if the recipient does poorly or rejects the organ. In this case, counselling facilities are provided for the donor at some centres.

Try not to make the recipient feel indebted

It is very important to maintain a normal, relaxed attitude towards the recipient and the rest of the family. People who receive kidneys are always grateful, but they are unable to repay the gift. So it is important to avoid reminding them of their 'debt'.

Getting back into a routine

The success of the transplant is judged by how well the transplanted kidney works and how quickly the patient returns to full health. The first 3 months after a transplant are when most problems occur. Once these 3 months have passed, both the donor and the recipient can settle back into a normal routine, quietly secure in the knowledge that a wonderful gift has been given and received.

Depending on their type of work, donors can expect to be at home recuperating after the operation for

Recuperation can take 12 weeks

up to 12 weeks. Sometimes this can be a frustrating time, wanting to return to a normal life, but without the energy and overall health. Patience is required, as is support from other family members.

If the donor regularly sees the recipient, this can be an added source of satisfaction – watching the recipient’s return to good health can ease some of the possible negative feelings. Other aspects of life can return to normal as soon as the donor feels up to it.

Driving

The DVLA in Swansea has no hard and fast rules with regard to starting to drive again. Generally, if the donor feels okay and his or her GP agrees to it, he or she can return to driving whenever he or she feels capable, usually after 4–6 weeks. However,



the donor must be aware that long journeys could prove problematic and so 'shouldn't overdo things'. Car insurance should be checked, as the length of time after an operation that you are not insured to drive varies depending on your policy.



Exercise

Maintaining a healthy lifestyle is as important after donation as beforehand. Any post-donation exercise programme should begin slowly, with the length of time spent exercising and the effort involved being increased over a period of time.

Sexual relationships

Donors should be able to resume their usual sexual relationships as soon as they feel comfortable. It may take a few months before normal activities can be undertaken, but this depends on the particular individual's recuperation.


Where can I get more information?

If you have a loved one with kidney failure who must have, or will need, a transplant, and you want to help – whether you are genetically related or not – please ask to speak to the transplant coordinator, the transplant surgeon or kidney specialist at the hospital where he or she is being treated.

Transplant coordinators are responsible for all the liaison between members of the transplant team and for the administration of the transplant operation. An important part of their work is to keep patients and their families informed during the preparation and progress of the operations. They have very wide experience and will be happy to spend time discussing your questions before arranging a preliminary meeting with the transplant surgeon or kidney specialist.

An accompanying booklet, entitled **Living Donor Kidney Transplantation – Donor and recipient perspectives**, is also available. This booklet gives a first-hand account of the living donor kidney transplant procedure from the point of view of the donors and the recipients.

Your transplant coordinator:



Alternatively, you can contact the following organisations for advice:

National Kidney Federation

6 Stanley Street, Worksop, Nottinghamshire, S81 7HX
Telephone: 01909 487 795
Fax: 01909 481 723
E-mail: nkf@kidney.org.uk
Helpline: 0845 601 0209
Website: www.kidney.org.uk/

National Kidney Research Fund

Kings Chambers, Priestgate, Peterborough, PE1 1FG
Telephone: 01733 704 650
E-mail: helpline@nkrf.org.uk
Helpline: 0845 300 1499
Website: www.nkrf.org.uk/

Transplant Support Network

Room 8, Temple Row Centre
23 Temple Row, Keighley, Yorkshire, BD21 2AH
Telephone/Fax: 01535 692 323
E-mail: phatton@tsnet.demon.co.uk
Helpline: 01535 210 101
Website: www.transplantsupportnetwork.org.uk

Glossary

Anaemia

A deficiency of the red blood cells that carry oxygen round the body.

Antibodies

Proteins that are secreted into the blood to kill bacteria, viruses or parasites. They can also attack transplanted organs.

Cadaveric donor

A cadaveric donor is a person who may have expressed a wish to give his or her organs after dying to help someone, and his or her family has allowed that their loved one's organs can be used for transplantation.

Creatinine

This is a natural substance derived from muscle. Creatinine is released into the blood and excreted via the kidneys. Measuring the creatinine level in the blood is a useful assessment of kidney function.

Cross-matching

This test indicates if specific immune reactivity is present between the donor and recipient. The test involves exposing the recipient's blood to the donor's blood cells. The recipient may have antibodies that could injure the donor's cells – a positive cross-match. This is a contraindication to transplant, as it signifies that the recipient has the ability to destroy the donor's cells and would, most likely, destroy the donor's implanted kidney.

Dialysis

Dialysis is a process of removing from the blood the body's waste materials, which are normally filtered from the kidneys. There are two main types – haemodialysis and peritoneal dialysis (CAPD).

End-stage renal disease

This is where the kidneys are no longer able to remove the waste products from the blood to maintain health. At this stage dialysis, or a transplant, is essential to take over the work that the kidneys used to do.

HLA

Human leucocyte antigen.

Hypertension

High blood pressure.

Nephrectomy

The name of the surgical operation to remove a kidney.

Pre-emptive transplantation

This refers to transplantation given just before the recipient needs to be given dialysis, thus saving the recipient the added stress and medical effects of dialysis.

Recipient

A person who receives an organ from someone else (a donor) to maintain his or her life without dialysis.



Tissue type

A blood test performed prior to transplantation to determine the HLA antigens of both the donor and recipient, and thereby evaluate the closeness of their compatibility (i.e. whether they 'match').

Transplant

This term is used for the surgical operation of removing an organ or tissue from one person, and putting it into someone else's body. It can also refer to the organ itself.

ULTRA

Unrelated Live Transplant Regulatory Authority.

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