Living Donor Kidney Transplantation

Your questions answered
Medical Information
Why do we need living donation?

A successful kidney transplant is the best treatment for many patients with established renal failure, from a medical, psychological and social point of view.

The survival of transplants from living donors is significantly better than those from deceased donors, allowing more people to receive and benefit from a kidney transplant. A living donor transplant performed pre-emptively (before dialysis) is the best option for patient and transplant outcome.

In the UK, the majority of transplanted kidneys are from people who have died. 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 the UK between 1 April 2003 and 31 March 2004, 1,724 kidney transplants were performed. Most of these transplants were from people who had donated their organs after their death (deceased donors), although 450 were from living donors. Of these living donor transplants, 350 were related and 100 unrelated. However, there were over 5,000 people who were on the waiting list to receive a transplant.

During the last five years there has been substantial growth in living donor kidney transplantation in the UK. In 2004 living donor transplants represented 25% of the total kidney transplant programme, but there is still considerable room for expansion in comparison with activity in Scandinavia and the United States of America. The British Transplant Society recognises the need to set standards in clinical transplantation and has developed guidelines. These guidelines recommend that a programme to increase the number of living donors is required to extend the benefits of transplantation to more patients and their families.
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One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will impact on their health 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. Long-term 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.

A pre-emptive (before dialysis) living donor transplant is the best option for patients and transplant survival

There is a good chance of a successful kidney transplant if the kidney is donated by a living relative. Living donors who are close relatives can be an excellent tissue-type match and the likelihood of the recipient's body rejecting the new kidney from a related family member is less.

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, the chance of a successful transplant is excellent. The advantage of living kidney donation is that living donor organs are in better condition, and the kidney will be without blood for only a very short time after it is removed from the donor, which increases the chances of a successful transplant. Although there is no guarantee that any kidney transplant will work, 90-95% of live donated kidneys are working one year after the transplant. This compares with a success rate of 80-90% for kidneys from deceased donors. These differences become more marked five and ten years after transplantation. Living kidney donation allows the transplant operation to be planned at a time that is convenient for the recipient and the donor and for some people this can be planned before the need for dialysis.

The success of living donor kidney transplants is better than deceased donor transplants

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The success of living donor kidney transplants is better than deceased donor transplants

Living Donor Kidney Transplantation - Your Questions Answered
Who can donate a kidney?

Generally, a close relative of the person with kidney failure considers donation. Under the current law, living organ donation is allowed in the UK. The Human Tissue Act 2004 which will come into force in April 2006 will replace the existing legal framework. The Act is only applicable to England, Wales and Northern Ireland. Separate legislation is being developed in Scotland. The Act outlines the legal framework governing the removal, retention and subsequent use of human tissue including organs donated from a living donor. This Act states that genetic confirmation of the donor/recipient relationship is required, while prohibiting certain practices such as offers of money or other gifts. Increasingly, non-related individuals, such as partners and close friends, are becoming organ donors.

In most cases in the United Kingdom, only people over 18 years of age would be considered as living kidney donors. There is no upper age limit, but all potential donors must meet the criteria to establish that they are fit to donate. Although one might think that most family members would want to give a kidney to a loved one, donation can raise psychological and cultural issues. A large amount of emotional pressure can be put on individuals and the emphasis should be on informed consent freely given. For the parents of children requiring a transplant the decision may be more straightforward, but even here loyalties may be divided between the desire to provide for one child, while inevitably depriving other children of a parent for a period of time. This is not a trivial consideration, as the transplant 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 consider the possibility that the kidney transplant may not function. Finally, there may be conflict between the parents as to who is best placed to donate a kidney.

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.

In the UK, the number of genetically unrelated donations is increasing rapidly, with the same transplant success rate as for more directly related family members. In these circumstances, a further simple procedure has to be followed which takes the form of a discussion with an independent third party. The third party assessment ensures that no coercion, pressure or payment has been made to the donor and that there is full and informed consent. A report is then submitted to the Unrelated Live Transplant Regulatory Authority (ULTRA), who must give approval before the transplant can go ahead.

The genetically unrelated donor and recipient are required to provide evidence of their relationship such as photographs, letters and, if appropriate, a marriage certificate. However this process is likely to change under the Human Tissue Act 2004.
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What does a potential living donor need to consider?

Someone who is thinking about donating one of their kidneys to help a loved one or friend has many things to consider. It is something that has to be thought about seriously from a personal point of view. The healthcare team 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 considerations, such as the time taken off work for the investigations and recovery after the operation, or the domestic responsibilities and arrangements, such as looking after children or the family pet. Coercion from other family members 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.

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. 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 consequence that may arise.

Donors need to consider the practical aspects of donation so that these can be addressed at an early stage.
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Donors need to consider the practical aspects of donation so that these can be addressed at an early stage.
What makes a donor suitable?

Before the healthcare team can agree to a person becoming a donor, a number of conditions must be met:
1) The potential donor and recipient must be blood group compatible
2) The “cross match” between recipient and donor must be satisfactory
3) The donor must be in excellent health and have normal kidney function

1) 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.

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<thead>
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<th>Recipient’s blood type</th>
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2) The cross match
Some recipients may have formed antibodies that are directed against a potential donor’s cells and will destroy them despite the use of drugs to suppress the immune system. Such antibodies arise as a result of previous transplant, blood transfusion, or, in the case of women, pregnancy. These antibodies can be detected by a laboratory test known as a “cross match”. In this test, the recipient’s blood is mixed with the potential donor’s blood in the presence of reagents. Any pre-formed antibodies against the potential donor’s cells can be detected. This is known as a positive cross match and would mean that the transplant could not be carried out as the implanted kidney would be rapidly and aggressively rejected. Because of the importance of this test, it is carried out more than once and within the last few days before the actual operation, to ensure it is still negative.

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.

* These are a very small number of transplant centres in the UK who are considering living donor transplantation in blood group incompatible donors and recipients. However this is not widespread and is usually considered in exceptional circumstances.
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3) Making sure the donor is healthy

All donors must meet the criteria to establish that they are fit to donate, regardless of age. They must be in excellent physical and mental health to ensure that they can undergo a major operation with minimum risk as well as live a normal life with only one kidney. A full medical history, physical examination, laboratory and radiological investigations will be performed to assess this. Blood tests will also be performed to check that the donor is not carrying any potentially harmful viruses that could be passed on with the transplanted kidney. A potential donor’s blood will be examined for the presence of antibodies to certain blood borne viruses, such as hepatitis B and C, human immunodeficiency virus (HIV) – the virus that leads to acquired immune deficiency syndrome (AIDS), and others including cytomegalovirus (CMV).

With the exception of CMV, if any of these viruses are detected, the transplant 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, over half the adult population carries it but it is harmless to them. CMV may be passed from the donor to the recipient with the kidney transplant. However in immunosuppressed recipients, CMV infection may cause symptoms that range from a mild influenza-type illness to a more serious infection that could result in the loss of a kidney, particularly in patients who may not have previously encountered the virus. Modern antiviral drugs can help combat the infection.

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. 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 closely related; however, more and more successful transplants are being performed in people who are not perfect ‘tissue-type’ matches.

What are 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 on page 14 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.
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Why are so many tests needed?

Checking that a donor is both suitable and healthy is an in-depth process usually taking three to six months. Rigorous tests ensure that the medical team is as certain as possible that the transplant will be safe and successful for both donor and recipient. It also gives potential donors plenty of time to consider their options and be sure that they want to proceed. A number of people who wish to donate find that they are not able to do so because health problems are discovered through the assessment process. Members of the healthcare team involved in your assessment will provide emotional support through this period of time.

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 1, 2, 3 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 a prior blood transfusion, previous transplant or pregnancy.

Unrelated donors, such as spouses, are unlikely to be well matched to the recipient. However, in all but the perfectly matched situation the success rates of these transplants are equal to those of related donors. If a kidney does fail, there is a possibility that antibodies will have developed that may affect the chances of finding a suitable kidney in the future, which sometimes reduces the chances of finding a second suitable donor. However, this must be balanced against the benefits and long-term outcomes of a living donor kidney transplant.
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How do I become a donor?

For most people with established kidney failure, their one wish is to receive a successful kidney transplant. However, they are often reluctant to ask family members or friends to be a kidney donor as they do not want to impose such a major undertaking on them. Therefore, the suggestion to donate will often originate from a family member, spouse or friend who wishes to help a loved one. Sometimes a direct approach by a member of the healthcare team to family members may be made if that is most appropriate. Wherever the suggestion originates, there is never any substitute for talking through the issues with an option, both for donors and recipients. The most suitable contact for the family member or spouse to approach is the transplant coordinator or nurse. He or she will be able to discuss how to take the process forward.

There are typically two situations in which living donation may be considered. 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 avoids the problems and difficulties that may be experienced with dialysis and offer the recipient the opportunity for better long-term rehabilitation and transplant survival.

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. The healthcare team will also be aware of an individual’s circumstances, such as the likelihood of a suitable deceased donor kidney becoming available (i.e. whether the person has a common blood group and/or tissue-type).

What are the risks and benefits for donors and recipients?

There are risks and benefits associated with living kidney donation 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 healthcare team is experienced in dealing with such situations quickly and appropriately.

Rarely, one in 3,300 donors die as a result of the operation. The most common causes of death are pulmonary embolisms (blood clot in the lung) or heart attack. However, the chance of this happening has been compared to the risk of having a fatal road accident.

The rigorous assessment process and dedicated hospital care aim to minimise these risks, but cannot remove them completely. In the longer term, the life expectancy of living kidney donors is better than the general population. This is due to the selection process which ensures only the very healthiest individuals are considered as potential donors.
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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 healthcare team is experienced in dealing with such situations quickly and appropriately.

Rarely, one in 3,300 donors die as a result of the operation. The most common causes of death are pulmonary embolisms (blood clot in the lung) or heart attack. However, the chance of this happening has been compared to the risk of having a fatal road accident.

The rigorous assessment process and dedicated hospital care aim to minimise these risks, but cannot remove them completely. In the longer term, the life expectancy of living kidney donors is better than the general population. This is due to the selection process which ensures only the very healthiest individuals are considered as potential donors.
Another issue for the donor is that the nephrectomy is more difficult and uncomfortable than the recipient’s operation. Post-operative pain can usually be controlled with painkillers, but 3% of donors may still suffer from pain one year after the operation. Following discharge from immediate surgical follow-up, all living donors will be reviewed clinically on an annual basis to ensure that all is well.

While the donor is undergoing assessment, an unexpected abnormality may show up. This can be a shock to the donor and may have implications for future life and medical insurance. The transplant team is always there for support and referral to the appropriate specialty will be organised. After the operation the donor may experience a sense of anticlimax.

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. 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 before the operation.

- The donor will need to spend four to ten days in hospital for the operation, and have a further six to twelve weeks off work, incurring possible loss of earnings or annual leave. This time may be reduced if keyhole surgery is performed.
- 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 one 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. With such an improvement in health, the recipient is usually able to contribute more to the life of his/her immediate family which indirectly is also enhanced. This very positive aspect of living donation often completely outweighs the physical disadvantages.

On a wider scale, living donation removes the recipient from the national waiting list and helps another potential recipient gain a deceased donor kidney more quickly.
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On a wider scale, living donation removes the recipient from the national waiting list and helps another potential recipient gain a deceased donor kidney more quickly.
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 one day before feeling unwell again. Also, many patients find the procedure very time-consuming.

After the operation, recipients are free from dialysis

Most recipients manage to return to employment following the transplant. In fact, in Europe, 79% of those with functioning kidney transplants are working after one year, 84% after five years, and 66% are still functioning after ten years. Furthermore, many recipients remain fit and well more than 20 years after their transplant. This represents excellent rehabilitation.

Recipient disadvantages

The risks associated with major surgery also apply to the recipient, although the operation to implant a kidney is usually more straightforward than the one to remove the kidney from the donor. Complications after the transplant operation can lead to early failure of the organ, causing 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 after one year, 84% after five years, and 66% are still functioning after ten years. Furthermore, many recipients remain fit and well more than 20 years after their 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 increase susceptibility 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.
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Most recipients manage to return to employment following the transplant. In fact, in Europe, 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.

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Long-term transplant survival can not be guaranteed but is best in living donor transplants

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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 wellbeing and anatomy of the kidney. This system of testing, and the order in which it is undertaken, may differ between transplant centres; however, below is an example of the types of tests that a potential donor can expect. These tests can usually be performed as an outpatient but in some centres sometimes involve a short stay in hospital (one to two days). Throughout the period of assessment, potential donors should bear in mind that these tests may reveal a reason for the kidney donation being unacceptable.

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 fitted with a portable device that measures blood pressure at home for 24 hours. If blood pressure remains higher than normal, it may be possible to treat and still proceed to donation provided that it is safe to do so. Additional tests on the heart would be required and each case assessed on an individual basis according to what treatment is required.

Kidney function tests

Blood tests
Blood samples will be taken for routine analyses. Haematology tests can show anaemia or signs of infection, and blood chemistry tests can determine kidney and liver function, or the suggestion of diabetes. Samples are also tested for hepatitis B and C, HIV, CMV, EBV 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 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.

Creatinine clearance
Creatinine is a substance that is produced naturally in our bodies and is normally removed by the kidneys. 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 to assess kidney function.

Glomerular filtration rate
A more accurate measure of kidney function is the glomerular filtration rate (GFR). This test assesses the ability 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 intervals over a number of hours to measure the individual’s clearance of the radioactive tracer through the kidneys.
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Kidney function tests

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

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Renal angiography

Most centres now use CT (computerised tomography) or MR (magnetic resonance) angiography to reveal the number and calibre of blood vessels taking blood to and from the kidneys. Both techniques also show more detailed anatomy of the kidneys, draining tubes and bladder. This information is then used to build a 3-dimensional view of the kidneys, blood vessels and draining tubes. The whole procedure takes about 30 minutes and can be performed as an outpatient appointment.

MR angiography is a similar technique using a powerful magnet rather than X-rays.

Some centres still use a more invasive form of direct angiography, which involves injecting dye through a cannula passed up to the region of the kidney arteries via a direct needle puncture of one of the large arteries in the groin. This technique may require an overnight stay in hospital.

Electrocardiogram (ECG)

This test is used to check that the heart is healthy and functioning properly. An ECG involves having several small electrosensitive 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 may be seen, and this could increase the risks associated with anaesthesia during the nephrectomy. Sometimes additional heart tests such as an exercise ECG test or ultrasound of the heart (echocardiogram) may be performed if required.

X-rays

A series of X-rays, including a chest X-ray, may be taken. In some centres, a special X-ray of the kidneys known as an IVP or IVU may be done. This involves having an iodine containing “dye” injected into a vein in the arm. The “dye” is then excreted into the urine into the bladder. A series of X-rays show the kidney outline and drainage tubes in detail. Similar information may be obtained from the CT/MR scan (see renal angiography section).

Renal ultrasound

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

Most centres now use CT (computerised tomography) or MR (magnetic resonance) angiography to reveal the number and calibre of blood vessels taking blood to and from the kidneys. Both techniques also show more detailed anatomy of the kidneys, draining tubes and bladder. This is obviously very important, so the surgeon can have a clear idea of which kidney is the better one to remove, and which has the easier access. CT angiography is a special kind of X-ray taken of the abdomen. Iodine containing “dye” is then injected into a vein in the arm and the scan is repeated. A computer is then used to build a 3-dimensional view of the kidneys, blood vessels and draining tubes. The whole procedure takes about 30 minutes and can be performed as an outpatient appointment. MR angiography is a similar technique using a powerful magnet rather than X-rays.

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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 four to ten days, in addition to needing about six to twelve weeks away from work. This could present the problem of earning very little, or no, money.

Although legislation forbids any form of payment as 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. It is important to raise these issues early with the transplant coordinator so that the relevant healthcare authority can be approached in advance of the transplant operation. 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.

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
- 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 is arranged for the journey to and on discharge from the hospital

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.

Financial issues need to be considered and addressed early in the process

Reimbursement of legitimate donor expenses is allowed and should be discussed at an early stage
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What other practical aspects need considering?

Living Donor Kidney Transplantation - Your Questions Answered [ 27 ]
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 / Live donor 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 smoothly 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 indicate 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.

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
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**Consultant kidney specialist (nephrologist)**

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. If at all possible the recipient and donor should be assessed by different kidney specialists who manage their care.

**Psychologist**

As 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 to consider, 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 updated regularly. 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 the 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.

**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 an uphill struggle. The physiotherapist can advise on methods to make rehabilitation easier.

**Pharmacist**

The hospital pharmacist will be able to offer you pain relief advice as appropriate.
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Consultant anaesthetist

There will usually be two anaesthetists, one for the nephrectomy 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 and commence appropriate pain relief during the operation.

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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 fewer than with other major surgery because donors are in excellent health at the time of the operation.

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 healthcare team.

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

The right decision is the one that is best for you

At any time, potential donors are free to raise specific concerns with the healthcare 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 healthcare team so that they are confident that they have made the right decision. The healthcare team would much rather know of any concerns that the donor may have about proceeding, regardless of at which stage this occurs. If the donor should decide to withdraw his or her consent, even at a late stage, then this will be kept confidential by the healthcare team. Nothing will be held against someone who decides that they do not wish to become a donor. If you have particular concerns you may wish to speak to an independent psychologist or counsellor and this should be available to you on request.

Sometimes talking to someone else who has been a living donor can be helpful as they have personal experience of the donation process. The transplant coordinator can arrange this for potential donors. It is very important that throughout this process close family members understand fully what is happening and consider carefully all the risks and implications.
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What is actually involved once the decision is made?

The nephrectomy (removal of a kidney)

Under a general anaesthetic, the removal of a healthy kidney is carried out in the same way as the removal of a diseased kidney. The kidney is lifted out of the wound and flushed with a cold solution to wash out blood and slow the metabolism. It is then carried into the adjacent operating theatre where the recipient is waiting, or stored cold until the recipient is brought into the operating theatre.

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 painkilling drugs can be given, as required. Tubes are usually removed after the first two to three 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.

There are two types of surgery which can be performed. These are briefly discussed on page 36 however your transplant coordinator will be able to give you further information on these procedures.
What is actually involved once the decision is made?

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There are two types of surgery which can be performed. These are briefly discussed on page 36 however your transplant coordinator will be able to give you further information on these procedures.
Open nephrectomy
This is the traditional operation to remove the kidney. It is a major operation that involves a nine inch incision below one side of the ribcage. 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.

Laparoscopic nephrectomy
A small but growing number of transplant centres are now using laparoscopic or ‘keyhole’ surgery to remove the donor kidney. The benefits of laparoscopic surgery are a shorter stay in hospital and an earlier return to work than with open surgery. Medical literature suggests that this technique is just as effective as open surgery but avoids the painful incision. The operation is performed through four 0.25 inch half cuts near to the rib cage and a small incision about three inches long through which the kidney is removed. It usually involves a three to four day stay in hospital; however this can vary depending on the individual. One drawback is that it requires special expertise. However, as experience of this newer technique grows, its use is likely to become more widespread.

Hand-assisted laparoscopic nephrectomy
During this procedure, which is similar to the ‘keyhole’ approach, the surgeon makes an additional incision about 3.5 inches long through which they insert a hand to aid removal of the kidney. This technique reduces the likelihood of the kidney being damaged during removal.

How long does it take to recover?

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

The wound can remain sensitive for several weeks. There may be ‘twinges’ or a ‘drawing’ sensation for up to six 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.

Before leaving hospital, a clinic appointment will be made for the donor. This will probably be for between four and six 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.

Laparoscopic nephrectomy
Laparoscopic surgery reduces the length of a donor’s stay in hospital. Post operative pain is also reduced, and the donor is usually able to resume normal physical activity more quickly than with open surgery. A period of four to six weeks for recuperation at home is required before the donor can return to their normal activities. The donor may feel some pain and discomfort but this will settle and painkillers are available to help reduce this. The donor will be asked to return to the hospital for a review appointment between four and six weeks following the operation.

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to ensure that they are recovering well. This technique avoids many of the problems related to the wound site and donors are reported to recover more quickly from their operation.

**There are different options for the donor operation. You should discuss what is available with your healthcare team**

**The kidney transplant**

The kidney is put into the recipient’s outer pelvis 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!

The recipient should be out of bed within one to two 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.

**Anti-rejection medications are essential and must be taken by the recipient for the entire life of the transplant**

Anti-rejection 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 as well as tablets; later this will change to tablets only. 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 one to two weeks after the transplant has been performed, by which time, he or she will probably already be feeling the benefit of the operation.

Recipients will have to visit the transplant outpatient clinic frequently to begin with, but this becomes less frequent as time progresses.

**Recipients soon feel the benefit of their new kidney**
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How do donors feel afterwards?

The donor will be asked to return to the hospital within the first few weeks after his or her operation to 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 can feel quite emotional. There can be a sense of anticlimax; so much time has been spent thinking 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 not make good progress or the transplant is unsuccessful. In some cases donors may need additional help and support, including counselling, which can be arranged. Counselling facilities are provided for the donor at some centres.

The relationship between donor and recipient and the impact of donation will be individual to each pair. 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’. The donor may be able to help by maintaining a normal relaxed attitude towards the recipient.

The donor kidney is a gift – freely given
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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 three months after a transplant are when most problems occur. Once these three 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 up to twelve 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.

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 four to six 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.
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**Future perspectives**

Following the new legislation, forms of living donation not currently practiced in the UK but increasingly being established elsewhere in the world may be possible. These include ‘paired donation’ and altruistic (“good Samaritan”) donation.

**Paired Donation**
A donor-recipient pair (Pair 1) may be incompatible for blood group or cross matching reasons. A second pair (Pair 2) may also be incompatible. However, donor 1 may be compatible with recipient 2, and vice-versa.

For example:

<table>
<thead>
<tr>
<th>Pair 1</th>
<th>Pair 2</th>
</tr>
</thead>
<tbody>
<tr>
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<td>Donor 2 (Blood group B)</td>
</tr>
<tr>
<td>Recipient 1 (Blood group B)</td>
<td>Recipient 2 (Blood group A)</td>
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There may be practical and logistical issues with this procedure, such as the identification of suitable pairs and the desirability that the operations are performed simultaneously (to prevent one donor withdrawing consent after “his” recipient has received the transplant), however other countries in the world have run such programmes successfully.

**Altruistic, Non-directed Donation**

An altruistic living kidney donor is a person who wishes to donate a kidney to the ‘national pool’ ie not to an identified recipient – so called “good Samaritan” donation. The kidney is allocated through standard procedures to the most appropriate patient on the list waiting for a deceased donor transplant. Such donors have only been accepted in other countries after an intensive psychological/psychiatric screening process, alongside the usual thorough medical assessment. Donor autonomy remains essential, and clearly the donor has none of the “indirect” benefits that occur following donation to a genetically or emotionally related recipient.
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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 liaison between members of the healthcare 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.

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

**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/](http://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](http://www.transplantsupportnetwork.org.uk)

**UK Transplant**
Communications Directorate
Fox Den Road, Stoke Gifford, Bristol, BS34 8RR
*E-mail:* enquiries@uktransplant.nhs.uk
*Helpline:* 0117 975 7575

**Organ Donor Line**
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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).

Established renal failure
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.

EBV
Epstein Barr Virus – a member of the herpes family.

Hepatitis B and C
Hepatitis is inflammation of the liver usually as the result of a viral infection.

HIV
Human immunodeficiency virus.

HLA
Human leucocyte antigen.

HPV
Human papilloma virus – a common virus, variants of which cause common and genital warts.

HTA
The Human Tissue Act 2004 which will come into force in April 2006. The Act is only applicable to England, Wales and Northern Ireland. Separate legislation is being developed in Scotland. The Act outlines the legal framework governing the removal, retention and subsequent use of human tissue including living donation.

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.

Deceased donor
A deceased 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.

CMV
Cytomegalovirus is a herpes virus. Infection with CMV is common and in healthy individuals usually causes no symptoms. It can be transmitted by a kidney transplant and may cause potentially serious problems in a recipient receiving immunosuppressive medication.

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, also destroy the donor’s implanted kidney.
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The members of the United Kingdom Transplant Coordinator’s Associations (UKTCA) Education Sub Committee and their colleagues.

Hypertension
High blood pressure.

Nephrectomy
The name of the surgical operation to remove a kidney.

Pre-emptive transplantation
This refers to transplantation performed just before the recipient needs to start 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.

Syphilis
A sexually transmitted bacterial infection with highly contagious early stages.

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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ULTRA
Unrelated Live Transplant Regulatory Authority.