



Living Kidney Donation:

# **Your questions answered**

**Organ Donation**  
**Gift of Life**



## Contents

Introduction	2
Why do we need living donation?	3
Who can donate a kidney?	6
What does a potential living donor need to consider?	11
What makes a donor suitable?	13
How do I become a donor?	21
What are the risks and benefits for donors and recipients?	22
What further assessments are necessary?	27
What other practical aspects need considering?	31
Who are all the different people involved in the process?	35
Who makes the final decision?	38
Possible model for donor assessment	40
What is actually involved once the decision is made?	41
How do donors feel afterwards?	46
Getting back into a routine	48
Where can I get more information?	50
Glossary	52
Acknowledgments	56

## Introduction

If you have a friend or relative with kidney failure, the treatment options are **dialysis**, and/or **transplantation**. A successful kidney **transplant** is the best treatment for many patients with **established renal failure**, from a medical, psychological and social point of view. A successful kidney transplant from a living donor is even better.

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 developed to provide information to those considering living kidney donation. There will be a great deal of verbal information given to prospective donors, both before and during the assessment period.

This booklet aims to make sure that all prospective living donors and their families have the opportunity to read about the risks, benefits, investigations, procedures and follow-up associated with donating a kidney. You can discuss anything in this booklet in more detail with the healthcare team at your local renal unit or transplant centre.

The information in this booklet is not a replacement for face-to-face meetings between the transplant team, the prospective donor, the **recipient** and their families, but is designed to give you the background information to ask the questions that are relevant to your individual circumstances.

The booklet also gives a first-hand account of what it is like to be involved in a living donor kidney transplant from the people who know best – those who have been directly involved – people like you.

All of the quotes used in this booklet are from people who have either donated or received a kidney. You will see how other people have coped with the transplantation process from start to finish; from the moment that the decision is made, through to the tests that must be undertaken, what happens before, during and after the operation, both in the short and long term.

It is hoped that this information will help you gain an insight into how you might deal with some of the difficult issues that you may encounter and ensure that you are fully informed to make the right decision.

## Why do we need living donation?

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). Approximately 2,000 kidney transplants are performed in the UK each year, but there are still too few kidneys available to help all those who require a transplant, thereby producing a waiting list.

Most of the transplants performed are from people who have donated their organs after their death (**deceased donors**).

One in three kidney transplants is now performed from a living kidney donor and this continues to increase year on year. However, with more than 5,000 people remaining on the national transplant list for a kidney transplant there is still considerable room for expansion in living kidney donation in comparison with activity in Scandinavia and the United States of America. The British Transplantation Society and Renal Association has developed guidelines that support an increase in the number of living donors to extend the benefits of transplantation to more patients and their families.

In September 2006, the Human Tissue Act 2004 (for England, Wales and Northern Ireland) and the Human Tissue Act 2006 (for Scotland) came into force and together they provide the legal framework for organ and tissue donation across the UK. The rules set out by the Human Tissue Authority (**HTA**), the regulatory body established under the Acts, allow more flexibility in who can be a living donor and who can donate to whom. These new options are paired/pooled and non-altruistic kidney donations and both will be explained in more detail later in this booklet.



## **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 blood relative (genetically-related). Living donors who are close relatives can be an excellent tissue-type match for the recipient.

Transplants from non-related living donors, usually spouses or partners and close friends who have a close emotional relationship but are not genetically-related are also common. Although it is less likely that the kidney will be as good a match with the recipient as a transplant from a close relative, the chances of success are still excellent. The advantage of living kidney donation is that living donor organs are in better condition, and the kidney will only be without blood for 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 kidneys donated from living donors 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 at five and ten years after transplantation. Living kidney donation has the benefit of allowing the transplant operation to be scheduled at a time that is convenient for the recipient and the donor. It provides the opportunity to plan it before the need for dialysis with all the added benefits of a pre-emptive transplant.

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 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 two. The amount of urine passed is the same 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 a 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. The donor is at no greater risk of developing kidney failure or ill health after donating than anyone in the general population.

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



## Who can donate a kidney?

Generally, a close relative or someone who has a close emotional relationship with the person with kidney failure considers donation. As previously discussed, since September 2006, the Human Tissue Acts provide the legal framework for organ and tissue donation in the UK, including living donation.

Under the rules set out by the HTA, it is illegal to exchange money or gifts for organs for transplant. It is important that any living kidney donor consents freely and is not under any pressure to donate. In order to safeguard the interests of the donor, the HTA has specified that all donors and recipients must see an Independent Assessor (**IA**) who is independent of their healthcare teams before the transplant operation can go ahead. IAs are trained by the HTA and are responsible for making sure that the relationship between the donor and recipient is genuine, and that appropriate evidence, such as marriage or birth certificates, photographs and testimonies are available to confirm this. The IA also makes a judgment about the nature of the relationship between the donor and recipient, the motivation for the donation and must be satisfied that the donor can provide free, informed consent for surgery.



The IA will interview the donor and recipient together and separately on the same occasion. This interview will usually be arranged in your local renal unit or transplant centre, once both donor and recipient have been thoroughly assessed as suitable for the donor and transplant surgery to proceed.

For more information about the independent assessment process please read the HTA leaflet *'Information about living donor transplants'* which is available from your local renal unit or transplant centre or via the HTA website at [www.hta.gov.uk](http://www.hta.gov.uk).

**The Human Tissue Act allows more flexibility in who can be a living kidney donor and who can donate to whom**

In most cases in the United Kingdom, only people over 18 years of age would be considered as living kidney donors, but in Scotland the age of consent is 16 years of age. 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.

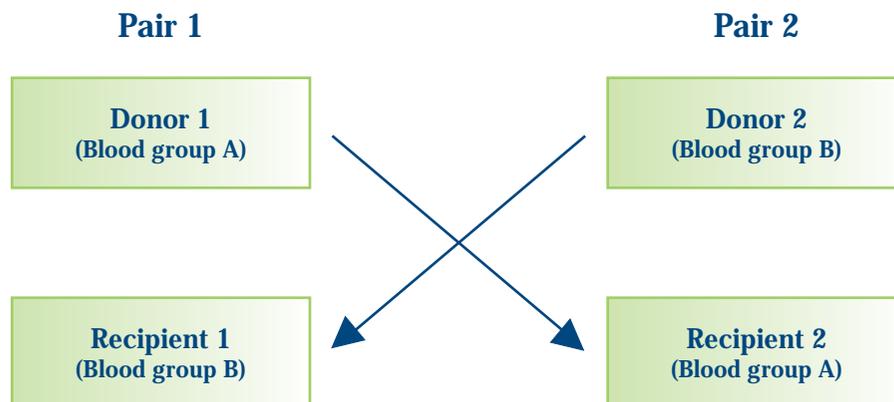
In the UK, the number of genetically unrelated donations has increased rapidly in recent years, with the same transplant success rate as for more directly related family members. This is recognised within the current legal framework and the additional options for living donor transplantation that the HTA has made permissible.



## Paired or Pooled Donation

When a donor and recipient are incompatible or mismatched with each other, either by blood group or tissue (**Human Leucocyte antigen (HLA)**) type, it may be possible for them to be matched with another donor and recipient pair in the same situation and for the kidneys to be exchanged or swapped. This is called paired donation and each recipient benefits from a transplant that he/she would otherwise not have had. When one or two pairs are involved in the swap it is known as pooled kidney donation.

For example:



## Non-directed Altruistic Donation

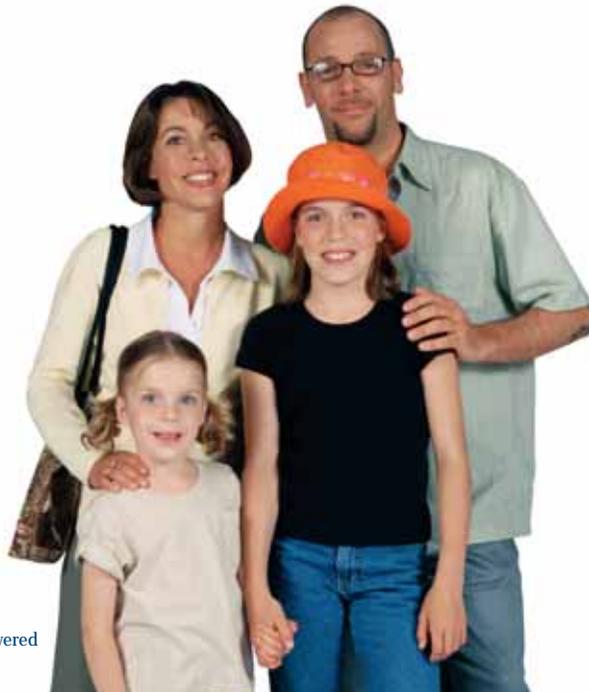
This is where a person volunteers to donate a kidney to an unknown recipient – someone they have never met before or who is not known to him/her. The kidney is donated to the most suitable recipient on the national transplant list.

There are special considerations to be taken into account for both paired/pooled and non-directed altruistic donation as the donors and recipients do not know each other which is very different from the usual living donor scenario.

It is essential that anonymity and confidentiality between all parties is maintained prior to the transplant operations in both scenarios. If all parties are in agreement, it may be possible for respective donors and recipients to meet or make contact with each other at some time afterwards.

For more information please read the HTA *'Information about living donor transplants'* leaflet available at the HTA website [www.hta.gov.uk](http://www.hta.gov.uk), and UK transplant leaflets *'Paired living kidney donation: your questions answered'* and *'Altruistic living kidney donation: your questions answered.'* Available on the website [www.uktransplant.org.uk](http://www.uktransplant.org.uk) or Organ Donor Line 0845 60 60 40.

The transplant team is fully aware of the potential problems that may arise – 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.



## What does a potential living donor need to consider?

Someone who is thinking about donating one of their kidneys to help someone else has many things to consider. 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 is a suitable organ for transplantation.

It is 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 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 needs to consider facing his or her future with one kidney.

**Donors need to consider the practical aspects of donation**

Elizabeth, who donated a kidney to her sister, comments, “When Joyce was told she had kidney failure, I cannot remember actually making the decision about asking to be considered as a donor. I just knew it was what I wanted to do. My husband and children were completely supportive too, which in my opinion is vital to the whole process, because it inevitably involves you all.”

Richard’s wife Christine who also donated her kidney to her husband notes that, “I offered to donate immediately and then began to think about the implications. My first doubts were about our two sons. The kidney disease that my husband suffered from was hereditary – should I therefore be prepared to donate to one of our sons instead? The more I thought about it the more I realised that, at the rate of progression of the disease, our sons would not require a transplant until they were in their late fifties, and by that time I would be in my eighties! Also, with the incredible advances in kidney research, transplants could be a thing of the past.”

## What makes a donor suitable?

Previously, the healthcare team could only agree to a person becoming a donor, if a number of conditions were met:

- 1) The potential donor and recipient had to be blood group compatible
- 2) The “cross match” between recipient and donor had to be negative
- 3) The donor must be in excellent health and have normal kidney function

Sometimes donors and recipients have blood groups that do not match or the recipient may have **antibodies** against the tissue (HLA) type of the donor kidney (sensitised) which causes a ‘positive’ or unsuitable **‘cross match’** (see section ‘The cross match’). In the past we were unable to carry out the transplant but now it is often possible to remove tissue-typing and blood group antibodies by treating the recipient’s blood so the transplant can go ahead. This is not always possible but it offers another option for a successful transplant for recipients who are not compatible with their donors. The alternative is paired donation (see section ‘Who can donate a kidney’).

It is always preferable to transplant a recipient from a compatible donor and it is important to know what is involved and the likelihood of success for you and your donor should you decide to consider antibody removal. You will need to discuss this in detail with your healthcare team. There are a small number of transplant centres in the UK who are offering antibody removal treatments and it may be possible for you to be referred to one of these to see if this is a feasible option for you.

## 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. 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. The blood group match is always the first step before further assessment is carried out. Family members may have different (i.e. incompatible) blood groups, so one person may be a preferable donor over another at this stage.

## 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 a 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 in the usual way 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 in the last few days before the actual operation, to ensure it is still negative.

Ken notes his experience, "The matching process took about six months with tests of many kinds (mainly blood). My brother Brian went to hospital in Portsmouth for these tests and I went to Leicester General. In the final stages, we both went to Leicester. Personally, this did not pose any problems as the possible outcome outweighed any minor inconveniences."

### 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**), cytomegalovirus (**CMV**) and Epstein-Barr virus (**EBV**).

With the exception of CMV and EBV, if any of these viruses are detected, the transplant cannot usually 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 and EBV are related to the chickenpox virus. Over half the adult population carries CMV and 90% carry EBV, but the viruses are harmless to them. However in immunosuppressed recipients, CMV and EBV infection may cause symptoms that range from a mild influenza-type illness to more serious infection, particularly in patients who may not have previously encountered the virus. Modern antiviral drugs can help combat CMV infection and knowing whether the donor and recipient have been previously exposed to these viruses before the transplant means that the recipient can be monitored more closely afterwards.

“When it became clear that I was compatible and my general health was good, a two-day hospital admission was arranged for a series of more specific tests. This was my first visit to hospital, excluding the birth of my children, but any apprehension was soon dispelled by the supportive attitude of the staff. The tests consisted of blood tests, blood pressure, a chest X-ray, an ultrasound scan and a renal angiogram. I actually quite enjoyed the experience!” Elizabeth remarks.

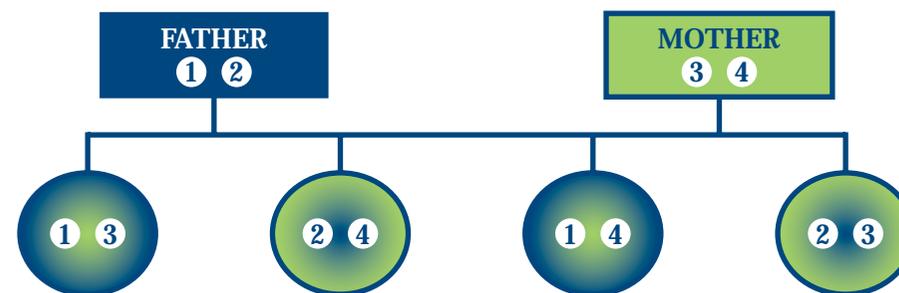
## What is tissue-type compatibility?

An issue that may influence the suitability of a potential donor is his/her tissue (HLA) 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 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 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. However, if a poorly maintained kidney does fail in the future, it is more likely that antibodies will have developed, 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 an in-depth process usually taking 3-6 months. Rigorous tests ensure that the transplant 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 to 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 any support that you need through this period of time.



## 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 the issues through. Direct personal communication is key to ensuring living kidney donation is considered as an option, both for donors and recipients. Often the most suitable contact for the family member or spouse to approach is the transplant coordinator or nurse. He/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. As previously discussed, this is the preferred option, because of the benefits of planning and long-term outcome.

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/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 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.

Richard was worried about what he might be about to put Christine through, “Part of me hoped that the tests would show that my wife could not donate so the decision would be taken away from me. The initial tests showed that further, more detailed tests were required, and I became very stressed with extremely mixed emotions. One of the tests was very painful and I decided that it should all be called off, but my wife persuaded me otherwise. The extra tests meant that the planned transplant date was not feasible and a new date was set. Needless to say, the delay gave me more time to go through more feelings of selfishness and guilt.” It was also an emotional time for Christine, “The self-preservation side of my mind kept thinking perhaps I won’t be suitable, whereas the sensible decision side hoped that I would be. I wanted to do it, but I was afraid. Once all the tests were over and everything was found to be OK, my mind was completely adjusted and I was ready to go ahead with it. I had a great deal of support from my consultant and from another consultant required to give an independent opinion of our case.”

### 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 challenges.

On a wider scale, living donation removes the recipient from the national transplant list and increases the opportunity for another potential recipient to receive a deceased donor kidney more quickly.

**Giving the gift of life is both satisfying and rewarding**

### 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** (removal of a kidney) 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 3,300 (0.03%) donors die as a result of the operation. The most common causes of death are pulmonary embolisms (blood clot in the lung), hepatitis 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 potentially more 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. Another way to look at this is that a health problem that is identified at an early stage can often be dealt with more effectively. It may be an advantage for the donor even if it excludes him/her from donating. 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 so it is important to think about your decision carefully.

### **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 happen even though the donor and recipient have been thoroughly assessed. This can be devastating, and needs to be considered carefully and realistically for everyone.

There are three practical issues that need to be considered pending the time of operation.

- The donor will need to spend 4-7 days in hospital for the operation, and have a further 6-12 weeks off work, incurring possible loss of earnings or annual leave. This time is usually 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

## **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 work 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.

## 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 1 year, 84% after 5 years, and over 60% 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/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/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 concerns with relatives or members of the transplant team.

To prevent the transplant being rejected, the recipient will receive medication to suppress his/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 himself/herself to avoid this risk.

## What further assessments are necessary?

There is a sequence of tests that are 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 may involve a short stay in hospital (1–2 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 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 (see section 'The cross match').

### 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 several urine samples that will be sent away for analysis.

## Blood pressure monitoring

As the kidneys can be a prime target for damage due to high blood pressure, the potential donor's blood pressure will be checked to exclude **hypertension** (high blood pressure). 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 the treatment that is required.

## Kidney function tests

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

### 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 or calculated 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 particular 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.

## 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, treadmill 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 Intravenous Pyelogram (**IVP**) or Intravenous Urogram (**IVU**) may be done. This involves having an iodine containing "dye" injected into a vein in the arm. The "dye" is taken up by the kidneys and 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 Computerised Tomography (**CT**) /Magnetic Resonance Imaging (**MRI**) scan (see next section).

## Renal ultrasound

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

## Renal angiography

Most centres now use CT or MRI angiography to reveal the number and size of blood vessels taking blood to and from the kidneys. Both techniques also show more detailed anatomy of the kidneys, draining tubes, ureters and bladder. This is very important so the surgeon can have a clear idea of which kidney is the most suitable one to remove and which kidney 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.

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.

## 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 4-7 days, in addition to needing about 6–12 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/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

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 or Primary Care Trust. 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.

One of the many benefits of living donation is that the date for the transplant operation can be planned in advance.

“We were able to fix a date for the transplant, which fitted in with family arrangements as John’s partner was expecting a baby. I was most concerned before the operation that it would not be successful – I was bothered by the worry that John would go through all of this for nothing,” explains Robert.

## Preparation

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

“Much to our delight the results showed that I was in good general health and I had two well functioning kidneys. Reality strikes! Dates were put into place and arrangements made. Joyce and I are both teachers and we are fortunate enough to have a long break in the summer, so it was arranged that this was when our operations would take place. This was at our request and another example of how well we were looked after,” remembers Elizabeth.

For Christine and Richard, the preparations were equally important. “As both my husband and I would be incapacitated at the same time, there were quite a number of arrangements to make. For example, provision had to be made for the dog, the freezer had to be well stocked and, most importantly, someone had to come and look after us for a few days.”

## Checklist

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
- ✓ Small change for the telephone/newspapers



“The faces I saw on the ward, on the way to the theatre and in the anaesthetic room were familiar. All had introduced themselves previously, which is so helpful when the surroundings are unfamiliar,” says Elizabeth.

## 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/Living 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/she will be aware of what stage has been reached and who is responsible for each part of the process. Simply put, he/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/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 (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.

## **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.

## **Transplant nurse practitioner**

The transplant nurse practitioner cares for 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.

## **Psychologist/Counsellor**

As previously mentioned, there can be important psychological effects in considering kidney donation. Whether it's family pressures or any other emotional discomfort, the psychologist/counsellor is there to help. You can always ask to be referred at anytime if you feel that it would be helpful for you.

## **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 sound advice and support.

## **GP**

The potential donor's family doctor should be updated regularly. Once the donor has been discharged from care by the hospital-based transplant team, it is then usual for his/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. There will be different arrangements for donor follow-up care in each transplant centre or local renal unit. Your local healthcare team will be able to advise you. Some transplant units run annual follow-up clinics for donors.

## **Pharmacist**

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

## 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 and discussed with the healthcare teams responsible for the donor and recipient. 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.

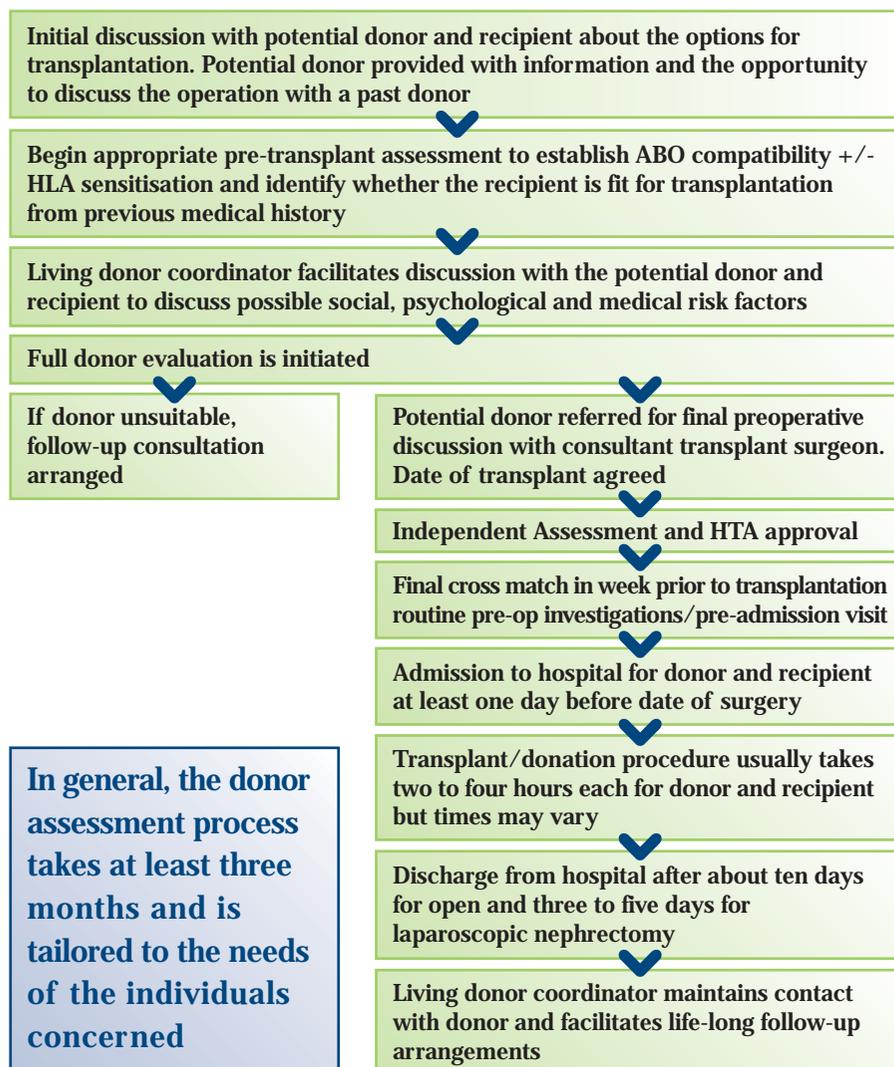


### **The right decision is the one that is best for you**

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 the donor may have about proceeding, regardless of when this occurs in the process. If the donor should decide to withdraw his/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 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. The transplant coordinator can arrange this for potential donors. 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/her family can sometimes make the decision making easier or more complex.

## Possible model for donor assessment



## What is actually involved once the decision is made?

### The nephrectomy (removal of a kidney)

Under a general anaesthetic, the kidney is removed in the same way it would be removed if it was diseased. 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/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 one 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 below 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, occasionally 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 and some have developed a technique using a much smaller cut 'mini-incision'.

## Laparoscopic nephrectomy

A 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 usually involves a three to four day stay in hospital; however this can vary depending on the individual.

## Hand-assisted laparoscopic nephrectomy

During this procedure the abdomen is inflated and the surgeon makes an additional incision about 3.5 inches long through which the kidney is removed by hand. This technique reduces the likelihood of the kidney being damaged during removal. These laparoscopic techniques require special expertise and training but are becoming increasingly widespread and popular with potential donors.

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

## How long does it take to recover?

### Open nephrectomy

A donor's stay in hospital is usually between five and seven days. He/she can expect to be out of bed the day after the operation and home within one week. 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. Sometimes 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. However, the scar should be the only permanent reminder of the donor's operation.

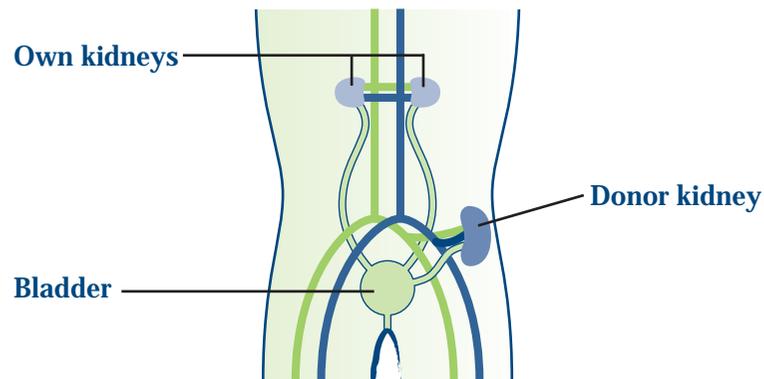
Before leaving hospital, a clinic appointment will be made for the donor. This will probably be for between four and six weeks after discharge. An annual appointment with the transplant centre or the GP is advisable as previously discussed.

### 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 at 12 weeks following the operation 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.

## 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 urethra 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 given to the recipient

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/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

## How do donors feel afterwards?

The donor will be asked to return to the hospital within the first few weeks after his/her operation to ensure that he/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/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.

Christine explains, "My decision to be a donor was totally the right one. Although it has been a more painful experience than I had hoped it would be, it has been so worthwhile seeing my husband looking so well and knowing that, all being well, we can look forward to many happy and healthy years together. I also believe that it has brought us even closer together as it has been a truly shared experience. I would not hesitate to recommend it to anyone thinking of becoming a living donor."

Elizabeth agrees, "Being a donor is a unique experience that not everyone who wishes to has the opportunity to take. I was fortunate to be able to do this and would encourage others to do so as well. Personally, I feel richer as a result of the whole experience and through meeting so many special people."

**Try not to make the recipient feel indebted**

## 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 is the 'settling down' period and when most problems tend to occur. Once these three months have passed, both the donor and the recipient can start to resume a normal routine.

Depending on their work or lifestyle commitments and the type of surgery, donors can expect to be at home recuperating after the operation for 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.

**The donor should allow between six to twelve weeks, depending on the type of surgery, to get back to full activity**

If the donor regularly sees the recipient, this can be an added source of satisfaction – watching the recipient return to good health can ease some of the possible negative feelings.

“After a week in the unit, I was allowed home. A follow-up six weeks after the operation ensures that blood and urine tests have returned to normal. It is also made very clear that if anything crops up at home that causes concern, there is always someone available at the transplant unit to answer questions and provide support,” comments Elizabeth.

“It is now about six weeks since the operation and I am feeling a lot more like my old self. I still experience quite a bit of discomfort from the wound site, especially when in bed – turning over still requires some care – and I usually make sure I take some pain relief before going to bed. I also find it difficult to walk very far. I am trying to increase the distance I walk a little each day and there is no doubt that I am improving,” notes Christine.

## Driving

The Driver and Vehicle Licensing Agency (DVLA) has no hard and fast rules with regard to starting to drive again. Generally, if the donor feels well and capable, he/she can usually return to driving after four to six weeks. Long journeys could be problematic and so he/she 'shouldn't overdo things'. It is sensible for the donor to seek advice from the transplant team or GP prior to getting back in the driving seat. 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. A 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 needs a transplant and you want to help, please ask to speak to the living donor transplant coordinator, the transplant surgeon or kidney specialist at the hospital where he/she is being treated. They are very experienced and will be happy to spend time discussing your questions before arranging a meeting with the transplant surgeon or kidney specialist.

Living donor transplant coordinators are responsible for ensuring that the preparation and administration of the donation and transplant operations run as smoothly as possible. They provide liaison with all members of the healthcare team and continuity for patients and their families throughout the assessment process and admission for surgery.

You can contact the following organisations for advice:

### **Human Tissue Authority**

Finlaison House, 15-17 Furnival Street,  
London EC4A 1AB

**Helpline:** 020 7211 3400

**E-mail:** [enquiries@hta.gov.uk](mailto:enquiries@hta.gov.uk)

**Website:** [www.hta.gov.uk](http://www.hta.gov.uk)

### **National Kidney Federation**

The Point, Coach Road, Shireoaks,  
Worksop, Nottinghamshire S81 8BW

**Telephone:** 01909 544 999

**Fax:** 01909 481 723

**E-mail:** [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk)

**Helpline:** 0845 601 0209

**Website:** [www.kidney.org.uk](http://www.kidney.org.uk)

### **National Kidney Research UK**

Kings Chambers, Priestgate, Peterborough PE1 1FG

**Telephone:** 0845 070 7601

**E-mail:** [enquiries@kidneyresearch.org.uk](mailto:enquiries@kidneyresearch.org.uk)

**Helpline:** 0845 300 1499

**Website:** [www.kidneyresearch.org.uk/](http://www.kidneyresearch.org.uk/)

### **Transplant Support Network**

6 Kings Meadow Drive, Wetherby,  
West Yorkshire LS22 7FS

**Telephone / Fax:** 01937 585 434

**E-mail:** [tsnetwork@tiscali.co.uk](mailto:tsnetwork@tiscali.co.uk)

**Helpline:** 0800 027 4490/91

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

### **The British Transplantation Society**

Association House, South Park Road,  
Macclesfield, Cheshire SK11 6SH

**Telephone:** 01625 504 060

**E-mail:** [secretariat@bts.org.uk](mailto:secretariat@bts.org.uk)

**Website:** [www.bts.org.uk](http://www.bts.org.uk)

### **NHS Blood and Transplant**

Fox Den Road, Stoke Gifford, Bristol BS34 8RR

**Helpline:** 0845 60 60 400

**E-mail:** [enquiries@nhsbt.nhs.uk](mailto:enquiries@nhsbt.nhs.uk)

**Website:** [www.uktransplant.org.uk](http://www.uktransplant.org.uk)

## Glossary

### **AIDS**

Acquired Immune Deficiency Syndrome

### **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

### **CMV**

Cytomegalovirus - a herpes virus

### **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

### **CT**

Computerised tomography – a specialised x-ray

### **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

### **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

### **GFR**

Glomerular filtration rate describes the flow rate of filtered fluid through the kidney

## **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

## **HTA**

The Human Tissue Act 2004 which will be enacted in April 2005. 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

## **Hypertension**

High blood pressure

## **IA**

Independent Assessor – trained and accredited by the HTA to assess certain types of living organ transplantation in the UK

## **IVP / IVU**

Intravenous Pyelogram / Urogram – a specialised kidney x-ray

## **MRI**

Magnetic resonance imaging – a detailed scanning technique

## **Nephrectomy**

The name of the surgical operation to remove a kidney

## **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

## Acknowledgments

The Association of the British Pharmaceutical Industry (ABPI)/National Health Service (NHS)/Department of Health (DH)/Association of Renal Industries (ARI)/Industry Renal Task Force would like to offer a special thank you to Lisa Burnapp and Jen Lumsdaine (see below) for all their time and hard work producing this new resource.

We would also like to thank the following people for their contribution to the completion of the original versions of this publication. Their hard work and dedication has been appreciated at all stages of the booklets' development.

### **Andrew Bradley**

Professor of Surgery, Addenbrooke's Hospital, Cambridge

### **Lisa Burnapp**

Consultant Nurse, Living Donor Kidney Transplantation, Guy's and St Thomas' NHS Foundation Trust

### **Marie Cummins**

Clinical Nurse Educator, Norfolk and Norwich University Hospital

### **Chris Dudley**

Consultant Nephrologist, Southmead Hospital, Bristol

### **Rose Elwell**

Transplant Coordinator, Leicester General Hospital NHS Trust

### **John Forsythe**

Consultant Transplant Surgeon, The Royal Infirmary of Edinburgh

### **Kay Hamilton**

Transplant Coordinator, Southmead Hospital, Bristol

### **Veronica Lennon**

Transplant Coordinator, Sheffield Kidney Institute, Sheffield Teaching Hospitals NHS Trust

### **Jen Lumsdaine**

Transplant Coordinator, The Royal Infirmary of Edinburgh

The members of the United Kingdom Transplant Coordinator's Associations (UKTCA) Education Sub Committee and their colleagues.

The following people for helping us understand what it is like to be involved in the living donor kidney transplantation process: Richard and Christine from Bristol, Joyce and Elizabeth from Edinburgh, Ken from Kettering, Robert from Leicester, David from Edinburgh and Paul from Sheffield.

This booklet has been developed as part of the Gift of Life campaign. This initiative is sponsored by an educational grant from Astellas, Novartis Pharmaceuticals UK and Roche, working in conjunction with NHS Blood and Transplant, Guy's Hospital London, the Association of Renal Industries and the Department of Health.



**Organ Donation**  
**Gift of Life**