

# **KIDNEY DONATION:**

# All You Need To Know

Organ donation, Gift of life



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Introduction



The treatment for people with kidney failure options are **dialysis**, and/or **transplantation**. A successful kidney transplant is the best treatment for many patients with established kidney failure, from a medical, psychological and social point of view.

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 donations.

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.

The information in this booklet is not a replacement for face-to-face meetings between the transplant team, the prospective doctor, 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.

It is hoped that this information will help you gain 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?

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 aslo 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 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 transplant 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.

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. Inorder to safeguard the interest of the donor, all donors and recipients must see an independent assessor (the counsellor or social worker) who is independent of their health care teams before the transplant operation can go ahead.

The independent assessors (IA) (counsellors) 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 and testimonies are available. They also make 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.

The human tissue act allows more flexibility in who can be a living kidney donor and who can donate to whom.



In most cases, 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. The physician will be able to assess the unsuitability of some donors if they are 18 years of age.

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.

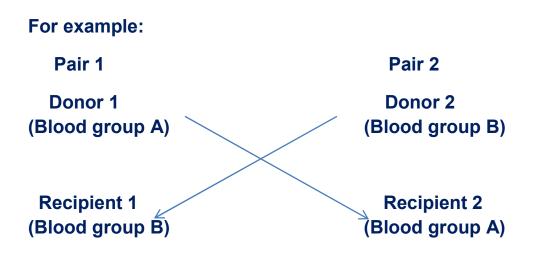
For the parents of children requiring a transplant, the decision may be more straightforward, but even here loyalties may be divided between the desires to provide for one child, while inevitably depriving other children of a parent for a period of time. This is not a trivial consideration, as the transplant may come after prolonged illnesses for the affected child, during which other children may come 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.

#### Paired or Pooled Donation (Not currently available in Kenya)

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.





#### Non-directed Altruistic Donation (Not currently available in Kenya)

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 are very different from the usual living donor scenario.

It is essential that anonymity and confidentially 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.

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 feel so that they are prepared for any eventuality and consequence that may ri vse.

#### 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. Tests will be done 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. 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.



#### What makes a donor suitable?

In Kenya, the following conditions must be met for a person to become a donor:-

- 1. The potential donor and recipient had to be blood group compatible
- 2. The 'crossmatch' 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 (sensitized) which causes a 'positive' or unsuitable '**crossmatch**'.

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. Before anything else, the blood group of the donor and the 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				
0	0			
A	O or A			
В	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 'crossmatch'. 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.

# 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 an exception of CMV and EBV, if any of these viruses are detected, the transplant cannot usually take place due to 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.

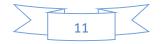
However, in immunosuppressed recipients, CMV and EBV infection may cause symptoms that range from a mild influenza-type illness to more serious infection, particularly in patients who may not have previously encountered the virus. Modern antiviral drugs can help combat CMV infection and knowing whether the donor and recipient have been previously exposed to these viruses before the transplant means that the recipient can be monitored more closely afterwards.

# 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.

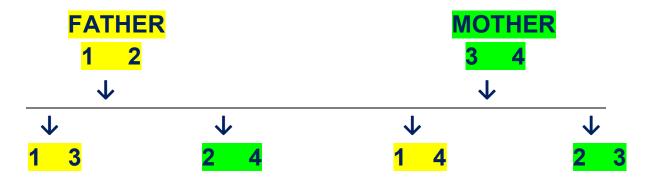
# What are marker proteins?

Each of our body's 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 for 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 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. 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?

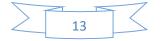
Checking that a donor is both suitable and healthy is an in-depth process usually taking 3-6 months. Rigorous tests ensure that the transplant team is as certain as possible that the transplant will be safe and successful for both donor and recipient. It also gives potential donors plenty of time to 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.

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.

# **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.

#### 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 **nephrectomy** (removal of a kidney) are usually relatively minor and can be treated appropriately. These include wound, urinary tract and chest infection, 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 minimize 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.

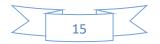
While the donor is undergoing assessment, an unexpected abnormality may show up. This can be a shock to the doctor and may have implications for future life and medical insurance. The transplant team is always there for support and referral to the appropriate specialty will be organized. Another way 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, infact 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.
- 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 recognize 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.

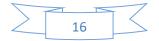
After the operation, recipients are free from dialysis

Most recipients manage to return to work following the transplant. In fact, most of them work full-time, or 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 him/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 dysfunction, 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 counseling can be provided before and after the test.

Another blood sample will be taken from both 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 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 is used to assess kidney function.



#### 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.

#### Chest x-rays

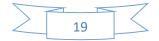
A chest x-ray will be done to look out for any hidden disease like tuberculosis.

#### Renal ultrasound

This is a non-invasive scan that checks the size, number and shape of the kidneys, and can exclude any anatomical abnormalities. If you have only one kidney you will not be able to be a donor.

#### **Renal angiography**

Mostly CT or MRI angiographies are used 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.

# What other practical aspects need considering?

The financial burden associated with donating a kidney frequently including 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 the 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.

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

#### 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
- Book or magazine to read
- Small change for the telephone/newspaper

# Who are all the different people involved in the process?

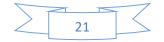
There are many different people in the transplant team and each has a specific role:

#### 1. Transplant coordinator/Living donor coordinator

She/he represents the hub of the team and is responsible for ensuring that the individual aspects of identifying a donor, all predonation 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. He/she will coordinate every stage to make sure that everything proceeds as smoothly as possible.

#### 2. Consultant kidney specialist (Nephrologist)

He/she 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.

#### 3. Consultant transplant surgeon

He/she is the one who removes and/or transplants the kidney. In some places, the same surgeon will perform the removal and transplantation of the kidney, while in other places each operation will be performed by different surgeons. 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.

#### 4. 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.

#### 5. Theatre Nursing Team

They ensure that all the necessary items required in the theatre are available and up to date.

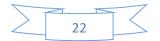
#### 6. Transplant nurse practitioner

She/he cares for the recipient after their operations

#### 7. 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.

#### 8. Counsellor



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

#### 9. Pharmacist

The hospital pharmacist will be able to offer you pain relief advice as appropriate and advice on transplant medications and other medications you may be taking.

#### 10. Laboratory team

They ensure all the tests required will be available and results promptly relayed to the doctor.

#### 11. Radiology

They report on all the radiological test done and discuss with members of the team of any abnormalities found.

# 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

Identify suitable donor with compatible blood group

#### $\mathbf{1}$

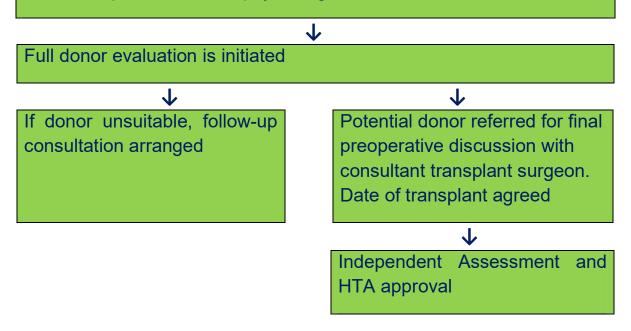
Begin appropriate pre-transplant assessment to establish ABO compatibility +/- HLA sensitization and identify whether the recipient is fit for transplantation from previous medical history

# $\mathbf{1}$

Initial discussion with potential donor and recipient about the issues involved in kidney transplantation. Potential donor provided with information and the opportunity to discuss the operation with a past donor

# $\mathbf{1}$

Counsellor facilitates discussion with the potential donor and recipient to discuss possible social, psychological and medical risk factors



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#### $\downarrow$

Final cross match in one week prior to transplantation, routine pre-op investigations/preadmission visit

 $\checkmark$ 

Final transplant team meeting and meeting with the donor and recipient.

 $\downarrow$ 

Recipient is adviced to start some of the immunosuppression medications before date of transplant.

 $\downarrow$ 

Admission to hospital for donor at one day before and recipient at least two days before date of surgery

 $\downarrow$ 

 $\checkmark$ 

CNI monitored and adjusted appropriately before surgery

Transplant/donation procedure usually takes two to four hours each for donor and recipient but times may vary

 $\checkmark$ 

Discharge from hospital after about 5 days for the donor and 10 days for the recipient

 $\downarrow$ 

Transplant coordinator maintains contact with donor and facilitates life-long follow-up arrangements

#### In general, the donor assessment process takes at least three months and is tailored to the needs of the individuals concerned

# 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 minimized.



There are two types of surgery which can be performed; open and laparoscopic nephrectomy.

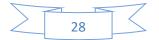
#### How long does it take to recover?

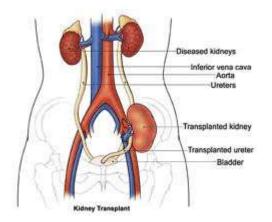
**Open nephrectomy:** A donor's stay in hospital is usually between 5 - 7 days. He/she can expect to be out of bed the day after the operation and home within 1 week. Some surgeon's uses stitches or clips to close the skin around the incision made during the operation. These are usually removed 10 days after operation. Sometimes a special kind of stitch is used; these stitches are not removed because they dissolve gradually by themselves.

**Laparoscopic nephrectomy:** A period of 4 - 6 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 within the first few weeks following the operation to ensure that they are recovering well.

#### The kidney transplant

The kidney is put into the recipient's outer pelvis low down and to one side of the bladder. 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 1 - 2 days. After only a few days, most or all of the various tubes necessary for the operation will be removed. Sometimes before, but always during and after the transplant, medication to suppress the immune system will be necessary.

#### Anti-rejection medications are given to the recipient

Anti-rejection medications will help the recipient's body to tolerate a 'foreign' organ. In early stages, the medication may be in the form of infusions as well as tablets; later this will change to tablets only.

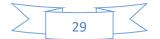
Although the dosage may be reduced over time, this medication will have to be taken by the recipient for the entire life of the transplant.

The most anxious time for both recipient and donor is the wait to see if the new kidney functions well. Depending on how successful the transplant has been, the recipient can usually expect to leave hospital 1 - 2 weeks after the transplant has been performed, by which time, he/she will probably already be feeling the benefit of the operation.

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

#### Recipient soon feels the benefit of their new kidney

How 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 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 case donors may need additional help and support, including counseling, which can be arranged.

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

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.

# Getting back into a routine

The success of the transplant is judged by how well the transplanted kidney works and how quickly the patient returns to full health. The first 3 months



after a transplant is the 'settling down' period and when most problems tend to occur. Once these 3 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 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 6 - 12 weeks 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.

Driving: Generally, if a donor feels well and capable, he/she can usually return to driving after 4 - 6 weeks. Long journey could be problematic and so he/she shouldn't overdo things. It is sensible for the donor to seek advice from the transplant team prior to getting back in the driving seat.

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 transplant coordinator, 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.

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 number:

Parklands Kidney Centre 3<sup>rd</sup> Parklands Avenue Parklands Mediplaza, 2<sup>nd</sup> floor P.O. Box 963 - 00606 Nairobi, Kenya Helpline: +254 (020) 264 1853, 3752727, 3740397 Fax: +254 020 375 2726 Mobile: +254 723 889 612 Email: <u>info@pkckenya.com</u>, <u>admin@pkckenya.com</u> Website: www.pkckenya.com

Mombasa Dialysis Centre Sajjad M. Rashid Road, Kizingo P.O. Box 90106 - 80100 Mombasa, Kenya Helpline: +254 (020) 4123 19958 Mobile: +254 718 900 400 Fax: +254 4123 19960 Website: www.mombasadialysis.com

Glossary

AIDS



Acquire 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 scan

Computerised tomography - a specialized x-ray

#### **Deceased donor**

A deceased donor is a person who may have expressed a wish to give his/her organs after dying to help someone, and his/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 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**

Hepatitis is inflammation of the liver usually as the result of a viral infection like Hepatitis B or c. It can also be the result of certain medications

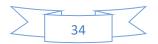
HIV Human Immunodeficiency Virus

HLA Human Leucocyte Antigen

Hypertension High blood pressure

#### 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/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 the recipient, and thereby evaluate the closeness of their compatibility (i.e whether they 'match')

#### Transplant

This term is used for 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

