



LIVE KIDNEY DONOR INFORMATION

BEAUMONT HOSPITAL

INTRODUCTION

For patients with kidney failure, the treatment options are dialysis and, in suitable patients, transplantation. Kidneys for transplantation come either from people who have donated their organs after death, or from a living donor – a living donor may be a relative, spouse, or close friend. This booklet has been written to give information to those considering live kidney donation. More information is always available from the Transplant Surgeon and Transplant Co-ordinators in Beaumont Hospital, telephone 8092298, 8093119.

This booklet has been prepared to make sure that all prospective live donors and their families can have the opportunity to read about the risks, benefits, investigations, procedure and follow up associated with donating a kidney. Everything covered in the booklet will be discussed on a personal level by the medical staff. The booklet is in no way a replacement for a face-to-face meeting between the transplant team, the prospective donor, the recipient and their families.

LIVING DONATION

A successful renal transplant is the best treatment for many patients with end stage kidney failure, from the medical, psychological and social points of view.

In Ireland, the majority of transplanted kidneys are from those who have been declared brain stem dead. This occurs in hospital intensive care units and often as a result of spontaneous brain haemorrhage or after a road traffic accident. Such donors are called deceased donors.

However, live donor transplantation is also performed in a small percentage of cases.

Since the make-up of the body within families can be similar, or more rarely – as in the case of identical twins – identical, the likelihood of the recipient's body rejecting the new kidney is less. Therefore there is a greater chance of a successful kidney transplant if the kidney is donated by a living relative. The advantage of live kidney donation is that live donor organs are transplanted with no storage, therefore the kidney will be without blood supply for a

shorter time, thus increasing the chances of a successful transplant. These advantages are also true for donors who are not genetically related to the recipient and so it is worth exploring this possibility.

One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will hamper them in later life. A healthy person can live a completely normal life with only one kidney, indeed, some people are born with only one kidney. If a kidney is removed, the remaining kidney increases slightly in size and capacity, and can carry on the function of two kidneys. Therefore it is possible to remove one kidney from a healthy living person and transplant it into someone who needs it, with no ill effects on the donor other than the operation itself. 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 effect on health.

WHAT DOES A POTENTIAL LIVING DONOR NEED TO CONSIDER?

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

It is worth remembering that the operation to remove a healthy person's kidney carries the same risk as any major surgical procedure. Although all possible precautions are taken, there is always a risk when undergoing surgery.

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

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

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

WHO CAN DONATE A KIDNEY?

Generally, a close relative, spouse, partner, or close friend who has demonstrated a longstanding emotional relationship can also consider becoming a donor. Donors are usually brothers, sisters or parents of the patient, less often other close relatives such as uncles, aunts, grandparents, sons or daughters.

Whoever becomes a donor must be over 18 years of age. There is no strict upper age limit in donating a kidney, but there is less chance that an older person will pass the medical examination necessary before donation is judged to be safe. As with many things, progressing age can bring additional uncertainties. Size of the kidney is also a factor to be considered, and young children who require a transplant can be too small to take a full size adult kidney.

Although, one might think that most family members would want to give a kidney, life is not nearly so simple. Donation between brothers and sisters can present some psychological

problems. A large amount of potential pressure can be brought to bear on individuals, which should be avoided.

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

The transplant team is fully aware of all the problems – psychological or otherwise – in volunteering as a potential 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 graft in honest terms. It is very important that before volunteering, and throughout the assessment process, close members of the family fully understand the process and consider all the risks and implications. Every family thinking about a living donor transplant, must openly discuss how they all feel, especially if the kidney were to fail and all the subsequent feelings and consequences that may arise.

It is important to consider the financial implications following donation such as salary protection for recovery out of work, life insurance, mortgage repayments etc.

WHAT MAKES A DONOR SUITABLE?

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

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

Recipient Blood Group:

O
A
B
AB

Donor Can Be:

O
O, A
O, B
O, A, B, AB

A suitable match of blood groups like this is necessary before any further assessment can be considered. Since family members may have different blood groups, it may not be possible for some family members to give a kidney.

Another blood test that must be undertaken fairly early in the process is to check the donor for virus. A potential donor's blood will be examined for the presence of antibodies to certain viruses, such as Hepatitis B & C, HIV and CMV. With the exception of CMV, if these viruses are detected, transplantation cannot normally take place due to the risk of disease transmission. CMV can be transmitted during transplantation. Recipients can be affected – from mild flu like symptoms to serious pneumonia – but usually modern anti viral drugs can help combat it.

To be quite sure that a potential donor will be able to offer an adequately functioning kidney to the recipient, be fit enough to undergo the operation and live normally with just one kidney, they must be in excellent physical condition and have a clear medical history. If tests show evidence of poor kidney function or if investigations show the possibility of

the donor being medically unsuitable, the donation would be refused.

An important issue regarding suitability of a potential donor is tissue type compatibility. The tissue type of an individual is determined by the type of 'marker' proteins on the surface of cells. These proteins can be varied. The higher percentage of these proteins that match, the greater the likelihood of a successful transplant.

The process of checking the suitability of a donor is a long, but in-depth one. To be as certain as possible that the transplant will be successful – for both recipient and donor – this extensive procedure is necessary and also gives the potential donor plenty of time to consider his/her options.

HOW COULD I VOLUNTEER?

It is usually the case that the potential recipient has already been on the transplant waiting list for some time and the prospective donor has witnessed a decline in their condition or seen the disruption to the individual's and the family's lifestyle that dialysis can bring.

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

Direct personal communications are the key to making sure living kidney donation can be successful, both for donors and recipients. The most suitable person for the potential donor to approach is the transplant co-ordinator or the transplant surgeon. They can often help to begin the whole long and complicated process involved with donating a kidney.

RISKS AND BENEFITS FOR DONORS AND RECIPIENTS

Recipient Benefits

- The main benefit to the recipient of a successful kidney transplant is freedom from dialysis, energy levels return to normal and they feel 'well' again.
- Although a transplant recipient will always have to take medications to prevent rejection, most aspects of their lives can return to normal. The majority of patients will return to work full time.
- Long term graft survival rates over 10 – 20 years are very good for kidneys from living related donors.

Recipient Disadvantages

- As with any surgical procedure, there are risks involved. However, when a living kidney is transplanted, because of the immediate transfer and optimum condition of

donor and recipient, the risk of death is less than two to three cases per thousand.

- Poor blood supply to the kidney or severe rejection can cause failure and great disappointment to everyone. However, it is estimated that 90% of live kidney transplants are still functioning at one year and many patients are fit and well twenty years on. Studies have shown that 10 years after living related transplantation approximately 80% of grafts are still working as opposed to 50% from a cadaveric transplant.
- Psychological problems can arise within the family for the proposed recipient as well as the donor. They may feel under pressure from other family members – even the donor – to go ahead with the procedure. It is a topic that needs to be discussed at length with all members of the family. It is not to be forgotten that the recipient may feel a tremendous sense of guilt about the donor and this needs to be accepted and spoken about.

- One of the most common psychological problems that a recipient may have to endure is fear – fear of graft failure and the knowledge that someone has made a major sacrifice on their behalf for the outcome not to be successful. By discussing these feelings openly, and all accepting that this is a possibility, some of the psychological problems of failure can be avoided.

Donor Benefits

- A prospective donor is likely to have experienced some practical or psychological adaptations that needed to be made to their own lifestyle i.e. as a sibling these could include greater domestic responsibilities, possibly feeling ‘less loved’ because the parents may appear to centre all their attention on the less well child and/or pain at seeing a brother/sister suffering.
- The main benefit of donating a kidney is purely a psychological one. The sense of satisfaction at giving a loved one the most special of gifts cannot be measured by words.

Donor disadvantages

- Any patient who has a general anaesthetic or a major operation runs a slight risk, but all the tests that are done before the operation try to ensure that this risk is made as small as possible.
- The removal of a kidney involves a rather more difficult and uncomfortable operation than the transplant operation. It involves a certain degree of post operative discomfort which can be kept under control by painkillers. However, the potential donor should keep in mind that they could feel less well after the operation than the recipient.
- While determining the suitability of a potential donor a test could show an unexpected abnormality which could indicate the potential donor as being a sufferer of a previously undiscovered condition.

- After the operation, the donor may experience a sense of anticlimax and may be at a slightly higher risk of depression.
- A psychological problem for the donor might be how he/she will face their future with only one kidney. Although it is known that most of us can quite happily live with just one kidney – there is the tendency for us to want the ‘assurance’ of the second, in case of serious accidents or illness.
- The issue of possible graft rejection or failure needs to be thought about very seriously. As we know, no matter how many tests are undertaken beforehand, there is still a risk that the transplanted kidney will fail and the recipient will have to return to dialysis.

Prior to consenting to donation, it is important to be aware of the potential risks of donor nephrectomy.

1. The risk of death (estimated to be approximately 1 in 1600 – 3300 cases)

2. Idiosyncratic reaction to anaesthetic or other drugs.
3. The general complications of major abdominal surgery
i.e.
 - a) Venous Thromboembolism
 - b) Intraabdominal bleeding and abscess formation
 - c) Wound complications
 - d) Chest complications
 - e) Urinary retention/urinary infection
 - f) The possible need for blood transfusions
 - g) Risk of adhesive small bowel obstruction
4. The possibility of short and long term wound pain
5. The need for a recovery period of between 4-12 weeks.
Potential donors should check their sick leave entitlement with their employers.
6. The possibility of increase in blood pressure and proteinuria.
7. The possible psychological after effects of donation.
8. The psychological impact on the donor of recipient death or premature transplant failure and vice versa.
9. The need to check the implications of donation with their insurance agency

**ASSUMING BLOOD GROUP AND TISSUE TYPE
COMPATIBILITY, WHAT FURTHER TESTS ARE
REQUIRED?**

There are a sequence of tests that are necessary to thoroughly examine the health of the potential donor as well as the function and anatomy of the kidney. The following is an example of the types of tests that a potential donor can expect.

Blood Pressure: To exclude hypertension

Urine Analysis: To identify any underlying conditions

Blood Tests: For routine analyses. Another blood test will be taken from both donor and recipient to check the recipient does not have antibodies which may react to the donor. This test will be repeated just before the operation.

Creatinine Clearance: If the kidneys are not functioning well the creatinine level rises. By measuring the creatinine and the amount being excreted in the urine, a more precise assessment of kidney function can be made.

X-Rays: A series of x-rays, especially of the chest area, are taken to ensure normal function.

ECG: A cardiograph of the heart function is recorded to exclude heart disease.

GFR: This is to assess the capability of the kidney to 'clear' the blood of a toxic substance.

Ultrasound: This is a scan which checks the size and shape of the kidneys and excludes anatomical abnormalities.

KUB: X-Ray of kidneys

Renal Angiogram: This is the most invasive test which involves an injection of dye into one of the large arteries. A special kind of x-ray is used to reveal all the details of the kidneys and the vessels going to and from them. This is important for the surgeons to see which kidney to remove and which has the easier access for them.

Spiral CT Scan:

WHO ARE ALL THE DIFFERENT PEOPLE INVOLVED

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

Transplant Co-ordinator

The co-ordinator is responsible for ensuring that the individual aspects of identifying a donor, pre-donation assessments and actual operations run smoothly. She will be aware of what stage has been reached and who is responsible for which part of the process. Simply put, she will co-ordinate everything to make sure the whole system can proceed as easily as possible.

Transplant Surgeon

A team of senior transplant surgeons, one for the donor and one for the recipient, with other surgeons to assist, will perform the operation. The transplant surgeons must ensure that all the results of tests point to a successful transplant. They must also be sure that the donor and recipient are fit to undergo surgery with the minimum risk. The surgeon who

removes the kidney carries overall responsibility for ensuring the safety of the donor.

Consultant Nephrologist

The Consultant Nephrologist is the one, together with the Consultant Transplant Surgeon, who has to be sure that the transplanted kidney would be likely to restore the health and reasonable lifestyle of the intended recipient, and that the donors health would not suffer as a result.

Consultant Anaesthetist

It is the responsibility of the anaesthetist to administer the anaesthetic and to ensure the health of both patients during the surgical procedure.

Physiotherapist

After any form of surgical procedure, returning to full activity can be an uphill struggle. The physiotherapist can

frequently advise on methods of making rehabilitation easier.

Psychologist

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

Follow UP

Follow up @ 3 weeks and 3 months by donor Surgeon
Annual follow up by living donor nephrologist

WHO MAKES THE FINAL DECISION?

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

All test results will be reviewed by the transplant surgeons and the operation will not go ahead until all these results are satisfactory.

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

Despite all the tests, there is a small risk that the transplanted kidney may be rejected by the patient during the first year.

At any time, a potential donor is free to raise specific concerns which they may not wish to share with other family members or the intended recipient. Equally, at any

time, the donor is completely free to withdraw. The reasons for doing so will be kept confidential.

Sometimes taking to someone else who has been a live donor can be helpful as they have personal experience of the donation, and this can be arranged.

THE OPERATIONS

The Nephrectomy (removal of kidney)

Under general anaesthetic, the kidney is removed by an operation in the same way as if the kidney was diseased. Most surgeons removed the kidney through an incision in the side, other surgeons prefer to remove the kidney through an abdominal incision. The kidney is lifted out of the wound and flushed with a cold solution to wash out blood and slow the metabolism before being carried into the adjacent operating theatre in which the recipient is waiting.

The incision is then sewn up and the donor is then transferred to the recovery room and subsequently the ward. Sometimes a temporary drain is fitted near the wound. Fluids can be administered via a drip and because the incision can be painful afterwards, injections of infusions of pain killers can be added to this. A catheter is inserted in the bladder. Tubes are usually removed after the first day and the donor is encouraged to get up and sit in a chair.

A donor's stay in hospital is usually between 7 and 10 days. They can expect to be out of bed the day after the operation and home in less than two weeks. The stitches are removed approximately 10 days post surgery. The wound may remain sensitive for several weeks. Sometimes a small area of numbness may be noticed on the skin of the abdomen, because small nerves have been cut by the incision at the side. However, the scar should be the only permanent reminder of the donor operation. The donor will have to take 8 – 12 weeks away from work to recuperate, depending on the individual and their occupation.

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 is advisable to ensure there are no long term side effects.

The Kidney Transplant

The kidney is put into the outer pelvis – protected by the hip bone – low down and to one side of the bladder, and the blood vessels of the kidney are joined to the large blood vessels supplying the leg. The kidney lies here away from the intestines and their covering and the ureter can more easily be sewn into the bladder.

The recipient should be out of bed within a day or two. After only a few days, most or all of the tubes will be removed. Medicines to suppress the immune system will be necessary. These drugs help the recipient's body to tolerate a 'foreign' organ. In the early stages, the medication may be in the form of infusions, later this will change to tablets. This medication will have to be taken by the recipient for the entire life of the graft.

The most anxious time for both donor and recipient is the wait to see if the new kidney functions well. Depending on how successful the transplant has been, the recipient can expect to leave hospital between one and three weeks post

surgery. By this time, they will usually be feeling the benefit of the transplant. Initially, recipients will have to be seen quite frequently in the out patients clinic but this becomes less frequent as time progresses.

WHEN TO RESUME NORMAL ACTIVITIES

Driving

There are no hard and fast rules with regard to driving again. In the main, if the donor feels okay and their doctor agrees to it, a donor can return to driving when they feel capable – usually after 4-6 weeks. However, they must be aware that long journeys could prove problematic and that they shouldn't overdo things. They should also check with their car insurance company that they are insured to drive.

Sexual Relationships

There is no standard typical period before sexual intercourse can be considered. 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 individual and their recuperation.

Exercise

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

If you require any further information or would like to discuss the option of living related transplantation, please contact the Transplant Co-ordinator, Beaumont Hospital, at 01-8092759/01-8092298.