# kidney donation by live donors

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SHPN (GMTT) 040163
ISBN 0 7347 3709 2

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October 2004

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# Purpose

This guide has been compiled to provide information about the process of live kidney donation to people who are thinking about becoming live kidney donors and to their families.

The guide provides a general overview of live kidney donation in the state of NSW, Australia. Any detailed information you require will be available from the Transplant Team at the specific hospital where the transplant surgery will be performed. (A list of Major Renal Treatment Centres appears on p 34).

## Acknowledgment

This guide has been produced by a sub group of the Greater Metropolitan Transition Taskforce (GMTT) Transplant Working Party.

Many people have contributed to the writing of this document. Our special thanks is extended to the staff of Renal Units at Monash Medical Centre, Royal Prince Alfred, Westmead, Royal North Shore, John Hunter, Prince of Wales, Christchurch (New Zealand) and Princess Alexandra Hospitals for sharing their knowledge and resources with the GMTT Transplant Working Party.

30 June, 2003

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# Introduction

**Live kidney donation is a gift. A gift by choice and not by chance. It is a gift of a normal functioning kidney from one living human being to another.**

Live kidney donation is usually charged with lots of emotion. Giving an organ to enhance another person's life is a momentous event!

This guide is designed to provide information for potential donors and their families about the live kidney donation process – to help them understand the potential risks and benefits and to provide some road signs for the journey.

The incentive to donate a kidney to a loved one or friend is strengthened by the knowledge that a successful transplant will end the recipient's dependence on dialysis and help them and their family to return to a more normal lifestyle. Although live kidney donation can be a very rewarding experience, not everyone will feel comfortable about it.

It is entirely normal to feel apprehensive at the thought of donating a kidney. The decision to proceed with live kidney donation is a very personal one and should not be influenced by anyone – not the potential recipient, nor their family, nor any member of the transplant team. **It is your decision alone**.

The removal of a healthy and normally functioning kidney is no small undertaking. You have no need for the operation to maintain your own health and there are inherent risks with any surgery.

We hope that this guide will help you as you consider live kidney donation. The booklet is unlikely to answer all of your questions. You may wish to use the space at the end of the booklet to note any questions you may have after reading it, for discussion with members of the transplant team.

**Remember that it is your decision....**
**It's OK to say NO!**

# Ethics

There are many ethical considerations regarding live organ donation. Some of the most commonly asked questions are listed below.

***Is it right to remove a perfectly healthy organ from one person and give it to another, when the medical and surgical procedures will not make the live donor feel better?***

This has been widely debated by doctors, consumers, ethicists and many others. It is generally accepted that if there is no evidence of pressure or coercion or the offering of money or incentives by other parties, then the potential donor is making an independent, altruistic decision to donate a kidney. If the donor is fully informed about the procedure and is assessed as physically and psychologically well, then the live kidney donation may proceed.

**Donor mother and recipient son**

***What are the financial motives and implications for live kidney donation?***

In Australia it is illegal to provide an organ in exchange for money. Recipients are not allowed to reimburse live donors for loss of wages or costs incurred. Such reimbursement could be interpreted as an incentive for donation.

***What kinds of pressures are put on potential live donors?***

Live kidney donation must be truly altruistic (see Glossary). There are strict conditions governing live kidney donation. The transplant team will discuss these with you.

The person offering to be a live organ donor must be:

- psychologically stable
- freely willing to donate
- free from any coercion
- medically and psycho-socially suitable
- fully informed of the risks and benefits
- fully informed of the effectiveness of current dialysis treatment available to the recipient.

The benefits to both donor and recipient must outweigh the risks associated with the donation and the transplantation of the live organ.

Donor wife and recipient husband

**Having said all this, it is important for you to know that if you change your mind about donating your kidney, your confidentiality will not be compromised. The reasons why you are not proceeding as a donor will not be revealed.**

# Who can be a live kidney donor?

For every transplant, there are two participants: the **donor** (the person donating) and the **recipient** (the person receiving).

A kidney donor may be either a **living related donor** (ie a relative) or an **unrelated donor**.

A living related donor is commonly a parent, brother, sister, grandparent, daughter or son of the recipient, or may be more distantly related to the donor, such as a cousin, uncle or aunt.

In recent years it has been accepted that **unrelated donors** may donate a kidney. An unrelated donor may be a husband, wife, partner or close friend of the recipient. These donors are often described as 'emotionally related donors'.

The alternative to live kidney donation is for the recipient to wait until a suitable kidney is available from a deceased donor.

Live **non-directed** kidney donation is a new practice in NSW, with the guidelines having recently been developed (by NSW Health and the Transplant Advisory Committee). It is a relatively new practice worldwide.

Like the practice for living related donors, all criteria of suitability need to be met including the mandatory psychological assessment, and the work-up as outlined in this document.

The difference between the live-related donation and the live **non-directed** donation is that the live **non-directed** kidney is donated to a person in NSW waiting for a kidney transplant. The **non-directed** live donor will have no say in determining who will or who will not receive the kidney.

The allocation of a live **non-directed** kidney donation will be to a consenting recipient in NSW according to the same allocation formula used for the deceased donor kidney.

As is the process for deceased donor donation, the donor's and recipient's anonymity is maintained throughout the donation and transplantation process.

The policy for live non-directed donation will be reviewed in two years.

# What are the advantages of a live donor kidney transplant?

- The gift of a kidney provides a significant boost in the quality of life of the recipient.
- Avoidance of lengthy dependence on dialysis for the recipient, whilst waiting for a transplanted kidney from a deceased donor.
- The transplant can be scheduled to take place before the recipient requires dialysis.
- The possibility of receiving a perfectly matched kidney from a relative.
- In live donor transplants, the period that the kidney is without blood supply and 'on ice' is shorter. This means that the live donor transplanted kidney usually works immediately.
- Statistically, results from live donation are better for recipients than kidney transplants undertaken with kidneys from deceased donors. (See ANZDATA Registry website for current statistics – www.anzdata.org.au)
- Live kidney donation can be a rewarding experience for both donor and recipient.
- The transplant can be scheduled in the operating theatres at a time that is suitable for the donor, the recipient and the transplant team.

**Donor and recipient friends**

Photo courtesy Central Sydney Area Health Service

# What are the disadvantages of a live donor kidney transplant?

- There are no guarantees that the kidney transplant will work, or for what length of time.
- The donor will need to take time out from their normal routine to attend hospital consultations and tests, to undergo the surgery and during their recovery period.
- The operation, like any surgery is 'not without risk'. However, every effort is made to minimise these risks.
- The ownership of the kidney shifts from the donor to the recipient. The donor has no control over the organ once it has been removed and transplanted.

**Donor and recipient friends**

Photo supplied by *The Sun Weekly*

# The donor's transplant team

The transplant team is made up of many people who all work together to support and educate you and your families about the donation process. This care does not stop at the time of donation. The same team will continue to monitor your health after the donation has occurred.

Staff involved in the transplant team are listed below with a brief description of their roles.

**Renal physician** will ensure you are well enough medically and physically for the donation operation. The renal physician will be involved in providing care before the operation, during the hospitalisation and with follow-up care after discharge. You and the recipient each have your own renal physician before, during and after the transplant.

**Transplant Coordinator** will be the first point of contact for any issue you may have before the operation, during hospitalisation and after discharge. The transplant co-ordinator will coordinate the entire process and will ensure that you are fully informed throughout. The coordinator will ensure you have all the information needed to provide informed consent for the operation.

**Surgeon** will be responsible for performing the operation to remove your kidney (nephrectomy) and will be involved in providing care before the operation, during hospitalisation and after discharge. The surgeon will ensure that you are fit enough surgically to undergo the donation operation and will also ensure that you are fully informed of the risks involved with surgery before you sign a consent form for the operation.

**Psychiatrist** It is essential that all potential live donors see a psychiatrist to ensure that they will be able to cope with all the stresses associated with this complex procedure, and to address any potential issues that may arise. The psychiatrist will ensure that you are not under any pressure to donate a kidney and that you understand that the offer to donate can be withdrawn at any time.

**Social Worker** You may see the social worker for individual or family counselling. Counselling may help to clarify and resolve feelings and attitudes which may arise during the transplant process. The social worker may also be able to provide practical help with any financial or other practical matters you or your family may have.

**Pharmacist** Prior to surgery it is important for the pharmacist to be aware of any medications you may be taking. The pharmacist will ensure that during hospitalisation the correct medications are given.

**Dietitian** If you have any special dietary needs these should be discussed with the dietician before admission. Good nutrition is essential for a speedy recovery after an operation. The dietitian will make this easier.

**Physiotherapist** Early return to activity after an operation is very important for a speedy recovery. After the operation the physiotherapist will assist you to move about and encourage deep breathing techniques. These are essential to prevent possible post-operative complications such as clots and chest infections.

**Pain Team** will ensure that you have adequate pain relief after the operation. They will visit every day during the first few days and discuss your needs. It is important that you are relatively free of pain so that you will move about and actively participate in your physiotherapy program.

**Nursing Staff** will provide the specialist care you will need before and after the operation and during your recovery.

# What work-up tests are undertaken to assess live donors?

The work-up for the potential live kidney donor is intense and thorough and may take 3–9 months. These tests are time consuming and may require the potential live donor to take time off work. Only about 60% of potential live donors proceed to live donor transplantation due to a variety of immunological, medical or social reasons. (The research literature suggests that this figure is much lower overseas).

## There are nine assessment steps

### 1 Initial assessment

- Referral from a general practitioner (GP) with a summary of the potential donor's health to a renal physician who is NOT responsible for providing care to the recipient.

  **Why?** Your GP has your medical history, and needs to be kept informed regarding your progress. The GP will be providing ongoing medical care after the donor operation.

- Assessment of the donor's blood group (must be ABO compatible)

  **Why?** Your blood must be ABO compatible to proceed to further testing. (See further discussion in the 'What is meant by blood group' section).

- Consultation with Transplant Coordinator.

  **Why?** The Transplant Coordinator will coordinate the tests, and be a mentor to the donor throughout the entire process.

- Review by renal physician. This involves a full medical assessment including a re-check of blood group to ensure ABO compatibility.

  **Why?** You must be fit enough to have an anaesthetic and undergo a major operation.

## 2 Education

To ensure that the potential live donor is properly informed before proceeding, the donor must:

- attend a renal transplant education day
- read the pamphlets available on live kidney donation
- view the live donor video.

**Why?** Potential donors need to make an informed decision fully understanding the risks and advantages of the operation.

## 3 Live donor cross-matching

*Stage 1*

- Human Leukocyte Antigen (HLA) typing (see Glossary).
- ABO blood group compatibility testing (see Glossary).
- Complement Dependent Cytotoxicity (CDC) cross-matching to confirm compatibility (see Glossary).

**Why?** Tissue typing will indicate the likelihood of rejection. The cross-match must be negative.

*Stage 2*

- ABO blood group confirmation.
- HLA tissue typing confirmation.
- Flow Cytometry cross-match (see Glossary).
- Repeat CDC cross-match.

**Why?** The flow cytometry cross-match is the final test of compatibility between a donor and a recipient. It is a good predictor of likely success. Sometimes initial screening cross-match tests do not detect subtle antibodies which can cause rejection.

*Stage 3*

- Repeat CDC cross-match.

**Why?** This step is only performed if the transplant is actually scheduled to proceed. It is carried out one week or so before the transplant. This step is especially important if a patient has had a blood transfusion.

## 4 Assessment of renal function – Glomerular Filtration Rate (GFR)

- Your exact renal functioning needs to be assessed. The best assessment technique is determined locally, eg 24-hour urine collection OR nuclear medicine scan OR renal laboratory test.
- Renal ultrasound.

**Why?** You must have two kidneys with normal renal functioning to minimise the risks associated with donating one.

## 5 General health assessment

- Chest x-ray and electrocardiograph (ECG) and may also include an echocardiogram, Exercise Stress Test, or Glucose Tolerance Test.
- Blood tests (full blood count, fasting glucose, and lipids, glucose tolerance test).
- Tests for transmissible diseases, eg hepatitis B and C, HIV (AIDS), syphilis.
- Blood tests are done to check your current status of Epstein-Barr virus (glandular fever) and Cytomegalovirus (CMV).
- For female donors over 50 years of age, pap smear and mammogram checks are undertaken.

**Why?** You must have tests to exclude or minimise the risk of developing a disorder which might later affect your own kidneys – eg diabetes mellitis – or some familial diseases – eg polycystic kidney disease.

**Why?** The donation of a kidney includes the risk of possible transmission of viruses and tumours in the donor to the recipient. Some such risks are unacceptable (eg hepatitis B), others are acceptable provided the risk is known (eg CMV-positive donors – 85% of the general population are positive).

## 6 Referrals

- Social worker

**Why?** The social worker will provide support throughout the process and may be able to offer information about practical matters and income support.

- Donor surgeon

  **Why?** The donor surgeon will assess you and may provide advice about reducing the risks of the operation. The donor surgeon will organise and/or review the renal angiogram (some donors have complex renal arteries that make donation impossible). The surgeon will obtain your informed consent for the operation.

- Psychiatrist / Psychologist

  **Why?** The psychiatrist/psychologist will consider psychological aspects of the donation, including your capacity to cope with possible adverse outcomes such as the rejection of the kidney.

### 7 Renal Angiogram

A renal angiogram is undertaken using one or more of the following: Helical CT angiogram, Magnetic Resonance Imaging (MRI), Angiogram or formal arteriogram.

**Why?** Angiograms provide a 'renal map' for the donor and recipient surgeons.

### 8 Review by renal physician of all data

**Why?** The renal physician will want to discuss all test results and address any questions you might have before determining a desired date of surgery.

### 9 Written advice to recipient's renal physician

**Why?** This will confirm that the work-up process of the potential live donor is completed and that a desired date of surgery can be planned.

*This list is not exhaustive. The renal physician may request other tests.*

# What is meant by blood group?

The donor and recipient **must** share the same blood group or a compatible blood group. It is better if they also have a similar tissue type (see Glossary).

Your blood group and tissue type never change.

The **blood group** is your **red cell** type. Red cells carry substances on the cell surface which differ from person to person. It is these red cell substances that identify a person's blood group. They are defined as A, B, AB or O.

In relation to donating blood or a kidney, blood group O is the universal donor. It can therefore be given to recipients with any blood group. Blood group AB is the opposite – the universal recipient. People with blood group AB can receive donations from any donor.

The following table shows the suitable combinations of blood type which allow a successful transplant:

| | | Donor blood type | | | |
|---|---|---|---|---|---|
| | | **A** | **B** | **AB** | **O** |
| **Recipient blood type** | **A** | Yes | No | No | Yes |
| | **B** | No | Yes | No | Yes |
| | **AB** | Yes | Yes | Yes | Yes |
| | **O** | No | No | No | Yes |

## What is meant by tissue typing?

The **tissue type** refers to your **white cell** type. The surface of white cells also have different substances (or molecules) on them called **antigens**. The white cell antigens that are important in transplantation can be divided into three groups – A, B and DR. Every person inherits one molecule in each of these groups from both of their parents, giving them six molecules which help make up their white cell 'fingerprint'.

White cell antigens are usually involved in protecting our bodies against infections, and are also found on most tissues of the body, including the transplant kidney. Therefore, the closer the match between donor and recipient of these white cell fingerprints (or tissue types), the lower the chances are of the recipient's immune system seeing them as foreign and trying to reject the kidney.

## What is meant by the term cross-match?

If someone is exposed to tissue type antigens from another person (such as through a blood transfusion, a transplant or pregnancy) their immune system has the opportunity to develop molecules (or antibodies) directed against the other person's tissue type antigens. In transplant terms, this means that once one has reacted to a particular tissue type, the chance of a successful transplant from a donor with those particular tissue type antigens is low.

To ensure that a transplant recipient has no antibodies against their potential live donor, blood is taken from both and serum from the recipient is put in a small plastic well together with white cells from the potential

donor. If the patient's serum kills the donor's white cells then the **cross-match** is positive, suggesting that the kidney transplant is highly likely to be rejected. **Transplants are not generally offered when there is a positive cross-match between the potential donor and recipient**.

# What to expect at the time of surgery

## Pre-operative preparation

After you have passed the preliminary assessment and investigations there is no specific preparation for the transplant operation other than staying fit and active and trying to lose any excessive weight. If you are a smoker, you **MUST** stop smoking before considering live kidney donation.

If you are taking any medication that thins the blood, such as Aspirin or Warfarin, you should discuss with your doctor when you should stop taking these medications.

There is some evidence that the oral contraceptive pill increases the risk of clotting in the veins. It is therefore recommended that this medication be stopped – if possible two to three months before the transplant operation.

## A team approach to renal transplantation

Living renal transplantation consists of two distinct operations involving the donor and then the recipient. Most units have two dedicated surgical teams, involving usually a surgeon and two assistant surgeons, an anaesthetist and assistant, as well as a perfusionist and multiple nursing staff. Many centres use two operating theatres side by side. Some use a single theatre performing the donor and recipient operations consecutively.

The organisation for such a complex application of technology is made more difficult by the scarce resources of our health system. One of the most commonly asked questions is, 'When will my operation be?' This is sometimes difficult to answer because, despite good planning, the demands on our health system are such that emergency situations must take priority.

## What to expect on the day of the operation

A degree of nervous tension is common. Depending upon the protocol used in your hospital, you may be admitted the day before or the day of the operation. (As the pre-operative workup is usually completed some weeks or months beforehand, you may be required to attend the pre-admission clinic shortly before the date of the surgery to ensure there are no last minute 'hitches'). You may be required to have a small enema the night before the surgery to clear out your bowel. This is designed to make you feel more comfortable after the surgery.

On the morning of the surgery various staff members will ask many questions. To reduce the risk of any error these questions may be repeated at different stages. When you reach the anaesthetic bay, the anaesthetist will insert a small cannula into one of your veins. A number of other monitoring devices and lines will be attached to ensure your safety during the surgery. You will usually then be wheeled into the operating theatre and transferred to an operating table. An anaesthetic agent will then be given. The next thing you know, the operation is over and you wake up in the recovery unit.

### The surgery explained

There are different techniques for removing a kidney for live donor transplantation. The current standard is an **open operation**; however increasing numbers of centres are adopting a **laparoscopic (keyhole)**

**approach** to kidney removal. Laparoscopic surgery involves inserting into your abdomen a slender, light-containing, fibre-optic 'telescope' attached to a camera which provides the surgeon with a view of the operative site. It permits smaller incisions than those used in conventional surgery. This can minimise post-operative pain, result in faster recovery and shorter time in hospital, and improve the cosmetic result. The two commonly used laparoscopic approaches are hand-assisted and pure laparoscopy.

## The operation

The open operation is generally performed through an incision either just above or below the 12th rib, usually on the left hand side of the body, for which a general anaesthetic is required. The incision may require removal of a portion of one of the 'floating ribs', although this is not usually necessary. The space surrounding the lungs may be opened. This occurs in 5–15 % of cases. Generally this does not cause any problems and requires only the closure of the opening at the end of the operation. However, it is possible that a temporary drain may need to be inserted to assist with re-expansion of the lung.

There are some potential additional risks of laparoscopic versus open donor nephrectomy. These risks mostly affect the recipient. There is the possibility of a reduced length of artery or vein on the kidney being taken, or an injury to the ureter. These complications may prolong the surgery for either the donor or the recipient, or may prolong the time to deliver the kidney after it has been separated from the donor's blood supply. Such delays can affect the likelihood of the kidney functioning immediately in the recipient. Centres with extensive experience in the laparoscopic technique for removing donor kidneys have reported a low risk of these problems occurring.

## Possible surgical complications

As with all major operations, complications can and do occur. An infection of the operation wound, a raised temperature and lung infection are possible, but fortunately uncommon, irrespective of whether the operation

is carried out by open or laparoscopic technique. The most common major complication associated with the surgery is deep vein thrombosis (DVT), which is the development of a blood clot in the leg veins. Very rarely, DVT is also associated with a pulmonary embolus (blood clot dislodging to the lung). Surgery-related death has been reported, but is extremely rare.

To minimise the risk of a clot and pulmonary embolism, special precautions are taken. Compression stockings are used during and after the operation. Heparin is used as an anticoagulant (thinning the blood) to help maintain circulation, and early mobilisation is encouraged after the operation.

The death rate after surgery has been reported to be approximately 0.03%. Causes of death following this surgery include pneumonia, pulmonary embolism and heart attack. These risks will be discussed with you by your doctor during your preparation for surgery.

The kidney is closely associated with and intimately attached to other abdominal organs. In particular, the left kidney is near the spleen, left bowel, and adrenal gland. The right kidney is only occasionally taken, and is closely associated with the liver, gall bladder, right bowel and adrenal gland. Any of these organs can be injured during the operation and preparation of the kidney for donation. Such an occurrence is extremely uncommon. There is no evidence of higher risk with either the laparoscopic or the open form of surgery.

**Recipient mother and donor daughter**

# After the operation

After the operation has been completed, you will be sent to the recovery unit for about an hour. You may not remember much of this time. If your operation has been laparoscopic you may be at home in two to four days. If your operation has been open, you can expect to remain in hospital for up to a week. Regular blood tests, checks and observations will be carried out while you are in hospital. Testing may be undertaken after you have gone home, to monitor your progress.

## Pain relief

After the operation a degree of pain is to be expected. This issue can be discussed with your surgeon and your anaesthetist before the surgery. Pain relief will be given appropriate to the severity of pain experienced. Pain reduction options include an epidural infusion for the first few days, or patient-controlled analgesia (PCA) where you can control, with a hand-held button, the amount of intravenous pain killers being administered according to the severity of the pain. Other effective analgesics include intermittent injection, tablets and suppositories.

Although pain does occur after every operation, both open and laparoscopic kidney surgery, appropriate pain relief will be provided during the course of your recovery. It is important that you perform regular deep breathing exercises to reduce the risk of lung infection, and undertake leg exercises and early mobilisation to reduce the risk of DVT.

## Follow up after discharge

After discharge, you can expect to be moving about freely. It is recommended that you do not perform any activity that involves heavy lifting or straining until the surgeon tells you it is okay. Generally after

laparoscopic surgery this period would last for at least 4 weeks, and after open surgery, 3 months. However, exercise such as walking is strongly recommended. Driving should be avoided for two weeks after laparoscopic surgery and 4-6 weeks after open nephrectomy.

After your discharge you will have a follow-up appointment with your surgeon within 2–4 weeks. An appointment with your renal physician will need to be made 6 weeks after discharge from hospital.

## How soon after surgery can I return to work?

In most cases, normal activity can be resumed 4 weeks after surgery. Some people have even returned to work by this time, depending on the type of work they do.

If you are in a position to do so, it is a good idea to take at least 6–8 weeks off work, just to rest fully and recover.

## What if the donated kidney does not work?

**Even if the donor and recipient have perfectly matched kidneys there is no guarantee that the kidney will work.**

**While the success rate of live kidney donation is very high, success is not guaranteed. For technical or medical reasons, the transplanted kidney may not work. This will be discussed with you by members of the team throughout the live donor assessment.**

# What are the long-term implications for a live kidney donor?

The risk of a live kidney donor ending up suffering renal failure in the long term, following donation of a kidney, is the same as for any healthy member of the population – extremely low. However, the literature does indicate that a small number of live kidney donors ultimately suffer renal failure.

Having only one functioning kidney does not have any effect on your activities or daily life. Life expectancy is unchanged by having only one kidney. However, care should be taken if you are playing contact sports to prevent injury to your remaining kidney.

High blood pressure is a potential risk and there have been some reports of minimal loss of kidney function related to high blood pressure.

Your doctor will want to check your kidney function every 1–2 years, at which time all or some of the following tests will be conducted:

- 24 hour urine collection to assess creatinine clearance and protein excretion
- Blood samples to test your electrolytes and haematology
- Mid-stream urine specimen to check your cell count and culture
- Blood pressure and general health test
- Renal function tests.

# What costs are associated with live kidney donation?

Different fees and charges may apply depending on your own health insurance and how the doctor and hospital charge for their services. Fees may be charged for medical tests, examinations, doctors' visits and other medical or surgical interventions. Before undergoing surgery you should discuss with your doctor any fees you will be required to cover.

If you have private health insurance and elect to be hospitalised as a private patient, it is likely that the specialist surgeon will conduct the entire procedure. If you are hospitalised as a Medicare patient, the specialist surgeon may not perform the entire operation.

You will need to cover other direct expenses such as travel costs and accommodation. If you wish to discuss financial matters related to the operation, please contact the social worker.

Most kidney donors are young and in their productive years. Stopping work for several weeks can have financial implications that the donor needs to be prepared for. If you are in paid employment you may be able to utilise sick leave entitlements (where available) and/or annual leave to ensure that income is maintained during hospitalisation and the post-discharge recovery period. In some cases a sickness allowance may be available. You may discuss these matters with the social worker.

Private health insurance and life assurance companies generally provide cover to those who have donated a kidney for transplantation; however, you should check your cover with your own insurance companies. Please feel free to discuss any concerns with the social worker.

# How might the decision to donate a kidney impact on my family and friends?

The psychosocial impact of live kidney donation on the families and friends of both the live donor and the recipient is well documented.

Some of the issues which arise include considerations of who in the family should donate, how the donor would feel if the kidney was rejected, and in the worst case scenario, how people would respond if the donor or recipient died during or following transplantation. These potential stresses will be discussed with you by members of the transplant team, including your doctor, social worker and transplant coordinator.

**Renal surgery operating theatre**

It is not uncommon for tensions to arise within marriages and families. Jealousy, resentment, rivalry, and anger may surface. Just as overwhelming are the positive feelings of love, comfort and protection that may arise, especially at the time of diagnosis or during medical crises. Questions such as, 'Why does he/she always steal the limelight?' or, 'Why can't he/she let me help', or 'After all I've done, why can't someone help me?' often arise. These feelings can be very real to some family members. The potential donor and recipient should try to be sensitive to and aware of the dynamics within the family and encourage open discussion about feelings regarding the kidney donation and the transplantation.

For donors, there is sometimes a real feeling of anti-climax after the transplant. This may be due to the fact that attention may suddenly shift from the donor to the recipient. These feelings do not necessarily last long. Reassurance and support from the transplant team and your family will ensure that these concerns do not become an issue for you or your family.

The majority of donors indicate that donation has not affected their general health, and that providing a new lease on life for the recipient has made the whole procedure worthwhile.


**Recognition of a live donor**

# Glossary

**24 hour urine collection / creatinine clearance** You collect and keep in a clinical bottle every specimen of urine for 24 hours. This is to determine your kidney function and identify any minerals that may be present in your urine that may lead to kidney stone formation.

**ABO blood group** The blood group system is known as the ABO system. There are four blood types within the group – O, A, B, AB. The donor and recipient must be the same or a compatible blood group.

**Altruistic** Simply means 'regard for others as a principle of action; unselfishness' – eg a person who freely donates a kidney without incentive or coercion. Some people are willing to donate an organ to a person in need whom they do not know.

**Analgesia** Pain relief medication.

**Antigens** Structures, usually proteins, which can be detected by the immune system. If the body is exposed to foreign antigens, for example from a blood transfusion or a pregnancy, it can start a fighting response and form antibodies.

**Antibodies** Proteins in the blood serum that the body makes when it detects a foreign antigen. If the foreign antigen is detected at a later time the body is ready to destroy it.

**Cannula/IVC (intra-venous cannula)** A small plastic tube inserted into a vein and kept in place by a plastic dressing, used for the delivery of fluids and medications.

**Catheter/IDC (in-dwelling urine catheter)** A tube will be inserted into your bladder and will be connected to a drainage bag. Your urine will drain into this drainage bag and will be measured. Usually the urinary catheter stays in place for approximately two days. It is kept in place by a small balloon. To remove the catheter, the balloon is deflated and the catheter is removed.

**Complement Dependent Cytotoxicity (CDC)** The laboratory technique used for routine cross-matching and typing of HLA antigens.

**Chest X-ray** A picture of the lungs is taken. Two pictures are usually taken, one where the X-rays pass through the chest from the back and one in which the X-rays pass through the chest from one side to the other. The breath must be held when the X-ray is taken.

**Cross-match testing** This is done by the Tissue Typing Department at the Red Cross Blood Service. The serum (the clear liquid in blood) of the recipient is mixed with white blood cells of the donor. This test detects antibodies in the recipient's blood that can be directed against the donor's cells. If the cells live once mixed, the cross-match is termed negative. If the cells die, this is termed a positive cross-match. It is a requirement for transplantation that there is a negative cross-match result.

**Donor** The person who donates a kidney. Kidneys used in transplantation may come from living or deceased donors. Organ donation from deceased donors has diminished over recent years, necessitating a greater reliance on living donors.

**Electrocardiogram (ECG)** A recording of the heart's electrical activity. Electrodes with wires linking them to a recorder are put on the chest, arms and legs. This test is painless.

**Echocardiogram** This test checks how well your heart is working. It uses sound waves to produce a picture of your heart. It will show the size of your heart's pumping chambers, how well your heart muscle is pumping and how well your heart valves are working.

**Exercise Stress Test** This is carried out if the donor is over 40 years of age or if otherwise indicated, to ensure there are no underlying heart problems.

**Flow Cytometry** This is a similar test to the CDC testing but with increased sensitivity. The flow cross-match may detect antibodies in the recipient serum that are not detectable by the CDC. A positive flow cytometry may argue against transplantation.

**Glucose Tolerance Test** This is a blood test performed over a couple of hours after drinking a glucose-loaded drink. Potential donors who have a family history of diabetes will be tested to ensure that they are not at risk of developing the disease. If diabetes is suspected, the donation will not be allowed.

**Helical CT Renal Angiogram** This is a non-invasive procedure that involves a non-contrast CT scan of the kidneys. This scan provides the medical team with an accurate assessment of the number, size and position of the renal arteries and veins in the living donor. This scan also assesses the status of the kidneys, and includes renal stones, the ureters and bladder. This scan is most important as it allows the surgeon to select the kidney that is most suitable for donation. Most people have one or two arteries that supply blood to each kidney. Occasionally people have extra blood vessels, which are normal for them but may make the operation technically very difficult. Such variations in structure may exclude you as a potential donor.

**HLA antigens** Human Leukocyte Antigens (HLA) help regulate the body's immune response and are found on the surface of white blood cells. HLA testing identifies which genetic markers we have inherited from our parents.

**Intravenous fluids** Fluids that are delivered via a cannula when you are not able to eat after the surgery. Your intestinal tract slows after abdominal surgery and anaesthesia. Once your intestines have started to work again you will be able to eat and drink.

**Kidney (renal) failure** A person's kidneys do not function normally to remove toxins from the blood. Some illnesses cause temporary renal failure and the kidneys recover. Permanent damage, however, will result in chronic or 'end stage' renal failure, the only treatment for which is regular dialysis or a kidney transplant.

**Mid-stream urine collection** This is a single urine specimen taken mid-stream, looking for any sign of infection.

**Nephrectomy** The removal of a kidney.

**Organ donation** Kidneys for transplantation can be provided from a live donor, usually a close family member, or from someone who has died and has previously agreed to their kidneys being donated.

**PCA – Patient Controlled Analgesia** Donors will usually return from the operating room with a PCA connected to an intravenous line inserted into their arm. The donor will be given a button to press when they suffer pain. When pressed the PCA will deliver a dose of analgesia. The pain team will make regular assessments of the effectiveness of medication.

**Perfusionist** A person who rinses the donated kidney of blood using a fluid that preserves the kidney.

**Recipient** The person who receives a kidney.

**Renal dialysis** There are two types of dialysis:

*Haemodialysis* – involves circulating a person's blood through a dialysis machine, which functions like a kidney to clean and filter toxins from the blood before it is returned to the patient. It has to be performed for 4–6 hours three times each week.

*Peritoneal Dialysis* – where special fluid is repeatedly washed through the abdominal cavity, drawing out toxins from the blood as it goes. The fluid can be exchanged 3–4 times each day or overnight with the use of a machine called a cycler.

**Renal transplantation** Surgically implanting a donated kidney.

**Renal ultrasound scan** A probe is moved over the skin, sending and receiving ultrasound signals, which are changed into images of the kidneys and bladder. This scan makes sure that you have two normal kidneys.

**Serology blood tests** Taken initially when all other blood tests are taken. Serology blood tests detect exposure to the following viruses – human immunodeficiency viruses (HIV), hepatitis B and C, cytomegalovirus (CMV), Epstein-Barr virus (EBV), herpes simplex virus (HSV), herpes zoster virus (Varicella).

# Checklist for Potential Renal Donors

- [ ] Referral from GP
- [ ] ABO blood group*
- [ ] Consultation with Transplant Coordinator
- [ ] Review pamphlets regarding live kidney donation
- [ ] Attend renal transplant education
- [ ] View live donor video
- [ ] Discussion with social worker
- [ ] *Stage 1* Red Cross tissue-typing and cross-match
- [ ] Assessment by renal physician
- [ ] Urinalysis*
- [ ] Urine microscopy and culture
- [ ] Measure renal function, GFR
- [ ] Renal ultrasound*
- [ ] Blood tests – Routine haematology / biochemistry*
- [ ] – Glucose tolerance tests / fasting lipids*
- [ ] – Hepatitis B and C / HIV / VDRL*
- [ ] – EBV / CMV Serology

*Stage 2* Red Cross Flow Cytometry* ☐

Pap Smear / Mammogram > 50 year old women* ☐

Chest X-Ray* ☐

ECG* ☐

Echocardiogram ☐

Stress test ☐

Assessment by psychiatrist ☐

Assessment by transplant donor surgeon ☐

Donor consent for surgery ☐

Renal angiogram ☐

*Stage 3* Repeat Red Cross CDC Cross-match ☐

Miscellaneous tests

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**GP can arrange: otherwise the Transplant Centre will do so.

## Major Renal Treatment Centres

**Royal North Shore Hospital**
www.nsh.nsw.gov.au/rnsh
Transplant Coordinator
02 9926 7111 pager 41620 or
02 9926 8499

**Prince of Wales Hospital**
www.sesahs.nsw.gov.au
Transplant Coordinator
02 9382 2222
pager 44983

**Royal Prince Alfred Hospital**
www.cs.nsw.gov.au/rpa
Transplant Coordinator
02 9515 6111 pager 60268 or
02 9515 7632 or 02 9515 7630

**Westmead Hospital**
www.westmead.nsw.gov.au
Transplant Coordinator
02 9845 5555 pager 27237 or
02 9845 5745

**John Hunter Hospital Newcastle**
www.hunter.health.nsw.gov.au
Transplant Coordinator
02 4921 3000 pager 5266 or
02 4921 4341

**St Vincent's Hospital**
www.sesahs.nsw.gov.au
Renal Clinical Nurse Consultant
02 8382 1111 pager 6519 or
02 8382 2362

**St George Hospital**
www.sesahs.nsw.gov.au
Coordinator of Renal Transplant Services
02 9350 2290

**Liverpool Hospital**
www.swsahs.nsw.gov.au
Renal Case Manager
02 9828 3000

**Wollongong Hospital**
www.iahs.nsw.gov.au
Renal Clinic Sister
02 4222 5443

## Further Information Resources

NSW Health
www.health.nsw.gov.au/pubs/index.html

Renal Resource Centre,
Sydney Dialysis Centre,
37 Darling Point Road,
Darling Point NSW 2027
02 9362 3995 or 1800 257 189
www.renalresource.com

Kidney Health Australia (formerly the Australian Kidney Foundation)
Kidney Information Line (free-call)
1 800 682 531
www.kidney.org.au

'Life with a single kidney', Kidney Health Australia brochure, January 2003

'Live kidney donation', Kidney Health Australia brochure, January 2003

Transplant Australia
www.transplant.org.au

Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)
www.anzdata.org.au

USA Internet information
www.transweb.org

Transplant Society of Australia and New Zealand
www.racp.edu.au

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*Laparoscopic donor nephrectomy information sheet*, Princess Alexandra Hospital.

*Live donor information package*, Westmead Hospital, Sydney.

*From me to you: so your relative needs a kidney*, Renal Resource Centre, Sydney.

*Live kidney donation… putting YOU in the picture*, John Hunter Hospital, Newcastle.

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## Notes

## Reminder

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NSW HEALTH

# kidney donation by live donors

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