RENAL RESOURCE CENTRE

An Introduction to Kidney Donation by Live Donors

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Kidney Donation by Live Donors

Foreword

The donation of a kidney to a loved one or friend or in some cases, an unknown member of the community, is an extraordinary act of love, sacrifice and generosity. It is essential that prospective living donors fully understand all the implications of donation. The provision of balanced and accurate information, through education and discussion, about the procedures and risks involved in live donor transplantation, is a requirement of NSW Health. This booklet serves as an introduction to this process and is only the beginning of the assessment process. Individual education and counselling of prospective donors is intended to safeguard their well-being and ensure that their consent to donation is fully informed. Positive outcomes for both donor and recipient are the main aim for all involved in organ donation.

The information provided in this booklet will assist donors, recipients and their families to understand the planning, investigations and procedures associated with live donor transplantation. Whilst the booklet provides a general overview of live kidney donation in the state of NSW, Australia, more specific information about individual circumstances and arrangements can be provided by the Transplant Team undertaking the donor's assessment and surgery.

Whether the transplant proceeds or not, the person to whom you are contemplating donation will draw comfort from and be inspired by your actions. We wish you well.

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October 2010

Acknowledgments

This booklet was originally produced in 2004 by a sub group of the Greater Metropolitan Transition Taskforce (GMTT) Transplant Working Party. Our special thanks are extended to the staff of Renal Units at the following Hospitals for sharing their knowledge and resources with the GMTT Transplant Working Party. John Hunter, Prince of Wales, Royal North Shore, Royal Prince Alfred and Westmead Hospitals, New South Wales); Monash Medical Centre, Victoria; Princess Alexandra Hospital, Queensland; Christchurch Hospital, New Zealand.

The information was further reviewed and updated in 2010 as an initiative of the NSW Agency for Clinical Innovation (ACI), under the guidance of the Renal Resource Centre and with assistance of staff from John Hunter, Prince of Wales, Royal North Shore, Royal Prince Alfred and Westmead Hospitals.

Kidney Donation by Live Donors

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The Renal Resource Centre will be relocating to new premises in February 2011

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This publication has been supported by an educational grant from the NSW Agency for Clinical Innovation (ACI)

ACI NSW Agency for Clinical Innovation

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Introduction

Live kidney donation is 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 booklet 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 signposts 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 booklet will provide guidance as you consider live kidney donation. However, it 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 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 by the offering of money or other incentives, 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 live kidney donation is a reasonable and justifiable procedure.

What about financial motives and incentives 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 conditions govern live kidney donation?

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 psychosocially 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 transplantation of a kidney from a live donor.

It is important to know that if you change your mind about donating your kidney, your confidentiality will not be compromised. The reasons 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 live kidney donor may be either a **related donor** or an **unrelated donor**. A related donor is commonly a parent, brother, sister, grandparent, daughter or son of the recipient. Sometimes, they 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'.

Live **non-directed (altruistic)** kidney donation is an established practice in NSW, with the policy developed by NSW Health Department and the Transplant Advisory Committee. Like the practice for live **directed** donors, non-directed donors need to meet all criteria of suitability, including the mandatory psychological assessment and the work-up that is outlined in this booklet.

The difference between the live **directed** donation and the live **non-directed** donation is that the live **non-directed** kidney is directed to the "best matched" potential recipient in NSW. The **non-directed** live donor has no say in who will or who will not receive the kidney. As for deceased donor donation, the donor's and recipient's anonymity is maintained throughout the process.

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

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.
- It may be possible to schedule the transplant to take place before the recipient requires dialysis (pre-emptive transplantation).
- The possibility of receiving a better 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, live donor kidneys work better and last longer than kidney transplants 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 at a time suitable for the donor, the recipient and the transplant team.

What are the disadvantages of a live donor kidney transplant?

- There are no guarantees if and how long the kidney transplant will work, just as with a deceased donor kidney transplant.
- The donor will need to take time out from their normal routine to attend hospital consultations and tests, to undergo the surgery and to recover from the surgery.
- 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.

The donor's transplant team

The transplant team is made up of many people working together to support and educate you and your family 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 medically assess your fitness to undergo the donation operation. The renal physician will provide care before the operation, during the hospitalisation and follow-up care after discharge. You and the recipient each have your own renal physician before, during and after the transplant.

Transplant Co-ordinator will be the first point of contact before the operation, during hospitalisation and after discharge. The transplant co-ordinator will make certain that all tests are completed and that you have all the information required to provide "informed consent" for the operation. The co-ordinator provide you with educational materials and the opportunity to meet a previous live kidney donor.

Surgeon will be responsible for 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 assess your medical fitness to undergo the donation operation and will ensure that you are fully informed of the risks of the surgery before you consent to the operation.

Psychiatrist All potential live donors see a psychiatrist to ensure they will be able to cope with the stresses associated with this complex procedure. They can also help with any specific worries or concerns that may arise. The psychiatrist will ensure you are under no pressure to donate a kidney and you understand the offer to donate can be withdrawn at any time.

Social Worker provides psychosocial assessment and individual or family counselling. Counselling may help to clarify and resolve feelings of doubt or concern that may arise during the transplant process. The social worker can also provide practical help with any financial or organisational matters you or your family may have.

Pharmacist must be made aware, before the operation, of any medications you are taking. The pharmacist will ensure that the correct medications are given during your hospitalisation.

Dietitian is available, before admission, to discuss any special dietary needs. Good nutrition is essential for a fast and successful recovery. The dietitian can help with this.

Physiotherapist Early return to activity after an operation is very important. The physiotherapist will assist you to move about and practise deep breathing exercises after the operation. These are essential to minimise the chance of 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 each day for the first few days to discuss your needs. It is important that your pain is controlled so that you can move about and actively participate in your recovery program.

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

Donor mother and recipient son

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

The work-up for a potential live kidney donor is intense and extensive and can take 3–9 months. The tests are time consuming and a potential live donor may need to take time off work. Only about 60% of potential live donors proceed to donation. The reasons some don't may be immunological, medical or social.

There are nine assessment steps:

1 Initial assessment

- A potential donor is referred by a general practitioner (GP) to a renal physician who is NOT responsible for the care of the recipient.

  Why? Your GP needs to be aware of your intentions and progress, can provide your health summary and will provide your ongoing medical care after the donor operation.

- Assessment of the donor's blood group

  Why? Your blood group must be known for testing and cross-matching. (See further discussion in the 'What is meant by blood group?' Page 15).

- Consultation with transplant coordinator.

  Why? The transplant coordinator will coordinate the tests and will be a mentor to the donor as they navigate this complex process.

- Review by renal physician. This involves a full medical assessment of you and your suitability to donate a kidney. Part of this will be blood group and tissue typing compatibility assessment.

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

2 Education

To ensure that a potential live donor is properly informed before making a decision about donating, the donor is expected to:

- attend the renal unit's education workshops on live kidney donation
- read the literature and/or view videos provided about live kidney donation

  Why? Potential donors need to make an informed decision and can only do that if they fully understand 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).
- Cross-matching by two different methods (Complement Dependent Cytotoxicity (CDC) and Luminex) to confirm compatibility (see Glossary).

  Why? Tissue typing will help to assess the likelihood of rejection.

Stage 2

- Repeat cross-match using CDC and Luminex testing

  Why? This step is only performed if the transplant has been scheduled to proceed. It is carried out 1 month prior the planned transplant surgery to ensure there has been no change in compatibility between the donor and recipient.

  Additional Flow Cytometry testing (see glossary) may be requested by your doctor depending on the results of the tests above.

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

- Your exact kidney function needs to be assessed. The method varies from unit to unit and can be by 24-hour urine collection and/or nuclear medicine scan and/or renal laboratory test.
- Renal ultrasound.

  Why? You must have two kidneys with normal function to ensure it is appropriate you consider donating one.

5 General health assessment

- Chest x-ray and electrocardiograph (ECG) and sometimes an echocardiogram or exercise stress test.
- Blood tests (electrolytes, liver function, full blood count, fasting glucose, lipids, oral glucose tolerance test).
- Blood tests for transmissible diseases, eg hepatitis B and C, HIV (AIDS), syphilis and human T cell lymphotrophic virus (HTLV).
- Blood tests to check your current status of Epstein-Barr virus (glandular fever) and cytomegalovirus (CMV).

- Female donors over 50 years of age require pap smear and mammogram
  Males over 50 years of age require PSA (Prostate Specific Antigen) blood test.

  Why? You need tests to find out whether you have or might later develop, any disorder which could affect your own kidneys. This would include conditions such as heart disease or diabetes mellitus or familial kidney disease, such as polycystic kidney disease.

  Why? It is possible to transmit a viral infection or a tumour in the donated kidney to the recipient.

  The risk from transmitting some infections is unacceptable (eg hepatitis B) but the consequences of transmitting less significant infections can be minimal, provided the risk is known (eg CMV-positive donors – 85% of the general population are positive).

6 Renal Angiogram

A renal angiogram will involve one or more of the following:

- 3D Helical CT angiogram, magnetic resonance imaging (MRI), angiogram or formal arteriogram.

  Why? Angiograms provide a 'renal map' of renal arteries and veins for both the donor and transplanting surgeons.

7 Referrals

- Social Worker

  Why? The social worker will conduct a psychosocial evaluation and will help you to clarify your thoughts and feelings about the donation. The social worker will also provide emotional support throughout the process and provide advice on practical, organisational and financial matters.

- Donor Surgeon

  Why? The donor surgeon will assess you, give you more detail about the operation and its risks, and may provide advice about what you can do to reduce the risks of the operation. The donor surgeon will also review your CT renal angiogram to get a clear picture of your renal arteries and veins and decide if your kidney is suitable for transplantation (some people have complex renal anatomy that makes donation impossible). The surgeon will obtain your informed consent for the operation.

- Psychiatrist / Psychologist

  Why? The psychiatrist or psychologist will talk you through the psychological aspects of donation, assess your capacity to cope with the process and with a poor outcome such as failure or loss of the kidney.

8 Review by renal physician of all data

Why? The renal physician will want to discuss all test results, answer any questions you might have and then check if and when surgery can be planned.

9 Written advice to recipient's renal physician

Why? This confirms that the work-up of a potential live donor is complete and a desired date of surgery can be planned.

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

Donor and recipient friend

What is meant by blood group?

Your **blood group** is your **red cell** type. Red cells carry reactive substances on their 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. Each blood group reacts with another group in a predictable way.

Some blood groups are immediately compatible with each other but incompatible with others. 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 compatibility of the blood groups:

		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

Transplantation Innovations

ABO Incompatible Transplants and Australian Paired Kidney Exchange

In the past, blood group compatibility was an absolute requirement for kidney transplantation. Newer treatments have changed this and blood group incompatible kidney transplantation is now an acceptable option for living donor kidney transplants. Some potential living donors, who would have been turned down in the past, can now proceed with donation. These donors undergo the same thorough evaluation as all other potential donors. The donor has no additional treatment.

Not every blood group mismatch can be overcome. Some potential donors remain incompatible to their potential recipient. For these people, paired kidney exchange may be an option.

Australian Paired Kidney Exchange

The Australian Paired Kidney Exchange is a nationwide live kidney donor exchange program. The Australian Paired Kidney Exchange Program increases the number of live kidney donor transplants by using incompatible donor-recipient pairs.

Participants in the program are individuals who wish to donate a kidney to a chosen recipient but can't because of an incompatible blood type, incompatible tissue match or other incompatibility. The Australian Paired Kidney Exchange Program collects a series of donors who don't match their chosen recipient, chooses the best matches within the total group, and kidneys are swapped in compatible pairs. The best matches across the country are found and all receive or donate a compatible kidney to the benefit of all.

This program should be discussed with your transplant coordinator and renal physician.

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 each of their parents. Everybody has a total of six molecules which forms their white cell 'fingerprint'.

White cell antigens are usually involved in protecting our bodies from infections. They are 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 chance of the recipient's immune system seeing the transplant as foreign and trying to reject the kidney.

What is meant by the term cross-match?

When 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 a person has reacted to a particular tissue type, if that person is exposed to that tissue antigen again, they will react against it using the existing antibodies. There is little chance a transplant from a donor with those particular tissue type antigens will succeed.

To make sure a transplant recipient has a safe level of antibodies against their potential live donor, blood from the donor and recipient are mixed to see if they react. If the patient's serum kills the donor's white cells, then the **crossmatch** is positive. This indicates 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

Once you have passed the preliminary assessment, there is no specific preparation for the transplant operation. You should stay fit and active and try to lose any excess weight. If you are a smoker, you **MUST** stop smoking before considering live kidney donation.

If you are taking any medicine that thins the blood, such as aspirin or warfarin, you should get advice from your donor surgeon about stopping these medications before your surgery.

There is some evidence that the oral contraceptive pill increases the risk of clotting in the veins. It is usual to stop the oral contraceptive two to three months before the transplant operation. You must get advice from your GP about alternative contraception for the time you have stopped the pill.

You will usually attend a pre-operative clinic where you will be reviewed by an anaesthetist and admission will be organised.

A team approach to renal transplantation

Living renal transplantation consists of two distinct operations; one for the donor and a second for the recipient. Most units have two dedicated surgical teams, each with a surgeon and two assistant surgeons, an anaesthetist and assistant and multiple nursing staff. There may also be a perfusionist.

Many centres use two operating theatres side by side, whereas others use a single theatre and perform the donor and recipient operations one after the other.

Organising such a large team and complex 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. In some units, donors are admitted the day before surgery and in others, the day of surgery. There may be a delay between completing the donor work-up and the proposed date of surgery. You may asked back to a pre-admission clinic just before your admission date to ensure there are no last minute 'hitches'. You may be given a small enema the night before the surgery to clear out your bowel. This is intended to make you feel more comfortable after the surgery.

On the morning of the surgery, various staff members will ask many questions. These questions may be repeated at different stages to reduce the risk of an error being made.

When you reach the anaesthetic bay, the anaesthetist will insert a small cannula into one of your veins. You will also have a variety of other monitoring devices and lines 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 two different techniques for removing a kidney for live donation.

An **open** or **laparoscopic (keyhole) approach** can be used for kidney removal. The surgical technique will be discussed with each donor at the consultation with the donor surgeon. The result of the kidney donor angiogram films need to be known at the time of this discussion.

The operation

Laparoscopic surgery involves completing the entire operation within the abdomen, before finally retrieving the completely freed donor kidney through a fairly small delivery wound. A variety of specialised operating instruments are inserted through 3 or 4 separate small access incisions. The whole process is viewed through a telescopic operating camera, introduced through its own access incision. The incision for each instrument is about 2cm and the incision to deliver the kidney may be 7–10cm.

The **open operation** is generally performed through a much longer incision (20–25cm in length) that starts at the back and sweeps forward along the 12th (lowest) rib. Sometimes, the rib is removed.

Both alternatives are performed under general (full) anaesthesia. Apart from the way the kidney is accessed, the technique of freeing the kidney in both options is very similar.

The smaller incisions of the laparoscopic method lead to less post-operative pain, a shorter hospital stay and a more rapid recovery and return to work. The laparoscopic scars are smaller and more discreet and are less likely to lead to wound problems such as bulging or pain.

There may be some down sides to the laparoscopic approach. These risks mostly affect the recipient. It is possible only a shorter length of artery or vein on the kidney can be retrieved. This may make the recipient's surgery longer and more difficult. It may take longer to get a laparoscopically removed kidney from the donor into ice. This may reduce the chance of the kidney working immediately. It may be more likely to damage the ureter during laparoscopic surgery and this may make the recipient's surgery more difficult. Centres with extensive experience in laparoscopic donor nephrectomy report a low risk of these problems.

Renal surgery operating

Possible surgical complications

Just like any major operation, complications can and do occur.

Infection can occur in the bladder, in the operation wound or in a lung. Each of these is uncommon, is usually quickly recognised and is easily treated. Infections can occur after either open or laparoscopic donor surgery.

Bleeding can occur during or after renal surgery because each kidney has a very rich blood supply. Bleeding may clot by itself, may need a blood transfusion or may require re-operation. This type of bleeding is extremely rare.

The top of each kidney lies just below a lung. The lung lining can be injured during kidney surgery, leading to collapse of a lung. This can usually be repaired without any further action but occasionally a chest drain will need to be left for a day or two.

Each kidney is intimately attached to other abdominal organs. The left kidney is near the spleen, left bowel and adrenal gland. The right kidney is near the liver, gall bladder, right bowel and adrenal gland. Any of these organs can be injured during the operation to mobilise and remove a kidney for donation. Such an occurrence is extremely uncommon. If an injury does occur, further surgery may be necessary to correct this. There is no evidence of higher risk with either the laparoscopic or the open form of surgery.

The most common major complication of this surgery is deep vein thrombosis (DVT), which is the development of a blood clot in the leg veins. Very rarely, a DVT may lead to a pulmonary embolus (blood clot dislodging to the lung).

Measures are taken to minimise the risk of a clot and pulmonary embolism and these include compression stockings, regular injections of heparin as an anticoagulant (blood thinner) to help maintain circulation and early mobilisation after the operation.

Surgery-related death has been reported but is extremely rare. 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.

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 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, to monitor your progress, may be undertaken after you have gone home.

Relief of pain and nausea

You must expect some pain after your operation. This can be discussed with your surgeon and your anaesthetist before the surgery. You will be given appropriate pain relief for the type and severity of pain you feel. Options include an epidural infusion for the first few days or patient-controlled analgesia (PCA). With a PCA, you have control, via a hand-held button, of the amount and timing of the pain killers you receive. Other effective analgesia includes injections, tablets and suppositories.

Although pain occurs after every operation, appropriate pain relief will always be provided during the course of your recovery.

Kidney donors, who have had laparoscopic surgery, sometimes experience shoulder tip pain. This is caused by the gas used in laparoscopy irritating the diaphragm. Nausea sometimes occurs after an anaesthetic. Medication to relieve any nausea and vomiting is provided as required.

It is important that you perform regular deep breathing exercises to reduce the risk of lung infection. Leg exercises and early mobilisation will 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, this will be about 4 weeks after laparoscopic surgery and about 2 or 3 months after open surgery. Regular exercise, such as walking, is strongly encouraged. Driving should be avoided for two weeks after laparoscopic surgery and 4-6 weeks after open nephrectomy.

You should have an appointment to see your surgeon 2–4 weeks after discharge and your renal physician, 6 weeks after discharge.

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.

You should discuss with your transplanting team how long you should expect to be off work. This varies and depends on your age, fitness and the type of work or activity you do. Some people need longer time off work than expected, so you must be prepared for this. It is a good idea to take at least 3-4 weeks off after laparoscopic surgery and 6-10 weeks off after open surgery, just to rest and fully 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.

Recognition of a live donor

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

The risk of a live kidney donor suffering renal failure in the long term is the same as for any healthy member of the population – extremely low. However, we know that a very small number of live kidney donors ultimately suffer renal failure and need dialysis or transplant themselves.

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. A kidney donor is wise to avoid contact sports or high impact recreations to prevent injury to the remaining kidney.

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

Your doctor will want to check your kidney function every year and at the same time may organise some or all of the following tests:

- 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.

** You will be asked to participate in the ANZDATA living kidney donor registry. This involves your annual kidney function assessments being entered into a national database that tracks the long-term follow up of kidney donors from Australia and New Zealand. Your transplant centre should send you a reminder every year to have your tests and see your kidney specialist or GP.

What costs are associated with live kidney donation?

Different fees and charges may apply, depending on your 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, though most should be bulk billed through Medicare. It is entirely reasonable to find out what it is likely to cost you before you decide to proceed.
The transplant co-ordinator is best positioned to either give you this information or tell you where to find it.

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 live more than 100kms away from the hospital you may be entitled travel and accommodation assistance. The social worker is best equipped to provide information about these issues.

Most kidney donors are young and commonly employed. Stopping work for several weeks can have financial implications for which the donor needs to be prepared. If you are in paid employment, you may be able to utilise sick leave entitlements (where available) and/or annual leave to ensure you maintain an income during hospitalisation and in the recovery period. In some cases, a sickness allowance may be available. You may discuss these matters with the social worker.

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

Live kidney donation certainly has a well documented psychosocial impact on the families and friends of both the live donor and the recipient. Some of the issues which arise include who in the family should donate; how the donor would feel if the kidney is 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 co-ordinator.

Sometimes, tensions arise within marriages and families. Jealousy, resentment, rivalry and anger may surface. Alternatively, positive feelings of love, comfort and protection 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 are not unusual for some family members. The potential donor and recipient should try to be sensitive to and aware of the dynamics within the family. All who may be affected by the proposed kidney donation and transplantation are advised to openly discuss their beliefs, feelings and attitudes with each other.

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 respond 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.

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 in your urine which may cause kidney stones.

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. Generally, the donor and recipient have the same or a compatible blood group. In the case of a donor and recipient having incompatible blood groups, new treatments may make a transplant possible.

Altruistic Simply means regard for others as a principle of action. In this context, it refers to a person who freely donates a kidney without incentive or coercion. Some people are willing to donate an organ to a person 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 Two pictures are usually takenof the lungs; 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 Service of the Australian 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.

Donor The person who donates a kidney. Kidneys used in transplantation may come from living or deceased donors. Organ donation from deceased donors does not currently meet demand, 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) These 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.

HTLV The Human T-cell Lymphotropic Virus is a human RNA retrovirus that causes T-cell leukaemia and T-cell lymphoma in adults and may also be involved in certain diseases of the nervous system.

Intravenous fluids These are the fluids, delivered via a cannula into a vein when you are not able to eat or drink 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 The kidneys are not functioning normally to remove toxins and excess fluid from the blood. Some illnesses cause temporary renal failure and the kidneys recover. Permanent damage will result in chronic or 'end stage' renal failure, the only treatment for which is regular dialysis or a kidney transplant.

Recipient's Luminex Testing This is a sensitive test that detects antibodies in the recipient's blood against a potential donor.

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 are provided by either a living donor or by a deceased donor.

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: the patient's entire circulation passes through a special filter or "artifical kidney" of a dialysis machine. This functions like a kidney to filter toxins and remove excess fluid from the blood before it is returned to the patient. It is performed for at least 4–6 hours, three times each week.

Peritoneal Dialysis: special fluid is repeatedly washed through the patient's abdominal cavity, drawing out toxins and excess fluid from the blood. 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 checks that both kidneys are normal.

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), HTLV (human T-cell lymphotropic virus).

Checklist for Potential Renal Donors

- ☐ Referral from GP
- ☐ ABO blood group*
- ☐ Consultation with Transplant Coordinator
- ☐ Review educational resources regarding live kidney donation
- ☐ Attend renal transplant education
- ☐ Consultation 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*
- ☐ 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 2* Repeat Crossmatch 1 month prior to planned transplant date

Miscellaneous tests

- ☐
- ☐
- ☐
- ☐

**GP can arrange, Transplant centre will facilitate all other tests.*

NSW Renal Transplant Centres

John Hunter Hospital Newcastle
www.hnehealth.nsw.gov.au
Living Donor Kidney Transplant Co-ordinator
02 4921 3000 (request to be paged)

Prince of Wales Hospital
www.sesiahs.health.nsw.gov.au/POWH/
Living Donor Kidney Transplant Co-ordinator
02 9382 2222 (request to be paged)

Royal North Shore Hospital
www.nsccahs.health.nsw.gov.au/
Living Donor Kidney Transplant Co-ordinator
02 9926 7111 (request to be paged)

Royal Prince Alfred Hospital
www.sswahs.nsw.gov.au/rpa/
Living Donor Kidney Transplant C o-ordinator
02 9515 6111 (request to be paged)

Westmead Hospital
www.westmead.nsw.gov.au
Living Donor Kidney Transplant Co-ordinator
02 9845 5555 (request to be paged)

Further Information

Renal Resource Centre
02 9362 3995 or 1800 257 189
www.renalresource.com

Kidney Health Australia
Kidney Information Line (free-call)
1800 682 531
www.kidney.org.au

Transplant Australia
www.transplant.org.au

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

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

Contributing Sources

A manual for potential live kidney donors, Royal North Shore Hospital, Sydney.

Live donor kidney transplantation – the facts, Transplant Unit, Monash Medical Centre.

Kidney transplants in Queensland, Princess Alexandra Hospital.

Kidney transplantation: what it means to be a living donor, Department of Nephrology, Christchurch Hospital, New Zealand.

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.

Kidney donation questions & answers Information for patients, University of Pittsburgh Medical Centre.

Questions for Your Health Care Team

The Renal Resource Centre is a national unit established to provided information and educational materials on kidney disease for patients and health professionals.

The primary objective of the Centre is to ensure that patients have easy access to such information, are well informed and can actively participate in their own health care.

The Renal Resource Centre is committed to providing education and service to the renal community

Kidney Donation by Live Donors

RRC
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The Renal Resource Centre will be relocating to new premises in February 2011

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Publications of the Renal Resource Centre are endorsed by The Australian and New Zealand Society of Nephrology and Transplant Australia.

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