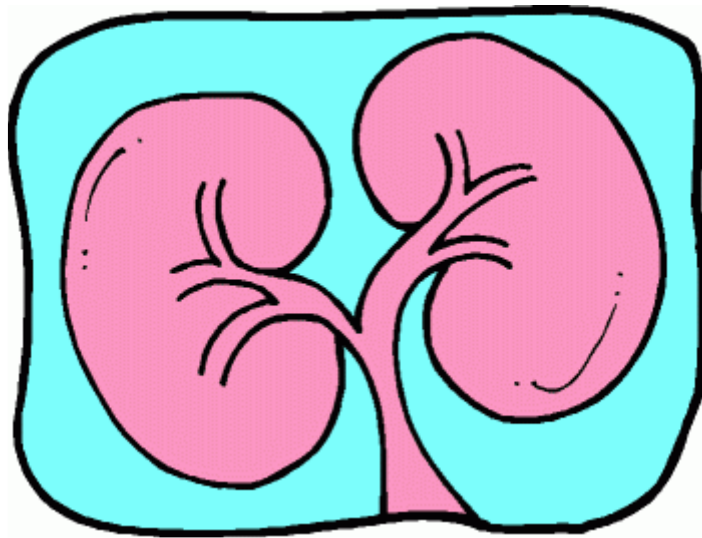


Dialogue on Donating



A Guide to Kidney Donation in British Columbia



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INTRODUCTION

The information in this booklet will be helpful if you want to learn more about the process of living kidney donor evaluation and the details of kidney donor surgery. The decision whether to donate a kidney is a very personal one and there is no right or wrong choice. The Living Donor Team at St. Paul's Hospital needs to ensure that a potential donor is coming forward without pressure, coercion or incentive and it is important that she or he understand this when entering the testing process. The donor should know that she or he might decline to donate at any time. The decision has to be the one that is best for the donor and the Living Donor Team is committed to supporting the donor throughout this decision making process.

Our living kidney donor program considers this booklet an important part of the consent process for those people who ultimately serve as kidney donors. A potential kidney donor must understand all aspects of their evaluation as well as the risks and benefits of donor surgery.

All information disclosed during the donor evaluation is confidential and remains with the Living Donor Team. Therefore, it is important that the donor and recipient maintain good communication throughout the donor's evaluation. The recipient will not receive any information about the donor's testing or suitability from the Living Donor Team (although the team is available to assist if the donor or recipient are experiencing frustrations or difficulties).

GENERAL PRINCIPLES UNDERLYING THE LIVING DONOR EVALUATION

1. The potential donor must have a blood group that is compatible with the recipient's blood group. Potential donors who are known to be blood group incompatible with the recipient may choose to participate in the *Living Donor Paired Exchange Program*. (**Appendix A**)
2. The recipient must not have antibodies against the potential donor's kidney, which would lead to quick rejection of the kidney. Potential donors who are ineligible because of recipient antibodies may choose to participate in the *Living Donor Paired Exchange Program*. (**Appendix A**)
3. The potential donor must be sufficiently healthy and fit to undergo a major operation with very little risk of complications.
4. The potential donor's pre-operative kidney function must be strong enough to expect normal kidney function following removal of one kidney.
5. The potential kidney donor must not have any medical condition that may possibly be transmitted to the recipient (i.e.: viral hepatitis or cancer).
6. The potential donor must be 19 years of age or older.
7. The potential donor must know and understand the operative risks and long-term risks of the donor operation.
8. The potential donor must have a pre-existing relationship with the recipient. This is to ensure that both people can make an informed decision about the appropriateness of the offer to donate and the consequences of accepting the offer. Potential donors may participate in the *Living Anonymous Donor Program* (**Appendix B**) if they do not personally know any individual in need of a kidney transplant.
9. The potential donor must not receive money or other valuable incentives to donate a kidney that they would otherwise not consider donating.
10. The potential donor must have enough psychological, social and financial resources to withstand the surgery and recovery period with minimal personal hardship.

PRE-EVALUATION GUIDANCE AND INFORMATION

There are some things you should know before starting an evaluation as a potential kidney donor.

1. Not every patient with chronic renal failure is a candidate for renal transplantation.

A patient with renal failure will need to undergo their own evaluation to determine their suitability for transplantation. In many cases, this will happen at the same time that potential donors are completing their tests, but there are exceptions. The Transplant Team and Living Donor Team will discuss matters and it may occur that the intended recipient must finish their testing before any donor evaluations are allowed to proceed.

2. Living donor transplantation is not the only option for patients with renal failure.

When the kidneys fail, there are two treatment options available: Dialysis and kidney transplant. Dialysis is a treatment that takes over some of the kidney's function by removing wastes, excess fluid, and salt from the blood. There are two types of dialysis that patients with end stage renal disease can choose from: Hemodialysis and Peritoneal dialysis. Each type of dialysis has advantages and disadvantages and each requires some restrictions to lifestyle. Although many people do well for years on dialysis, some develop problems that can make dialysis difficult or less effective.

As well as living donor transplantation, a dialysis patient may receive a kidney from a *deceased donor*. Due to the length of the waiting list, patients will have to be on dialysis for several years before they receive a deceased donor transplant.

3. The entire donor evaluation will take some time to complete – often three months or longer.

The medical questionnaire and basic laboratory tests take a certain amount of time to complete and must be reviewed before you can proceed to the special radiologic tests and an interview with the Living Donor Team. Some tests may need to be done several times to confirm a 'borderline' result.

If the donor lives outside of British Columbia or Canada the evaluation will take longer than that for a B.C. resident.

The Living Donor team will not contact you to remind you to do your tests – it is up to the potential donor to complete their testing and confirm that the Living Donor Team has received the results.

4. There are risks to the donor evaluation itself.

Potential donors need to undergo a large number of laboratory tests as well as some x-rays. These tests may lead to the discovery of previously unknown infections, tumours or other medical problems. Even if your health is not affected at the time the problem is identified, knowledge of the problem may affect future insurability. By law, positive tests for certain infections must be reported to health agencies.

The HLA testing (done to determine the “degree of match” between donor and recipient) may reveal the true identity of family relationships that some family members may not wish exposed.

Intravenous injections of contrast or radioisotopes are required for certain x-ray studies and these injections may cause severe allergic reactions (although this is very rare).

INFORMATION ABOUT KIDNEY TRANSPLANTATION

Kidney transplantation is the preferred treatment option for most people with kidney failure. A kidney transplant provides a patient with the best chance to return to a normal life, free from the restrictions of dialysis. Many studies have shown that people usually live longer, healthier lives with a kidney transplant as compared to dialysis. Most people state that they have an improved quality of life following transplant.

Prior to, or at the same time as, a living donor work-up, recipient suitability for transplant must be assessed. The Transplant Team assesses each potential recipient individually to decide if the benefits of a kidney transplant outweigh the risks. The Transplant Team must believe that the person is healthy enough to survive the surgery and benefit from getting a transplant.

Kidney transplantation is considered a treatment rather than a cure for kidney disease. It is considered when a patient's kidney function is less than 20%, there is no hope of reversing the kidney failure and the patient is having symptoms of kidney disease. Following a transplant, medications to suppress the recipient's immune system and prevent rejection must be taken as long as the transplanted kidney is in place. These powerful medications have a number of side effects and risks that are explained carefully before a patient decides to have a transplant. It is possible that a kidney transplant may be technically successful and functioning well but the patient has complications related to the anti-rejection medications, which limits the overall success of the procedure.

A transplanted kidney can function well for many years. Recent Canadian statistics show that approximately 80% of transplanted kidneys are still working well five years after the surgery. However, rejection of the transplanted kidney can occur even if medications are taken faithfully. Approximately 20% of patients will experience an episode of rejection. Rejection most often occurs in the first six months after surgery but it can happen at any time. With early detection and proper management, the rejection is usually treatable and the kidney function preserved. If it is not possible to reverse the rejection, the patient will lose the function of the transplanted kidney and return to dialysis. If a transplant is lost due to rejection or other reasons, a patient may be considered for a second transplant.

There is no known limit to how long a transplant kidney may function (it may last a lifetime) but the average length of time before return to dialysis is 18-20 years for living donor transplantation.

Patient and Graft Survival, BC and Canada Comparison

Program	<u>Patient Survival</u>	
<i>Kidney (Deceased Adult Donor)</i>	BC	CANADA
1 Year	97.1%	96.7%
5Year	88.8%	89.2%
<i>Kidney (Adult Living)</i>	BC	CANADA
1 Year	98.7%	99.1%
5Year	94.4%	96.0%

Program	<u>Graft Survival</u>	
<i>Kidney (Deceased Adult Donor)</i>	BC	CANADA
1 Year	93.1%	91.0%
5Year	81.2%	79.1%
<i>Kidney (Adult Living)</i>	BC	CANADA
1 Year	96.7%	96.4%
5Year	89.8%	89.5%

If the Transplant Team decides that a patient is suitable for a kidney transplant but they do not have a living donor, they are placed on the *deceased donor waiting list*. They are listed according to their blood type and how long they have been on dialysis. People with certain blood types may have longer waiting times than others. Currently, in British Columbia, it takes about five to ten years after starting dialysis to receive a deceased donor transplant.

Program	Year of Transplant	Average Time Waiting (Months)
Kidney (Adult Deceased Donor)	2000	35.9
	2001	50.1
	2002	55.8
	2003	57.6
	2004	57.7
	2005	65.4
	2006	72.6
	2007	60.3

Waiting Time by Blood Type* (Deceased Adult Kidney Donor)			
Year	Blood Type	Number of Transplants Done in BC	Average Time on Dialysis before Transplant (Month)
2007	A	11	64
	AB	1	41
	B	4	92
	O	11	85
2006	A	9	71
	AB	1	18
	B	5	89
	O	23	97

PHASES OF THE LIVING DONOR ASSESSMENT

The purpose of the living donor assessment is to ensure that donation is safe for the donor and that donation will result in a safe and successful kidney transplant. The evaluation includes a collection of your health history, various blood and urine tests, radiology studies, and clinical assessments by a nurse coordinator, social worker, and doctors.

If you or someone you know is interested in donating a kidney, initial screening will be carried out over the phone or in person.

A potential donor must be at least 19 years of age to be considered but there is no upper age limit. Please note that by the time people reach their late 60's there is often a normal reduction in kidney function making these people less than ideal as donors.

Common Conditions That Normally Prevent Kidney Donation

- High blood pressure
- Diabetes
- Cancer – even if it has been treated
- Heart disease
- Very overweight
- Kidney stones

If you have any of these conditions, you are unlikely to be suitable as a kidney donor. There are exceptions however, and if you have any doubt about your suitability, we encourage you to discuss matters with the Living Donor Nurse Coordinator.

Testing is usually performed in a stepwise fashion so that if the initial tests show that the donor and recipient are not compatible, no further testing is necessary. If a potential donor starts the assessment process, information obtained by the transplant centre is confidential. Test results will be given to the donor only. In certain cases, and only if the donor gives permission to do so, the information will be discussed with the recipient and their doctors.

If a potential donor decides to start testing, arrangements for the tests are made through the Nurse Coordinator. The tests can be done at a laboratory close to the home or work place.

If the potential donor lives outside British Columbia, the Nurse Coordinator will need to make special arrangements.

Step 1: Initial Health Screen and Compatibility Testing

To ensure kidney donation will be safe for both you and the recipient, there are a variety of areas we need to ask you about. We do this in a standard way by having you complete a detailed medical and social health questionnaire (MSHQ). This will help us gain an understanding of your health history, and what your current level of health may be.

Transplantation involves a potential risk of disease transmission from the donor to the recipient (i.e. HIV, hepatitis, West Nile virus, cancer etc). Therefore, a screening process is performed for all potential organ and tissue donors. This is a mandatory requirement of Health Canada. This MSHQ needs to be completed in order to comply with established government regulations and safety guidelines for organ and tissue donation. You will find that many of the questions in the questionnaire are similar to those asked when donating blood.

A negative blood test does not guarantee that a person is free of infection such as HIV and hepatitis. This is because there may be a period of time between getting the infection and medical tests being able to detect the infection. Therefore, we also need to ask some questions about personal activities including sexual practices and lifestyle choices that are associated with the spread of these diseases. Please be assured that all information gathered is confidential and is used only to assess your suitability as a donor. No information will be discussed with the potential recipient unless your permission has been obtained.

Also, it is crucial to determine whether the potential donor and the recipient are compatible. There are some incompatibilities that cannot be overcome with our anti-rejection drug treatment. The critical compatibility tests are:

- Blood typing
- Crossmatching

Blood Typing

If you are blood group:	You can donate to:	You can receive from:
* O	A, B, AB, O	O
A	A, AB	O, A
B	B, AB	O, B
**AB	AB	O, A, B, AB

* universal donor

** universal recipient

Matching for the Rhesus (Rh) factor – the ‘positive’ or ‘negative’ part of the blood group – is not necessary for kidney transplantation

Crossmatch

A crossmatch blood test identifies antibodies in the blood of the recipient, which would attack the donated kidney as soon as it is transplanted. Therefore, if the crossmatch is *positive*, the potential donor cannot donate to that recipient. A *negative* crossmatch means there is no antibody reaction and the donor assessment can proceed. Immediately prior to the transplant, a repeat crossmatch is done to ensure the result has remained negative.

Another test is also done at the same time as the first crossmatch, which is called **tissue typing**. Tissue typing determines the degree of “match” between the donor and the recipient. In other words, it determines how closely the donor and recipient’s tissues resemble each other.

In theory, the closer the tissues resemble each other, the less likely there will be rejection of the kidney. In practice, with modern anti-rejection medications, the degree of matching has little influence on the outcome after kidney transplantation. So, cases where there is little or no matching between donor and recipient are still expected to do very well.

If a donor and recipient are blood group incompatible or the crossmatch is positive, the potential donor may choose to participate in the *Living Donor Paired Exchange Program* (Appendix A). If the potential donor does not register in this program then no further testing is done.

The *Living Donor Paired Exchange Program* is also available to any donor and recipient pair that are compatible, but both still wish to participate in an exchange. (i.e. this may benefit the recipient in finding a more medically compatible donor)

Step 2: Laboratory and X-ray Studies

To qualify as a kidney donor, the donor must be in excellent health with excellent kidney function. This is to ensure that future health will not be compromised. To evaluate the donor's health, further testing is done:

- Infectious Disease screening
- Blood pressure readings
- Blood tests including fasting blood tests
- Urine tests
- Chest x-ray
- Electrocardiogram (ECG/EKG)
- Kidney ultrasound

Instructions for these tests are sent to the donor and their family doctor. Potential donors are encouraged to make an appointment with their family doctor to get an independent opinion about their suitability as a living kidney donor, as well as getting their blood pressure checked and getting the paper work for the laboratory tests. The tests usually take a couple of weeks to complete and can be done at most community laboratories.

NOTE: Abnormal test results that prevent kidney donation and require further testing or follow-up will be referred back to the family doctor.

Infectious disease screening is carried out on all donors. The purpose is to check for infections which may transmit to the recipient with the transplanted kidney. If the donor shows evidence of infection from HIV, syphilis, Hepatitis B, Hepatitis C or West Nile virus, we will not be able to proceed with the transplant. Positive test results for some infectious must be reported to an appropriate health agency for follow-up.

Certain extra tests may be required depending on the age, past medical history and family history of the potential donor. For example, some potential donors may need to undergo cancer screening tests like pap smears, mammograms, colonoscopy or PSA blood tests if they have not been done recently.

All tests are reviewed by the Living Donor Team to make sure the donor is a suitable candidate. If any results are unclear, additional tests may be required.

The Living Donor team will not contact you to remind you to do your tests – it is up to the potential donor to complete their testing and confirm that the Living Donor Team has received the results.

If the tests in Step 2 are complete and look favourable to the Living Donor Team, all donors must undergo a nuclear medicine study called a **renogram**. This is booked at a hospital in Vancouver through the nurse coordinator.

During this test, a radioactive tracer is injected into the bloodstream and is excreted by the kidneys into the urine. A scanner detects the tracer and shows:

- how well the kidneys are functioning (expressed as a number, ml/min., normalized for your body weight and height)
- the percentage of function contributed by each kidney.

This test usually takes about 4 hours.

Step 3: Team Evaluation

If the results of the testing are suitable for kidney donation and the donor wishes to continue with testing, appointments are made with members of the Living Donor Team in Vancouver. There are three kidney transplant hospitals in Vancouver (St. Paul's Hospital, Vancouver General Hospital, and British Columbia's Children's Hospital). Where the donor goes for their Living Donor Team assessment will depend on where the recipient has been referred.

Members of the Living Donor Team include:

- Transplant Nephrologist (kidney specialist)
- Transplant Urologist (surgeon)
- Nurse Coordinator
- Social Worker

All potential donors will undergo a psychosocial evaluation by an individual with mental health training (e.g. clinical social worker, nurse specialist, psychologist or psychiatrist) in order to determine if the donor will be able to cope with the effects of the donation process. There are potential psychosocial and financial risks, and it is the job of the examiner to explore such issues with the potential donor as part of the informed consent process.

The following are questions for potential donors to consider prior to their evaluation by the Living Donor Team:

How do I feel about donating to the intended recipient? In some cases, family conflicts may already exist. In other cases, a potential donor may feel uncomfortable (e.g. about the lifestyle of the recipient) and feels that a conflict could arise after donation. Maybe, one cannot yet pinpoint the reason that she or he is reluctant. Some concerns can be worked through during the Team appointments and through discussion. It is perfectly acceptable for a potential donor to come to the evaluation knowing he or she feels ambivalent or uncertain about donation. Possibly, during the appointment, the ambivalence can be lessened or resolved based on information sharing. If not, the Living Donor Team may suggest the potential donor “opt out” of the process after a period of reflection.

Can I afford to be a living donor? There are many costs associated with becoming a living donor and there are few options for financial support available to donors. Will the potential donor be able to take 6 to 8 weeks away from work following surgery with the support of their employer? Will there be financial stability during this time? There is no financial remuneration specifically for living kidney donors. If the donor has an Extended Benefits plan through work, they will qualify for the Sick Benefits as described by the plan for any similar illness or surgery. The fact that this may be a voluntary medical procedure does not disqualify the donor from receiving benefits.

Potential financial risks to consider include, but are not limited to: Personal expenses of travel, housing, and lost wages related to live donation; Child care costs; Elder care costs; Pet care expenses; possible loss of employment; Potential impact on the ability to obtain future employment; Potential impact on the ability to obtain or afford health, disability, and life insurance; Health problems experienced by out-of-country living donors following donation may not be covered by their insurance; Potential cost of providing transportation and accommodations for support person to accompany donor for surgery

The Kidney Foundation of British Columbia administers the *Living Organ Donor Expense Reimbursement Program (LODERP)*, which is a program that has been funded by private sponsors and the British Columbia Provincial Government to help reduce some financial barriers to organ donation. This program does not eliminate all potential costs to donors and does not serve as an incentive to recruit otherwise reluctant donors. Please see **Appendix C** for frequently asked questions about this program.

What will my insurance cover? This is a question that needs to be explored prior to donation. *If a potential donor is not a Canadian citizen, the costs incurred for the surgery and hospital stay are covered under the recipient's British Columbia health care insurance.* For donors who are not Canadian citizens, we strongly recommend discussing matters with your insurance company before donation takes place. If complications arise from donation, you may not be covered for ongoing care after leaving the province of BC. Even if there are no complications, it is expected that donors undergo check-ups regularly to monitor their health and recovery after surgery. It is possible insurance companies outside of Canada may not pay for all of the costs incurred.

What about my future insurability (e.g. with respect to loan, mortgage, disability, critical illness and life insurance)? These are important issues that a potential living donor needs to explore prior to donation. A living donor does undertake certain risks in terms of current and future insurability. The insurance industry has a wide range of policies, attitudes and approaches to the insurance needs of individuals who may undergo a donor evaluation and donor surgery. Below are three potential examples:

Example 1: A prospective donor will undergo extensive medical testing and may learn about a pre-existing condition she or he may not have discovered for many years, if at all. In the case of a young donor, it might be important to purchase health insurance and life insurance policy before undergoing such a rigorous testing process, learning of an unknown medical condition and potentially rendering yourself uninsurable.

Example 2: An individual is approved as a living donor and later (post-donation) decides to increase his or her life insurance limits. The insurance company does the necessary blood work and notices that the donor's renal function is lower than expected (compared to someone with two kidneys). The donor's kidney function may be perfectly acceptable for someone who has donated a kidney; however an insurance company may deny or limit further coverage. The Living Donor Team works to advocate for the rights of our living donors however we cannot guarantee that discrimination will not occur.

Example 3: An individual has a complication from the donor surgery and is temporarily or permanently disabled. It is important to consider obtaining disability insurance that includes protecting a donor's mortgage and other debt, in the event that a complication occurs.

Do I know enough to make a logical and educated decision? Research shows that many potential donors come to their clinic appointment already determined to be a kidney donor. They may have little information about the risks to the donor or the recipient as well as other treatment options available to the recipient. The Living Donor Team encourages all potential donors to keep an “open mind” prior to and throughout the testing process and to ask important questions that will help them make a logical decision. The Living Donor Team would like to see that potential donors have not only read the information in this booklet before their assessment appointment, but that they also do outside research in order to have an interactive discussion with the Transplant Specialists. It is recommended to make notes about any questions or concerns and to bring those questions to the clinic appointment.

Am I being pressured to be a living donor? A potential donor may come forward based on a feeling of obligation or duty to family. Organ donation is a gift and it is important to view it as such. Once the “gift” is given, it cannot be returned. Whether one is a spouse, family member or friend, giving a gift that one may resent at a later time is neither helpful to the donor or the recipient, and could cause future conflict. It is the belief of the Transplant Program that no one individual is obligated to donate a kidney. However, some individuals feel an obligation that comes from within, even though no outside person is pressuring him or her. These are feelings each individual must explore and can be discussed during the clinic appointment.

If there is more than one possible donor, how will the living donor be chosen? There are many factors that are taken into consideration about who the “number one” donor will be. The Living Donor team will work closely with the recipient’s Transplant team to determine if there is a medical reason to choose one donor over others. If there is more than one suitable donor and there is no preference for medical reasons then the decision is usually made by the recipient and various donors discussing it among themselves. The Living Donor Team will be available to help assist with this decision process if needed.

What are the medical risks involved? It is important for potential donors to explore the risks and to inquire about the facts around the long-term health effects to previous living donors. This is reviewed in detail later in the booklet. Questions that need to be considered include:

- Possibility of death or a major disability arising from living donor during surgery
- Potential impact of donation on the donor’s lifestyle: A potential donor who is involved in extreme sports (e.g. boxing, football and skydiving) would need to discuss how kidney donation might impact his or her lifestyle.

- Potential for problems with body image? A potential donor would need to be aware that he or she would have a scar where the kidney is removed.
- Potential risk of developing an illness later in life that could affect kidney function (e.g. high blood pressure, diabetes)
- Potential for death or major disability in the recipient arising from the transplant operation or the medications required after transplantation.

How does my religion or spiritual belief or culture view organ donation? The donor must look at factors that might cause conflict in his or her life, after kidney donation. If there were the potential of a major conflict affecting one's relationship with important people in the donor's life, it would be helpful to consider those issues.

Do I have a "support network" to help me through this process? The support of family and friends will assist in preparing for surgery and recovery. Support can reduce healing time and will contribute to an overall sense that the decision to be a donor is the right one. On a more practical level, family and friends may help with some cooking, shopping, homemaking, yard work, transportation and child - care after the donor's discharge from hospital. Some people have a difficult time asking for help and are used to being independent. This is the time to think about finding a support network to be on hand and to determine how they can be helpful. Many people would like to be of service, but do not know how they can help and simply need a little direction.

As with other similar surgeries, a nephrectomy is considered an acute illness (temporary) and therefore homemaking support is not available through the BC Provincial Long Term Care Program. If the donor's financial situation allows this, some people choose to hire a homemaker for a short period of time during their recovery.

How will I feel if I am rejected as a result of the screening process? Most potential donors come forward to help a loved one (family, friend or colleague) and are extremely committed to the process. Many potential donors have self-determined before coming to their assessment appointment that they will be the "chosen donor". They are often sure they will be found medically suitable and, in these cases, can suffer an emotional letdown if they learn that they would be placed at medical risk, and therefore not allowed to donate.

Am I prepared to deal with the possible rejection of the organ? The kidney is always at risk and may be lost at any time due to rejection, recurrence of the original kidney disease or other medical complications. While the Transplant team works carefully with the recipient to protect and preserve the kidney, the possibility for a poor outcome always exists and it is vital for potential donors to think about how they might cope with this loss.

Step 4: CT scan

A CT scan is the final medical test routinely required for the donor evaluation. **It will only be performed if all of the investigations and the clinical assessment of the donor are acceptable for donation.** Its purpose is to evaluate the anatomy of the kidney, and this may influence which kidney will be used for donation.

The CT scan is done in a Vancouver hospital in the radiology department. A contrast medium (similar to dye) is injected intravenously immediately before the CT scan.

The procedure is not painful but does carry a small risk of complications such as an allergic reaction to the dye. If you have had a similar test in the past and developed a reaction to the intravenous contrast, it is important to let the Living Donor Team know.

Team Meeting

After the living donor evaluation is complete, all of the tests and information obtained during the Team consultations will be carefully reviewed.

Donation can proceed only if all the tests, medical examinations, and other consultations indicate that it would be a safe procedure.

If there are any concerns that donating a kidney puts the donor at risk beyond the usual accepted risks (surgical risks are described in a later section), donation will not be possible.

SURGICAL ASPECTS OF KIDNEY DONATION

A donor nephrectomy is considered major surgery. Since it is only performed on healthy individuals, the complication rates are low. The most important consideration when planning this surgery is the safety of the donor.

Planning the operation

Every donor operation is unique and there are many different factors that need to be considered when planning the operation. One of the first decisions to be made is whether to remove the left or right kidney. If one of the kidneys appears to be slightly smaller than the other (on ultrasound) or one of the kidneys appears to provide slightly less function than the other (nuclear renogram study) then this smaller kidney would be preferred for transplantation in order to leave the larger, stronger kidney with the donor. If the medical evaluation suggests the two kidneys are equivalent in size and function then the vascular anatomy (seen on the CT scan) will determine which kidney is preferred. Your surgeon will also discuss whether you are a candidate for a laparoscopic nephrectomy or a traditional open nephrectomy.

Choosing a date for the surgery requires discussion between the donor, recipient, surgeon, nephrologist and nurse coordinator. After completion of the medical evaluation and review of the X-rays and scans, the Living Donor Team will be able to offer a date for surgery depending on the availability of operating room time. Families often decide to delay the operation for many practical reasons such as arranging for time off work.

Pre-Assessment Clinic

An appointment may be arranged with the Pre-Assessment Clinic. The main purpose of this appointment is to prepare for the day of surgery and the donor's hospital stay. A nurse will review the admission procedure for the day of surgery. An anaesthetist will discuss any anaesthetic issues as well as pain control following the operation.

Many donors do not need a Pre-Assessment visit given their excellent health and low risk for complications. If you need to go to the Pre-Assessment clinic, you will be notified in advance.

The Surgical Team

The actual operation is performed with the help of a number of individuals. There is an anaesthetist (and often an anaesthetic resident) who is responsible for administering the general anaesthetic as well as monitoring vital signs and maintaining normal cardiac and respiratory function during the operation. The anaesthetist will also be involved in the post-operative pain management.

A Transplant surgeon and surgical resident will perform the surgery.

A team of nurses will assist with the operation and stay with the patient from the time they come into the operating room until they are stable in the recovery room.

The Operation (Donor Nephrectomy)

Laparoscopic donor nephrectomy:

The majority of donors have the surgery performed laparoscopically. When the patient is asleep, four small incisions are made in the abdomen then a camera plus three other long, thin instruments are introduced into the abdominal cavity (see diagram). The surgery takes about four hours. The kidney, along with a length of artery, vein and ureter, is removed and the cut ends of the artery, vein and ureter are closed with staples. The adrenal gland is not removed. The kidney cannot be removed through one of the four small incisions so a fifth incision (approx. 4 inches) is made in the lower abdomen to extract the kidney. All skin incisions are closed with absorbable sutures.

During laparoscopic nephrectomy, it is possible that intra-operative bleeding or an injury to the bowel may require conversion to open surgery. This is estimated to occur in approximately 3% - 5% of cases.

Not every potential donor is a good candidate for laparoscopic nephrectomy. Examples include people with previous abdominal surgery or complicated renal anatomy seen on the CT scan. The transplant surgeon will discuss these matters with you.

Traditional (open) donor nephrectomy:

The kidney is removed through an incision in the back and flank area. The incision is typically six to seven inches in length, depending on the size of the donor. The kidney, along with a length of artery, vein and ureter, is removed and the cut ends of the artery, vein and ureter (remaining in the donor) are tied off with sutures (stitches). The adrenal gland is not removed. A rib is not removed or broken. After the kidney is removed, absorbable stitches are used to sew muscles of the flank and abdomen back together. Absorbable stitches are used to close the skin. The length of the operation is about three hours.

The recovery following an open nephrectomy is expected to be somewhat longer and more painful than with laparoscopic nephrectomy. Eventually, the patients having open surgery make a complete recovery and there is no long-term benefit to laparoscopic nephrectomy over open nephrectomy.

Diagram 1: Normal Renal Anatomy

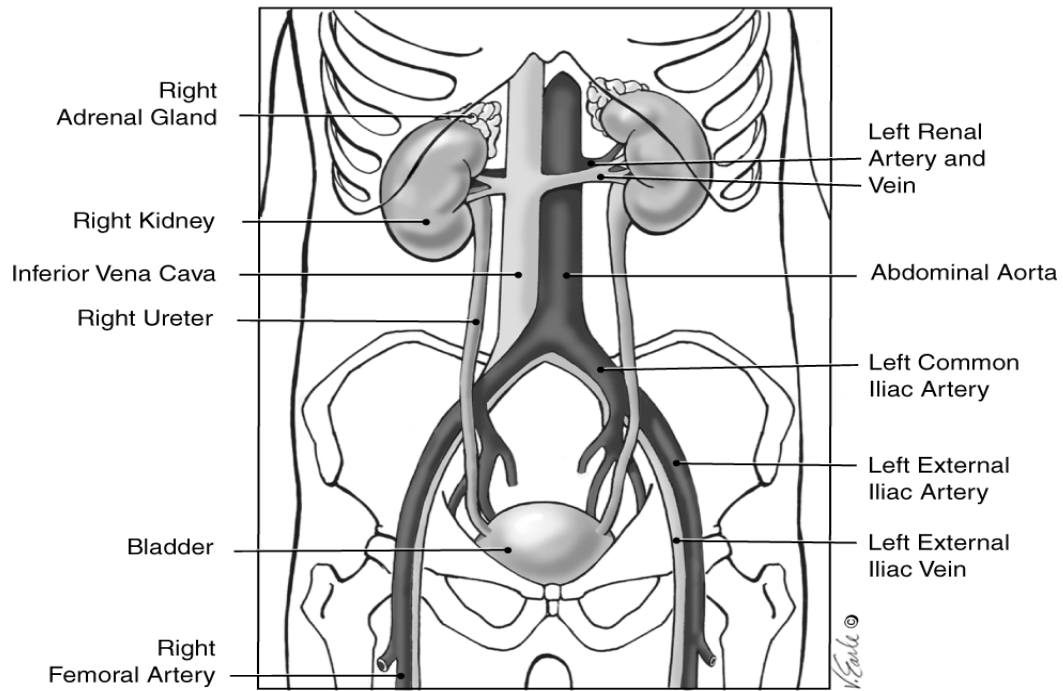
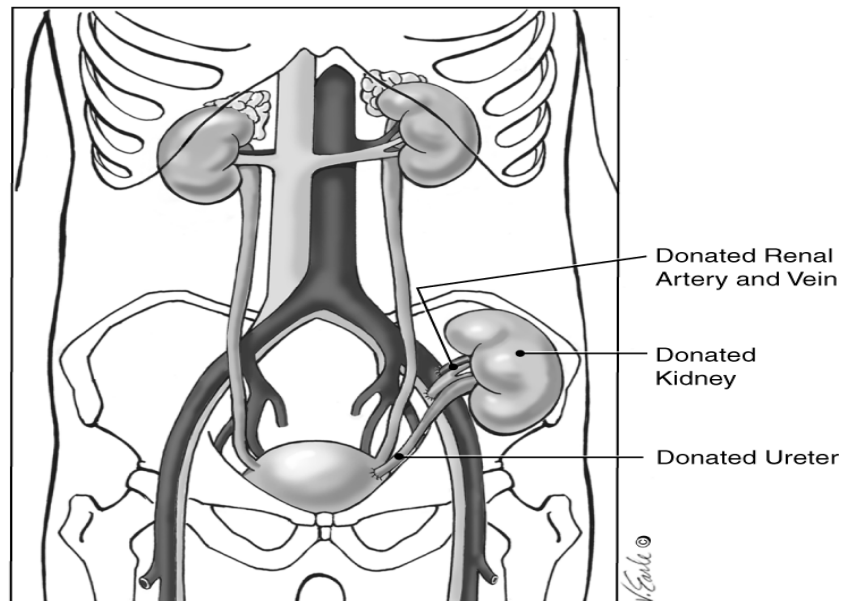
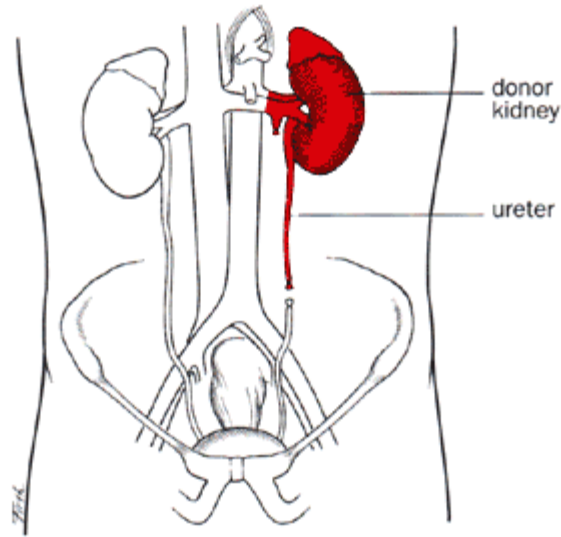


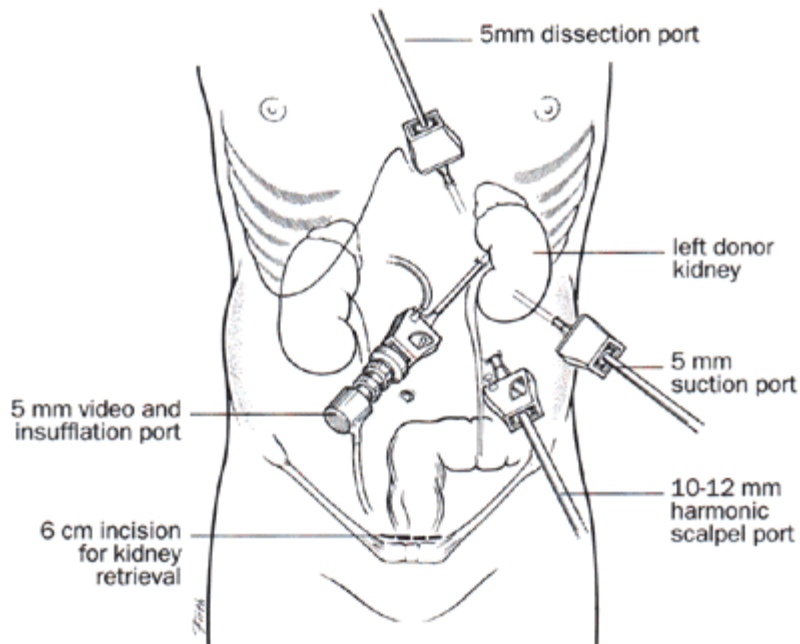
Diagram 2: Transplanted Kidney



Laparoscopic Donor Nephrectomy



Four small incisions are made in the abdomen so that instruments can be inserted; the surgeon then retrieves the donated kidney through a fifth, slightly larger incision.



Intra-operative and Post-operative Risks

The estimated risk of dying or suffering a heart attack or stroke as a result of the donor operation is estimated to be 3 in 10,000. Laparoscopic nephrectomy is not safer than open nephrectomy. The main benefit of laparoscopic nephrectomy over open nephrectomy is a faster recovery and less pain in the early days after surgery.

Risk of Surgical Complications	
Heart Attack / Cardiac Arrest/ Death	<0.03%
Pulmonary Embolism (blood clot traveling to the lung)	<0.1%
Venous Thrombosis (blood clot) in the leg(s)	<0.5%
Bleeding requiring a blood transfusion	<0.5%
Injury to bowel, spleen, liver, pancreas requiring further surgery	<0.5%
Pneumothorax (collapse of the lung)	1%-2%
Post-operative pneumonia	1%-2%
Post-operative urinary tract infection	1%-2%
Post-operative wound infection	2%-5%
Post-operative flank "bulge" (seen in open surgery only)	20%-25%
Post-operative back and shoulder ache lasting days to weeks (seen in laparoscopic surgery only)	20%-25%
Conversion to open surgery (seen in laparoscopic surgery only)	3%-5%
Areas of skin numbness around incisions	Common
Other Risks	
Post-operative pain for 1-3 weeks	Universal
Post-operative nausea for 24-48 hours	Very common
Post-operative constipation for 1-2 weeks	Very common
Risk of Anaesthetic Complications	
Injury to teeth, pharynx, larynx during intubation	<1%
Serious Allergic/Adverse reactions to anaesthetic or other medications	1%

POST-OPERATIVE INFORMATION

Pain Control

Pain is a ‘complication’ of surgery that is unavoidable but it is also something that can be well controlled with appropriate analgesics (painkillers). Immediately after surgery there are two ways of controlling pain:

- patient-controlled analgesia
- epidural analgesia

The first option for pain control is called *patient-controlled analgesia* (PCA). This is offered to patients undergoing laparoscopic nephrectomy. This involves the use of an intravenous narcotic (usually morphine although other narcotics may be used in certain cases). There is a control button the donor can push to give themselves a dose of narcotic whenever the pain increases. There is a limit to how frequently the button will work so it is impossible to administer a large dose accidentally.

A patient cannot become addicted to narcotics when they are used in a controlled setting for a limited period of time. The intravenous narcotics do have some side effects such as nausea, drowsiness and itchy skin.

The second option is called *epidural analgesia* and is offered to patients undergoing open, traditional nephrectomy. Epidural analgesia involves placement of a small flexible plastic catheter in the upper back close to the spinal nerves. Placement of the catheter is done in the operating room while the donor is still awake (using local anaesthetic) and does carry some small risk such as injury to a spinal nerve (rare) or bleeding around the spinal cord (very rare). Narcotics are infused through the catheter and this blocks the pain signals coming from the incision. This catheter is usually left in place for three to five days. The narcotics do not block normal sensation or motor function so the patients can walk around with the epidural catheter still in place.

For patients undergoing traditional open nephrectomy, the choice of pain control is largely up to the patient (epidural or PCA). Some people with prior back surgery or back problems may not be good candidates for the epidural catheter.

The In-Hospital Recovery

Typically, a kidney donor remains in hospital for about two to three days following laparoscopic surgery, and four to five days following open surgery.

The evening after surgery, most patients are drowsy or fatigued so they stay in bed until the following morning. Nausea and dry mouth/thirst are commonly experienced. The patients are not allowed to eat and can drink only small amounts of fluids, as this may make the nausea much worse. A nurse will be monitoring the vital signs, urine output and level of pain. A catheter drains the urine from the bladder so the patient does not

need to go to the washroom (the catheter is placed in the operating room when the patient is asleep).

The day after surgery, the donor is encouraged to sit in a chair for short periods of time. A physiotherapist will be available to assist in recovery by demonstrating deep breathing and coughing exercises and movement post-surgery. The donor may walk around the room if pain control is adequate and may start taking fluids by mouth if the nausea has stopped.

The second day after surgery, the donor is encouraged to walk as much as possible. The catheter in the bladder is removed. The remainder of the hospitalization will focus on increasing activity levels and switching the painkillers from intravenous to pills that could be taken at home.

The First Two Months After Surgery

Although the skin incisions may appear to be well healed, the muscles underneath are still healing and knitting together for about six weeks after surgery. It is very important to avoid straining these abdominal and flank muscles during this healing period as they are vulnerable to stretching and may develop permanent weakness.

We encourage walking and light activities as soon as the donor is able but there should be no heavy exercising, stretching or physical labour until six weeks has passed. Many people start driving around ten days after discharge from hospital.

Some donors return to work around two to three weeks after surgery if the job does not involve much physical activity, however, most people go back to work between six and eight weeks after surgery.

Sexual function should not be affected because of donating.

Post-Donation Experience:

The period leading up to donation may be very intense. There will be many tests, appointments and frequent contact with the Living Donor Team. There may be practical affairs to arrange such as leave from work, short-term disability applications to be completed, and perhaps child-care arrangements to be made. The donor usually spends a lot of time talking about the donation with friends and family and a sense of anticipation is normal.

Many donors report a sense of relief after the surgery. Watching the recipient recover with restored kidney function may give the donor a sense of satisfaction and well being while recovering from the surgery. Donors often feel a very strong conviction that they made the right decision and express a desire to speak with other donors about their experience.

Occasionally, donors report feeling a sense of let-down or disappointment, even if the transplant is successful. This may be a normal response to the pre-transplant excitement. The letdown that some donors experience usually does not last long and disappears with regained strength and as the donor discusses the experience with family and friends. It may be helpful to talk about these feelings with the Living Donor Social Worker.

LONG-TERM FOLLOW UP

There are no special dietary restrictions for donors.

No medications are required after donation (other than post-operative painkillers).

We encourage the donors to be physically active and this includes returning to most recreational activities such as skiing, snowboarding, running, soccer, hockey, rugby etc. There are a few activities that may be considered high risk for someone with one kidney including skydiving, boxing, competitive martial arts, equestrian sports, and highly competitive or professional contact sports. Some university varsity sports teams or professional sports teams may deny participation if a person is known to have only one kidney (this will vary according to the sport and institutional policy).

It is important that donors are seen on a regular basis by their family doctor for a blood pressure reading and laboratory tests to monitor kidney function. The Team will send out requisitions for medical testing to the donor and family doctor, and request the results be returned to the Living Donor Program for review.

The recommended timeframe for these tests/visits are at the following time points post-surgery:

- 2 weeks
- 2 months
- 6 months
- 1 year
- Yearly thereafter

Members of the Living Donor Team will be available for any follow-up that may be required. The donor has provided an immeasurable gift to the recipient and it is our program's wish to provide long-term support and encouragement to our donors.

In addition, the Living Donor Social Worker will make an annual attempt to contact the donor in order to ensure that he or she is coping well both medically and emotionally. The Transplant Team cannot always predict or guarantee how long the donated kidney will survive in the recipient. Therefore, the Living Donor Team recognizes that there may be a time when a donor may need emotional support, especially if their loved one's medical condition has worsened.

The Living Donor Team leaves the door open for the donor to contact the Living Donor Social Worker or the Nurse Coordinator at any time.

Live-donor kidney transplantation has been performed since the late 1950s. Donors from this early period have been evaluated in several long-term follow-up studies to document the safety of the procedure:

- There has been no convincing evidence that kidney donation leads to any medical problems, even 30 years after the operation.
- Several studies have shown that there is no increased rate of renal disease, cancer, heart disease, or diabetes among former kidney donors as compared to the general population.

High Blood Pressure After Donation:

Some studies have suggested that former kidney donors are slightly more likely to develop high blood pressure than healthy people with two kidneys. Other studies have shown no increased risk of high blood pressure in former kidney donors. This is an area of ongoing research and there is no consensus yet in the medical literature.

High blood pressure is a common condition, which affects many people, whether they have one or two kidneys. If a former donor does develop high blood pressure, it will be important that they are followed closely and that the blood pressure is brought under control. Poorly controlled high blood pressure (hypertension) may lead to progressive kidney disease, particularly in the setting of a solitary kidney.

Kidney Function After Donation:

After one kidney is removed, the remaining kidney will increase its function, although not enough to completely replace the lost kidney. It is expected that a donor's kidney function will achieve approximately 75% of their pre-donation level. It may take two or three months to arrive at this new baseline and any testing done in the early months after donor surgery may appear to suggest poor renal function.

The Living Donor team tries to keep a complete database on all kidney donors to monitor their kidney function over time.

Protein in the Urine After Donation:

Some studies have found that up to 30% of kidney donors may develop protein in the urine 10 to 20 years after donation. Protein in the urine is not normal, but it is not a disease by itself. Former donors who have developed protein have not been seen to go on to kidney failure so it is uncertain whether this is a significant problem or not.

If a donor does develop protein in the urine, they would normally be assessed by a kidney specialist (nephrologist) to determine if any treatment is required.

Pregnancy:

Many women are concerned about future pregnancies and whether kidney donation will complicate the pregnancy or delivery. The medical evidence available suggests that there is no additional risk to a former kidney donor's kidney function if she becomes pregnant. Likewise, having a solitary kidney does not appear to interfere with a woman's chances of becoming pregnant or delivering a healthy baby.

It is recommended to avoid becoming pregnant for six months after surgery. If a former kidney donor does become pregnant, we generally recommend an ultrasound of the kidney during the first and third trimesters to verify that the kidney is healthy during the pregnancy.

Thank you for your interest in the Living Kidney Donor Program. If you have any questions or concerns, we will be pleased to discuss them with you.

APPENDIX A: The Living Donor Paired Exchange Program

When a potential donor and recipient have incompatible blood groups or there is a positive crossmatch, they may be eligible for the *Living Donor Paired Exchange (LDPE) Program*. It is also available to any donor and recipient pair that are compatible, but both still wish to participate in an exchange (i.e. this may benefit the recipient in finding a more medically compatible donor).

In this program, we attempt to match donor and recipient pairs with another pair in a similar situation. If appropriate pairs can be matched then the donor kidneys can be swapped and allow both recipients to receive a transplant (see examples 1 and 2 below).

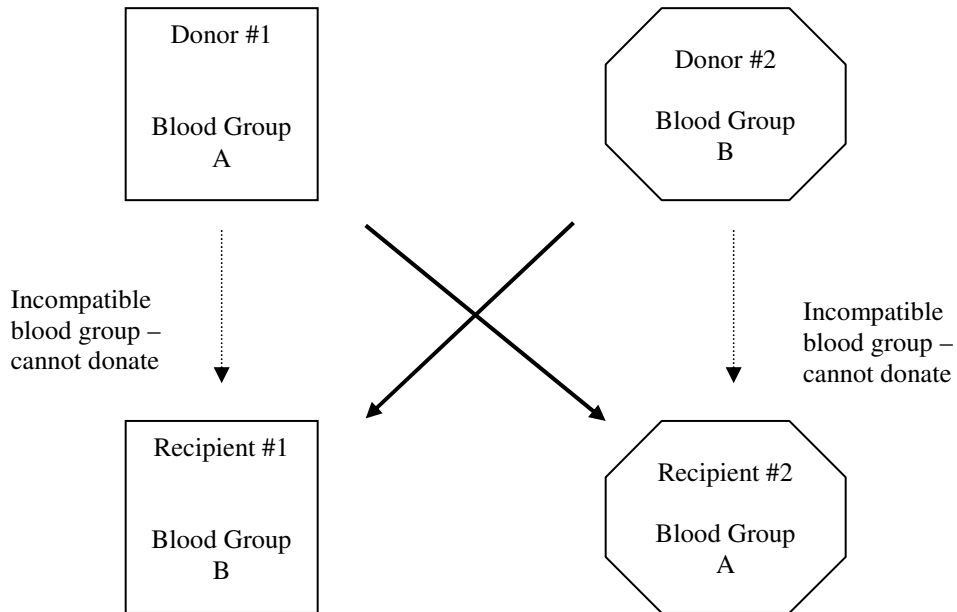
Both the donor and recipient must be evaluated and approved before they can be listed in this program. They must also sign a consent form indicating that they understand the program. The Transplant Team and Living Donor Team will periodically review the database for potential matches and efforts will be made to find comparable matches (so that the donor kidneys are not too dissimilar in age and kidney function). If a suitable match is found, the two pairs will have to undergo further testing, such as a crossmatch, before we can plan the surgery. ***It is quite possible that a suitable match will not currently exist on the database and that a pair may have to wait many months, or years, before a match can be found.***

An important aspect of this program is that the pairs will remain anonymous to each other. You will not know any personal or identifying details about the other pair and you must agree not to seek out or attempt to identify the other pair. We will usually perform the surgeries at two different hospitals so that the pairs do not meet while recovering in hospital. The two donor operations will be performed at the same time so that there is no chance that one donor will go through with the surgery while the other donor changes their mind at the last minute. ***Because the surgeries require a great deal of coordination and planning, you may not have much control over the date of the surgery.***

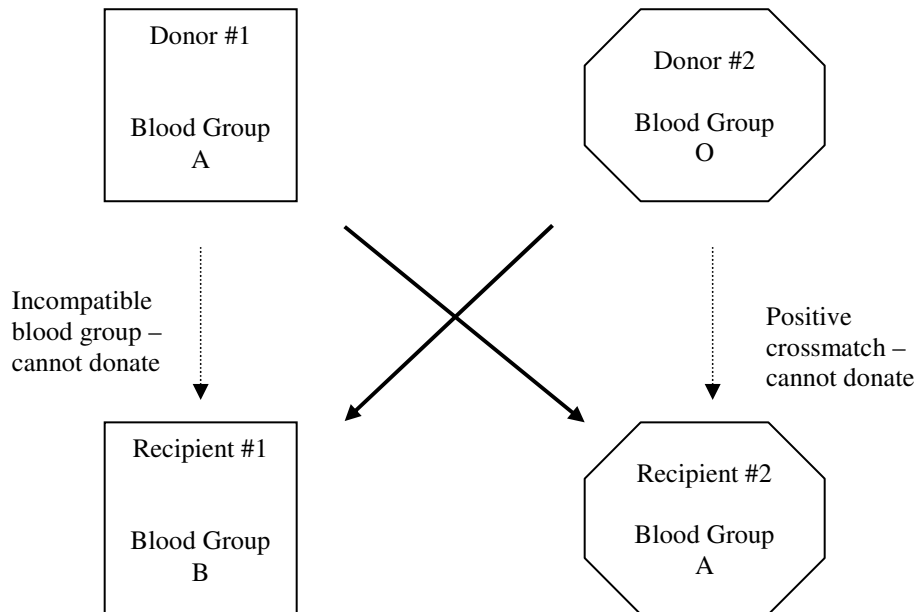
There is now a national program for Living Donor Paired Exchange, which is overseen by the Canadian Blood Services. This is a benefit to all donor and recipient pairs as there will be more pairs to draw from, and therefore, more chances to find a match. Patients enrolled in this program will be asked if they are willing to travel for the surgery as they may be offered an opportunity for a transplant that would require them to go to another transplant centre. This would be discussed in detail if appropriate.

There is also an opportunity for a Living Anonymous Donor kidney to be utilized in the Living Donor Paired Exchange. This is described in APPENDIX B.

Example 1



Example 2



APPENDIX B: Living Anonymous Donor Program

It is possible that a motivated person may wish to donate a kidney but they may not personally know any patients in need of a kidney transplant. Phone survey studies of the general public have shown that up to 30% of people would “seriously consider” donating a kidney to a complete stranger. These potential donors may participate in the *Living Anonymous Donor* (LAD) program.

In addition to the standard donor evaluation previously described, the potential anonymous donor is also required to:

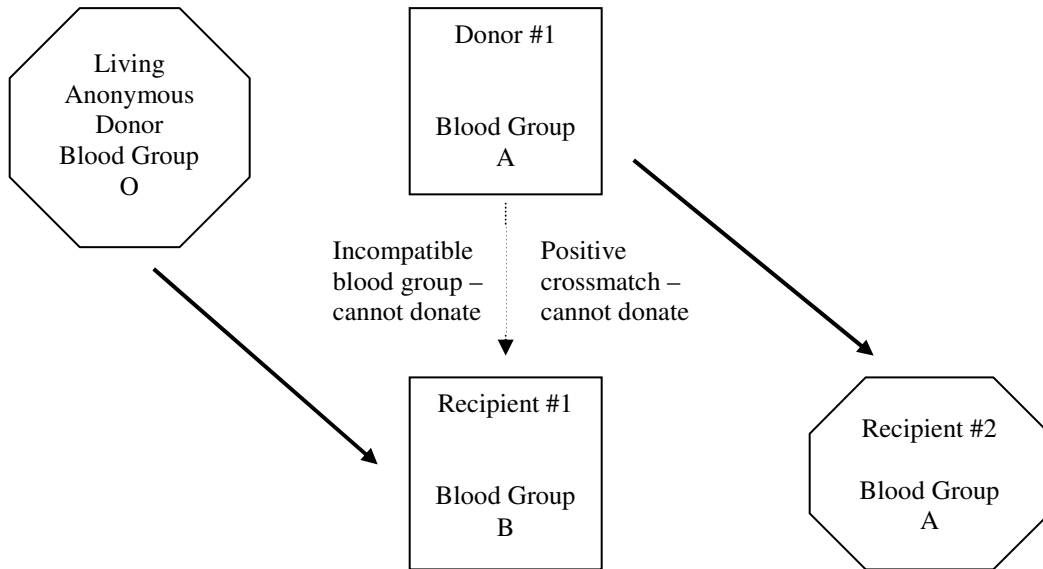
- Be 25 years of age or older
- Be evaluated by a psychologist or psychiatrist to better understand their motivation to donate.
- Have a mandatory wait period from time of the Team decision of suitability to operation time being set.

After successfully completing the full evaluation, a person may donate anonymously to the waiting list and the kidney would be transplanted into the first suitable recipient at the top of the list. ***The donor is not allowed to choose the recipient, and the two are not allowed to meet afterwards.***

The LAD may also be offered the opportunity to participate in the *Living Donor Paired Exchange* (LDPE) program. In such a case, the anonymous donor would donate to a recipient (listed with an incompatible donor) and the second donor would then donate to the deceased donor waiting list (see example 1 below). In this arrangement, two people get transplanted due to the anonymous donor, rather than one, as when the anonymous donor gives directly to the waiting list. A “domino” paired exchange can also be generated if more donor and recipient pairs on the list match than just one (i.e. 5 to 6 donor/recipient pairs may benefit)

It may occur that a person hears of a story or a particular person’s need for a kidney and they decide that they would like to donate even though they do not personally know the intended recipient. There are even Internet websites that promote this concept; where potential donors can review a list of patients in need of a kidney transplant and read their posted case histories. We feel that soliciting donors from the general public is unfair to the other patients waiting who have not done this, so we encourage donors wishing to help a stranger to do so in the anonymous donor program. That being said, we cannot regulate how people get to know each other and our policy does not prevent potential donors and recipients from meeting and developing a relationship over the issue of donation and transplantation. Simply, a meaningful relationship must exist before a potential donor is allowed to proceed with their evaluation.

Example 1



APPENDIX C: Living Organ Donor Expense Reimbursement Program (LODERP)

FREQUENTLY ASKED QUESTIONS (FAQs)

What does the program aim to achieve?

The program aims to remove financial barriers to living organ donation thereby potentially increasing the number of transplants in BC and increasing the quality of life for transplant recipients.

Who is eligible for funding in this program?

Funding will be considered for individuals who provide a kidney or partial liver to a BC resident (who must be covered by the BC Medical Services Plan), only after all other potential sources of financial support have been exhausted.

Can the living organ donor come from outside of BC?

Yes, living organ donors, who have been pre- screened to the final assessment stage, may come from across Canada or anywhere else in the world.

How does someone apply for funding?

Applications for funding must be made through the transplant programs at BC's three transplant centers – St. Paul's Hospital, Vancouver General Hospital, and BC's Children's Hospital. Please contact the Living Donor social worker to make an application. Completed applications will be forwarded by the Living Donor social worker to The Kidney Foundation of Canada, BC Branch for review and approval.

Expenses must be pre-approved by The Kidney Foundation of Canada, BC Branch before the expenses are incurred. Retroactive expenses will not be covered.

How will funds be provided to living organ donors?

The Kidney Foundation of Canada, BC Branch will manage this program and provide reimbursement to approved applications. Receipts and completed Expense Forms are required for reimbursement.

For donors living within Canada, LODERP has a Loss of Income Subsidy that will assist those who do not have access to company benefits of sick and vacation time off work. For those who exhaust all of their benefits and/or have access to Medical EI, or short and

long - term disability benefits, there may be a waiting period without pay. The LODERP program will provide up to 50% of a donor's weekly net income or \$350 per week (whichever is less) during the waiting period. If a potential donor has no access to company benefits and no access to Medical EI (e.g. self-employed), LODERP will provide the loss of income subsidy for the entire time off of work, up to 8 weeks. **The Loss of Income Subsidy Program does not apply to donors from outside of Canada (including the United States).**

For donors traveling from regions outside of the lower mainland, (Greater Vancouver) other provinces, or for out of country donors, the following benefits are made available during the surgery phase:

Travel expenses (economy airfare and/or mileage reimbursement), hotel accommodations, food allowance, airport shuttle reimbursement and/or parking reimbursement.

NOTE*During the assessment phase, only travel expenses will be reimbursed for potential donors traveling outside of the lower mainland. More information will be discussed during the potential donor's assessment appointment.**

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*We would like to extend a special thank you to all of those who helped
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