

When You Are Thinking About Donating a Kidney

Information about Living Kidney Donation

**Organ Donation:
A Gift for Life**



**Kidney Urinary Program
St. Joseph's Healthcare Hamilton**

When You are Thinking About Donating a Kidney

Inside this book:

	Page
Introduction	1
Information about Kidney Transplantation	2
General Principles of the Living Donor Evaluation	4
Frequently Asked Questions	5
Medical Risks of Donating a Kidney	10
Phases of the Living Donor Assessment	13
Members of the Living Donor Team	19
Surgical Aspects of Kidney Donation	22
Post-Operative Information	26
Kidney Foundation of Canada and Trillium Gift of Life Network	31
Appendix A	32
Appendix B	34
St. Joseph's Healthcare Living Donor Team Contact Information	36

When You are Thinking About Donating a Kidney

Introduction

The information in this booklet will be helpful if you want to learn more about the process of a living kidney donation evaluation and the details of living kidney donation surgery.

The decision about whether or not to donate a kidney is a very personal one and there is no right or wrong decision.

The Living Donor Team at St. Joseph's Healthcare Hamilton needs to be sure that a potential donor is coming forward without pressure, intimidation or incentive, and it is important that he or she understands this if they begin the testing process.

The donor should also know that they can change their mind about donating at any time. This decision has to be the one that is best for the donor and the Living Donor Team is committed to supporting the donor throughout the decision making process.

All information disclosed during the donor evaluation and testing is confidential and remains with the living donor team. It is important for the donor and recipient to 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. The team will be available to assist if the donor and recipient are feeling frustrated, having difficulties, or to answer any questions.



Information about Kidney Transplantation

Kidney transplantation is the preferred treatment option for most people with kidney failure as it 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 improved quality of life following transplant.



Kidney transplantation is considered a treatment rather than a cure for kidney disease. It is considered when a patient's kidney function is very low, there is no hope of reversing the kidney failure and the patient is having symptoms of kidney disease.

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.

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 medications have a number of side effects and risks that are explained 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.

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.

When You are Thinking About Donating a Kidney

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 12-20 years for living donor transplantations and deceased donor transplantations last about 10-12 years.

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. Currently, in Ontario, it takes **about four to eight years** after starting dialysis to receive a deceased donor transplant.

Types of Donors

Deceased Donor

In this case, the kidney comes from a person who has just died. Most dialysis patients go on a waiting list for a deceased donor. Patients cannot go on the waiting list until they start dialysis.

In Ontario, adults usually ***wait four to eight years*** for a kidney to become available although this can vary depending on recipient characteristics such as blood type. About 3 to 5% of people on the waiting list die each year.

Kidneys from deceased donors, on average, last 10 to 12 years.

Living Donor

In this case, the kidney comes from a living person who has volunteered to donate a kidney to the recipient. Advantages to living donation are that the waiting time is shorter since transplant date is planned. This allows time for the donor and recipient to prepare for surgery. In some cases, transplant can happen before the recipient ever needs to start dialysis.

Kidneys from living donors, on average, last 12 to 20 years.

General Principles of the Living Donor Evaluation

1. The potential donor must have a blood group that is compatible or matches the recipient's blood group and recipient must have no antibodies against the donor. Potential donors, who have a blood group that does not match the recipient, can choose to participate in the Living Donor Paired Exchange Program.
2. The potential donor must have pre-operative kidney function that is strong enough to expect normal function following the removal of one kidney and be sufficiently healthy and fit to undergo a major operation with very little risks or complications.
3. The potential kidney donor must not have any medical conditions that may possibly be transmitted to the recipient (for example: viral hepatitis or cancer).
4. The potential donor must be 18 years of age or older and know and understand the operative risks and long-term risks of the donor operation. There is no upper age limit for donation. Each donor is considered on an individual basis according to many different factors.
5. The potential donor must not receive money or other valuable incentives to donate a kidney and must have enough psychological, social and financial resources to withstand the surgery and recovery period with minimal personal hardship.

Frequently Asked Questions



What are kidneys and what do they do?

Kidneys are located at the back of the body, above the waist, and tucked under the lower ribs. Most people are born with 2 kidneys. When blood flows through the kidneys, waste and water are removed and the blood is cleaned. The waste is removed by the body as urine.

Kidneys need to work well to keep bones, heart and muscles working properly. Kidneys also make hormones, which control things like blood pressure and red blood cell production.

Why does someone need a kidney transplant?

When you have kidney failure, your kidneys no longer function enough to meet your body's needs. When this happens, you become very sick.

There are two treatment options for kidney failure:

- dialysis
- kidney transplantation

Most of the time, the best treatment is to have a kidney transplant. The success rate for a transplant is more than 95%. When the transplant is successful, the recipient is able to live a dialysis free life.

It is important to know that a kidney transplant is not a cure; it is a treatment option to help the recipient live a longer and better quality of life. There are times when a kidney transplant recipient may need a second transplant in the future.

Who can donate a kidney?

Most people are born with two kidneys, but a person can live a normal life with one kidney. This is why living donation is possible.

Living donors may be blood relatives such as a brother, sister, parent, or child. A living donor can also be unrelated such as a spouse, friend or a person you do not know.

When You are Thinking About Donating a Kidney

What are the benefits of being a living kidney donor?

You may have one or more of these benefits:

- the health care team may find health issues that you did not know about during your assessments
- you may feel satisfied with the decision to help another person and may have an improved sense of your own self-esteem
- you will also benefit from seeing the restored health of your recipient if you know the recipient

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 or the donor may feel uncomfortable or unsure. Some concerns can be worked through during the Living Donor Team appointments and through discussion. It is perfectly ok for a potential donor to come to the evaluation knowing he or she feels uncertain about donation.

Sometimes, during the appointment, the uncertainty 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. Will the potential donor be able to take six to eight away from work following surgery with the support of their employer? Will there be financial stability during this time?

There is no financial reimbursement 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. Even though this is a voluntary medical procedure, it does not

When You are Thinking About Donating a Kidney

disqualify the donor from receiving benefits.

- Potential financial risks to consider include, but are not limited to:
 - expenses of travel, housing, and lost wages;
 - possible loss of employment or 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.

To minimize the potential financial burdens associated with the living donation process, the Government of Ontario established the Program for Reimbursing Expenses of Living Organ Donors (PRELOD). PRELOD reimburses eligible reasonable out-of-pocket expenses for potential and actual donors for travel, parking, meals, accommodation and loss of income. Potential and actual Living Organ Donors may apply to PRELOD for reimbursement of eligible expenses. See appendix C for more information.

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 Ontario Health Insurance Plan. Further follow-up in the donor's home country is not covered.

For donors who are not Canadian citizens, we strongly suggest discussing the surgery with your insurance company before donation takes place. If complications arise from donation, you may not be covered for ongoing care once you leave the province of Ontario.

Even if there are no complications, it is expected that donors undergo check-ups regularly to monitor their health and recovery after surgery. Insurance companies outside of Canada may not pay for all of the costs incurred.

When You are Thinking About Donating a Kidney

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 their decision. It is suggested that you 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 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.

What about my future insurability (for example: 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:

When You are Thinking About Donating a Kidney

Example 1: A potential donor will undergo extensive medical testing and may learn about a pre-existing condition she or he may not have discovered. In the case of a young donor, it might be important to purchase health insurance and life insurance policy before starting the testing process, in case you learn of an unknown medical condition that may make you uninsurable.

Example 2: An individual is approved as a living donor and later (after donation) decides to increase his or her life insurance limits. The insurance company does the necessary blood work and notices that the donor's kidney 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.

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 the 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 the various donors discussing it among themselves. The Living Donor Team will be available to help assist with this decision process if needed.

When You are Thinking About Donating a Kidney

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 decided before coming to their assessment appointment that they will donate. They are often sure they will be found medically suitable and, if they learn that they would be placed at medical risk, and are not allowed to donate, they become upset.

What are the Medical Risks of Donating a Kidney?

It is important for potential donors to explore the risks and to inquire about the facts around the long-term health effects of previous living donors. 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 sports (for example, boxing, football, or 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 (for example high blood pressure or diabetes)
- Potential for death or major disability in the recipient arising from the transplant operation or the medications required after transplantation.

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. Family and friends may help with cooking, shopping, homemaking, yard work, transplantation and child care after the donor's discharge from hospital.

When You are Thinking About Donating a Kidney

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 may need some ideas.

As with other similar surgeries, kidney donation is considered an acute (temporary) illness and therefore homemaking support is not available through the Ontario Community Care Access Centre (CCAC) 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.

Am I prepared to deal with the possible loss of the donated kidney?

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 important for potential donors to think about how they might cope with this loss.

It is up to the donor going forward to contact the transplant coordinator to continue the donor evaluation. In order to ensure that donors do not feel pressured, the Living Donor Team will not contact potential donors.

Pre-Evaluation Guidance and Information

Some things you should know before starting an evaluation as a potential living kidney donor.

- 1. Not every patient with chronic kidney disease is a candidate for a kidney transplant:** Recipients undergo their own evaluation to see if they are suitable to receive a transplant. In most cases, this will happen at the same time as the potential donors are completing their tests.
- 2. The entire donor evaluation will take about six months to a year to complete:** The medical questionnaire and basic laboratory tests can take a certain amount of time to complete and must be reviewed before you can proceed to the special imaging tests and an interview with the Living Donor Team. Some tests may need to be done several times to confirm “borderline” results. If the donor lives outside of Ontario or Canada this process will take longer.
- 3. There are risks to the donor evaluation itself:** Potential donors need to undergo a large number of tests that 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 your ability to get insurance in the future. By law, positive results for certain infections must be reported to health agencies.
The Human Leukocyte Antigen (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 want exposed.
Intravenous injections of contrast or radioisotopes (dyes) are required for certain imaging studies and these injections may cause severe allergic reactions (although this is very rare).

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 tests and confirm the Living Donor Team has received the results.

When You are Thinking About Donating a Kidney

Phases of the Living Donor Assessment

The purpose of the living donor assessment is to ensure that donation is safe for both the donor and the recipient and that donation will result in a safe and successful kidney transplant.

If you or someone you know is interested in donating a kidney, an initial screening questionnaire is sent that must be completed complete and returned to the donor program. If you have any questions, there will be a contact number available for you to call.

Common Conditions That Normally Prevent Kidney Donation

- Difficult to control high blood pressure
- Diabetes
- Cancer (people with successfully treated cancer may be able to donate depending on the type of cancer and how long they have been cancer free)
- Heart disease
- Obesity
- Kidney stones

There are exceptions however, and if you have any doubt about your suitability, we encourage you to discuss matters with the Living Donor Transplant Coordinator.

The evaluation also includes a collection of your health history, various blood and urine tests, imaging studies, and clinical assessments by a nurse coordinator, social worker, and doctors.

Testing is usually performed so that if the initial tests show that the donor and recipient are not compatible, no further testing will be done. 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.

When You are Thinking About Donating a Kidney

If a potential donor decides to start testing, arrangements for the tests are made through the Transplant Coordinator.

Most tests can be done at a laboratory close to the home or work place.

If the potential donor lives outside Ontario, the Transplant 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 is.



Transplantation involves a potential risk of disease transmission from the donor to the recipient (for example: 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

When You are Thinking About Donating a Kidney

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

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 how closely the donor and recipient's tissues resemble, or match 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.

When You are Thinking About Donating a Kidney

If a donor and recipient are blood group incompatible or the crossmatch is positive, the potential donor may choose to consider one of these alternative ways to donate:

- **The Living Donor Paired Exchange Program** permits pairs of incompatible donors and recipients to donate to each other. For example, donor A gives a kidney to recipient B and donor B gives a kidney to recipient A.
- **The List Exchange Program** allows a recipient to move to the top of the waiting list. The donor gives to the top of the blood group compatible deceased donor list. The recipient associated with the donor will move to the top of the donor list according to his or her blood group.
- **ABO-Incompatible Desensitization Program** allows a donor to donate directly to the intended recipient. This is associated with more risk to the recipient because more immune suppressing drugs are required so the Living Donor Paired Exchange Program is preferred as a better method when pairs are not compatible

The Living Donor Paired Exchange Program is also available to any donor and recipient pair that are compatible, but whom still wish to participate in an exchange. This may benefit the recipient in finding a more medically compatible donor

When You are Thinking About Donating a Kidney

Step 2: Laboratory and Imaging Studies

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

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



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 their blood pressure checked and get 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, they may require treatment for the infection first, and depending on which infection they may not be able to donate at all. Positive test results for some infections must be reported to an appropriate health agency for follow-up.

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, or colonoscopy if they have not been done recently.

When You are Thinking About Donating a Kidney

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.

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** to accurately determine their kidney function. This is booked at St. Joseph's Healthcare through the Transplant coordinator.

During this test, a radioactive tracer is injected into the bloodstream and is excreted by the kidneys into the urine. The radioactive tracer is not dangerous. A scanner detects the tracer and shows:

- how well the kidneys are functioning
- the percentage of function contributed by each kidney. This test usually takes about 4 hours

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. This is done to ensure that the donor does not feel pressured by the Living Donor Team to proceed.

When You are Thinking About Donating a Kidney

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 at St. Joseph's Healthcare.

Members of the Living Donor Team include:

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

All potential donors will undergo a psychosocial evaluation by an individual with mental health training (for example, a 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.

Members of the Living Donor Team You Will Meet

At this stage you will meet with the social worker, transplant nephrologist and perhaps the psychiatrist.

Social Worker

The social worker meets with all potential donors and their families to review each person's situation and family supports. The social worker reviews how you decided to donate a kidney, your understanding of donation and the possible effects on you, your family and the recipient.

The social worker helps you and your support persons plan for the donation keeping your needs in mind. He or she can advise you about employment, financial and practical issues. Your Social worker also provides supportive counselling for you and your family, before and after the donation to address any emotional issues related to donation.

When You are Thinking About Donating a Kidney

If you need help dealing with other agencies and institutions, the social worker can connect you.

Transplant Nephrologist

You also see the transplant nephrologist. The transplant coordinator arranges this appointment for you. The transplant nephrologist is not the same nephrologist that the recipient sees.

During this visit you will:

- give a detailed medical history
- have a physical exam
- talk about the risks and benefits of donating a kidney



This meeting takes about one hour. You are welcome to bring a friend or family member with you to this meeting. The recipient cannot come to this meeting. This ensures that the donor can talk freely about any concerns they have without the recipient being there. The nephrologist may order more tests after this appointment.

Psychiatrist or psychologist

A psychiatrist or psychologist is a member of the Living Donor Team that you may meet during the transplant work-up process. The psychiatrist or psychologist can help the team decide if this is the right time for you to donate a kidney.

When You are Thinking About Donating a Kidney

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 determine if the donor can proceed and which kidney will be used for donation.

The CT scan is done St. Joseph's Healthcare in the radiology department. Intravenous contrast (similar to dye) is injected 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 Living Donor 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, donation will not be possible.



When You are Thinking About Donating a Kidney

Surgical Aspects of Kidney Donation

Kidney donation 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 provides slightly less function than the other (determined in the nuclear renogram study) then the kidney providing less function would be preferred for transplantation in order to leave the stronger kidney with the donor.

If the medical evaluation suggests the two kidneys are equal in function then the anatomy of the arteries and veins (seen on the CT scan) will determine which kidney is preferred. Your surgeon will also discuss whether you are a candidate for a laparoscopic donation (using cameras through small holes only) or a traditional open donation (longer scar to open up the side during surgery).

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.

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 heart and lung function during the operation. The anaesthetist will also be involved in pain management after the surgery.

A transplant surgeon and surgical resident will perform the surgery.

When You are Thinking About Donating a Kidney

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)

Nephrectomy is a medical term for removing the kidney and can be completed 2 ways.

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. A camera plus three other long, thin instruments are then introduced into the abdominal cavity.

The surgery takes about four hours. The kidney, along with a length of artery, vein and ureter, are removed and the remaining ends of the artery, vein and ureter are closed with staples. The adrenal gland is not removed. A fifth small incision is made in the lower abdomen to extract the kidney.

During laparoscopic nephrectomy if there is intra-operative bleeding or an injury to the bowel the surgeons may have to switch to an open surgery. This occurs in about 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 15 cm, depending on the size of the donor.

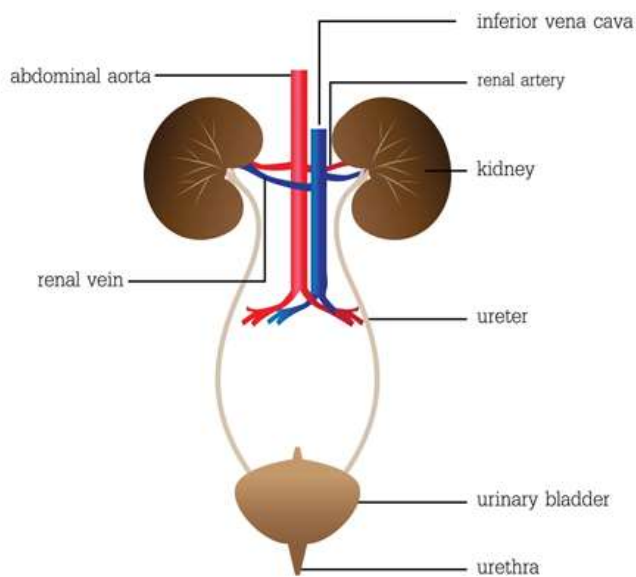
The kidney, along with a length of artery, vein and ureter, is removed and the cut ends of the artery, vein and ureter are tied off with sutures (stitches). The adrenal gland is not removed. A rib is not removed or broken.

When You are Thinking About Donating a Kidney

After the kidney is removed, dissolvable stitches are used to sew the inside tissues back together and the incision is stapled closed. The length of the operation is about three hours.

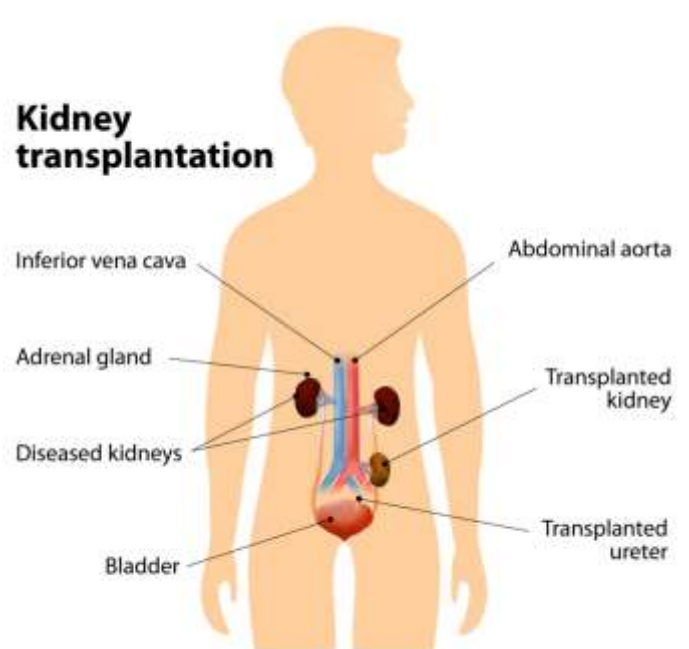
The recovery following an open nephrectomy is expected to be somewhat longer and more painful than with laparoscopic nephrectomy. Eventually, the patients having open surgery make a complete recovery and there is no long-term benefit to laparoscopic nephrectomy over open nephrectomy.

Normal Renal Anatomy



Urinary system

Transplanted Kidney



When You are Thinking About Donating a Kidney

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)	<0.5%
Post-operative pneumonia	<1%
Post-operative urinary tract infection	<1%
Post-operative wound infection	1% - 2%
Post-operative flank "bulge" (seen in open surgery only)	<10%
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
Injury to teeth, pharynx, larynx during intubation	<1%
Serious Allergic/Adverse reactions to anaesthetic or other medications	1%

When You are Thinking About Donating a Kidney

Post-Operative Information

Pain Control

Pain after surgery is common but can be well controlled with pain medications.

The In-Hospital Recovery

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



The evening after surgery, most patients are drowsy or fatigued so they stay in bed until the following morning. It is important to get moving and the nursing team will try to have you sit up in bed and dangle your feet off the bed as soon as possible. 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 worse.

A nurse will monitor the vital signs, urine output and level of pain. A catheter drains the urine from the bladder so we can monitor intake and output accurately so the nurses can make sure the remaining kidney is working well. (A catheter is inserted in the operating room when the patient is asleep).

The day after surgery, the donor is encouraged to get out of bed and walk around. 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 drinking 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 pain medications from intravenous to pills that could be taken at home.

When You are Thinking About Donating a Kidney

The First Two Months after Surgery

Although the skin incisions may appear to be well healed, the muscles underneath are still healing for about six weeks after surgery. It is important to avoid straining these muscles during the healing period as they may stretch and become weak.

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 stressful. There will be many tests, appointments and frequent contact with the Living Donor Team. There may be things to arrange such as leave from work, short-term disability application to be completed, and child-care arrangements to be made. The donor usually spends a lot of time talking about the donation with friends and family.

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 donating was the right decision and may want to speak with other donors about their experience.

Some donors might 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 as they start to get better 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.

When You are Thinking About Donating a Kidney

Long-Term Follow-Up

There are no special dietary restrictions for donors.

No medications are required after donation (other than pain medications after surgery).

We encourage the donors to be physically active and this includes returning to most recreational activities such as skiing, snowboarding, running, soccer, non-contact hockey, 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).

Donors need to be seen on a regular basis by their family doctor for a blood pressure reading and laboratory tests to monitor kidney function. The Living Donor 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 times after donation:

- Two months
- One year
- Yearly thereafter

Members of the Living Donor Team will be available for any follow-up that may be required. The donor has provided a gift to the recipient and it is our program's wish to provide long-term support and encouragement to our donors if they choose. If patients prefer following up with only their family doctor (for reasons such as distance for travel), after the visit one year after donation, instructions can be given to the family doctor regarding what to follow and when to ask the donor to be seen again by the Living Donor Team if necessary.

Donors can contact the Living Donor Social Worker or the Transplant Coordinator at any time.

When You are Thinking About Donating a Kidney

Long Term Risks of Kidney Donation

Living donor kidney transplantation has been performed since the late 1950s. Donors have been evaluated in several follow-up studies to document the safety of the procedure. Kidney donation is safe but not without long-term risk. Potential donors need to consider these risks prior to agreeing to donate.

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 return to approximately 75% of their function before donating. 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.

High Blood Pressure after Donation:

The kidney is partly responsible for controlling blood pressure. Blood pressure likely rises slightly (about 5 mmHg) after kidney donation.

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 if you only have one kidney.

When You are Thinking About Donating a Kidney

Pregnancy after Donation:

Many women are concerned about future pregnancies and whether kidney donation will complicate the pregnancy or delivery. There may be an increased risk of pregnancy complications (hypertension during pregnancy and a condition called pre-eclampsia).

It is unclear if there is also a small increased risk to the fetus. In each case, the risk is small and the majority of women who become pregnant after donation have normal pregnancies, however, women who have not yet completed having children need to consider this increased risk.

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.

Where can I find more information about kidney donation?

Kidney Foundation:

The Kidney Foundation of Canada has a lot of information on this subject and much more.

National Office

The Kidney Foundation of Canada

310-5160 Decarie Blvd.

Montreal, QC H3X 2H9

Telephone: 514-369-4806 or 1-800-361-7494

General information: info@kidney.ca

Website: www.kidney.ca

Ontario Branch (Hamilton and District Chapter and Niagara Branch)

1599 Hurontario Street,

Suite 201,

Mississauga, ON L5G 4S1

Telephone: 905: 278-3003 or 1-800-387-4474

Email: kidney@kidney.on.ca

Website: www.kidney.ca/ontario

Trillium Gift Of Life Network

Trillium Gift of Life Network (TGLN) is a not-for-profit agency of the Government of Ontario. TGLN plans, promotes, coordinates and supports organ and tissue donation and transplantation across Ontario. Its mission is to save and enhance lives through the gift of organ and tissue donation and transplantation in Ontario.

Website: <http://www.giftoflife.on.ca/en/>

When You are Thinking About Donating a Kidney

APPENDIX A-The Kidney Paired Donation Program

When a potential donor and recipient have incompatible blood groups or there is a positive crossmatch, they may be eligible for the *Kidney Paired Donation (KPD) Program*. This is a national program run by Canadian Blood Services and attempts to find matches across the country. It is also available to any donor and recipient pair that are compatible, but still wish to participate in an exchange (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 from pairs across Canada. If appropriate pairs can be matched then the donor kidneys can be swapped and allow both recipients to receive a transplant (see example 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 compatible matches.

If a suitable match is found, the two pairs will have to undergo further testing, 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.

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.

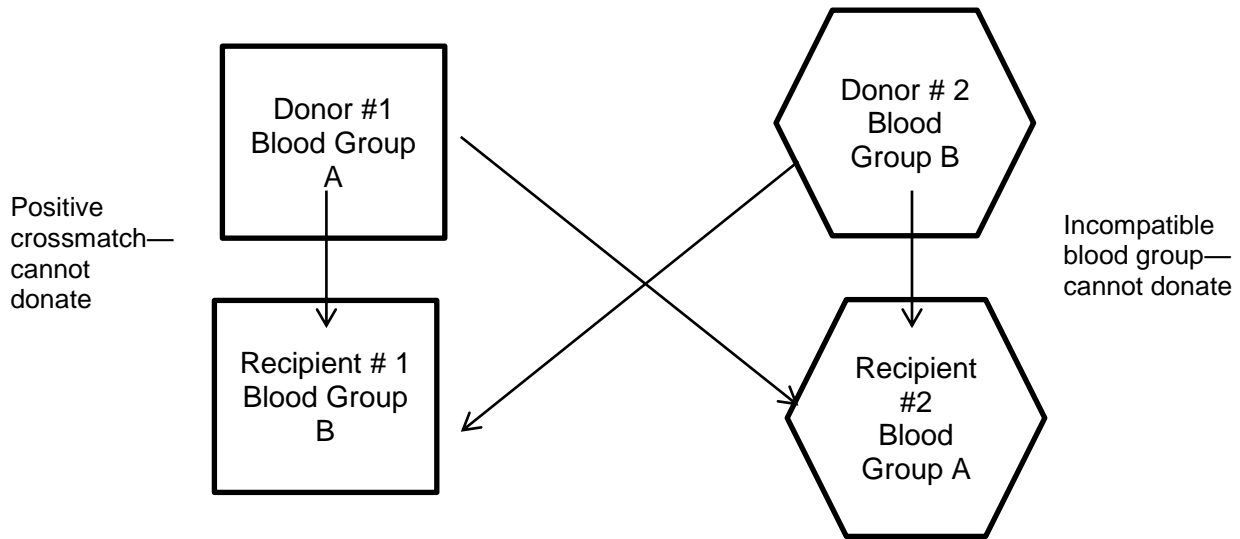
Because the surgeries require a great deal of coordination and planning, you may not have much control over the date of the surgery.

There is also an opportunity for a Living Anonymous Donor kidney to be

When You are Thinking About Donating a Kidney

utilized in the Kidney Paired Exchange. This is described in APPENDIX B.

Living Donor Paired Exchange Example



When You are Thinking About Donating a Kidney

Appendix B

Living Non-Directed Anonymous Donor Program

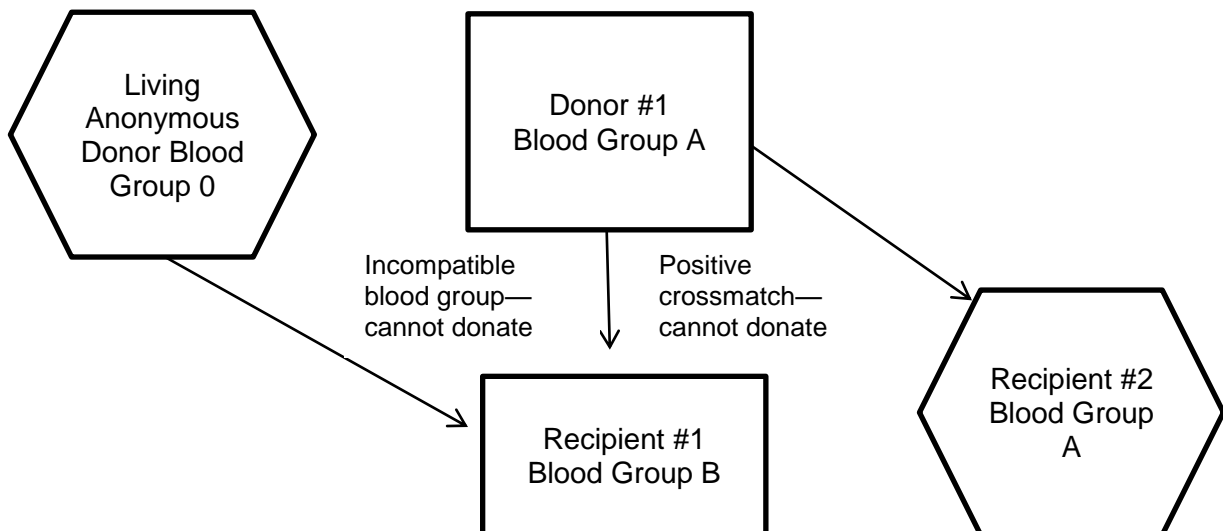
It is possible that a motivated person may wish to donate a kidney but they may not personally know any patients in need of a kidney transplant. These potential donors may participate in the Living Non-Directed Anonymous Donor Program (NDAD).

In addition to the standard donor evaluation previously described, the potential anonymous donor is also required to be evaluated by a psychologist or psychiatrist to better understand their motivation to donate.

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 NDAD may also be offered the opportunity to participate in the Kidney Paired Donation 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). This can allow for the creation of chains rather than pairs so that multiple incompatible pairs benefit due to the Non-Directed Anonymous Donor's donation.

Living Non-Directed Anonymous Donor Example



When You are Thinking About Donating a Kidney

Directed Anonymous Donation

Occasionally, potential donors may wish to donate to a specific individual. This can occur due to public solicitation through social media, newspaper, television, or other public forums, this is called Directed Anonymous Donation.

There are increased social and psychological risks and considerations with this kind of donation. Directed Anonymous Donation is not performed at St. Joseph's Healthcare. Should potential donors be interested in Directed Anonymous Donation, they will be provided the contact information of a kidney transplant program that does.

When You are Thinking About Donating a Kidney

St. Joseph's Healthcare Living Donor Team Contact Information

Living Donor Program

Telephone: 905-522-1155 ext 32156

Email: livingdonors@stjoes.ca

Nursing Staff	
Staff Member	Extension
Tracy Hamilton	33193
Maria Roberts	33236
Melodie Jansen	33136
Courtney Roche	33236

Administrative Support		
Staff Member	Extension	Email
Anna Amatangelo		livingdonors@stjoes.ca
Kim Guastadisegni		livingdonors@stjoes.ca
Elora Kirby		livingdonors@stjoes.ca

Donor Doctors	
Physician	Office Extension
Dr. M. Miller	34055
Dr. K. To	33452

Nephrologists	
Physician	Office Extension
Dr. A. Gangji	33386
Dr. C. Ribic	33261
Dr. D. Treleaven	33261

Urologists	
Physician	Office Extension
Dr. A. Kapoor	33218
Dr. S. Lambe	34988
Dr. K. Piercey	34987

When You are Thinking About Donating a Kidney

Departments	
Department	Extension
Firestone Chest and Allergy Clinic	36000
Electro-Diagnostic Services	36082
Nuclear Cardiology	36095
Social Work	33101
Diagnostic Imaging	36009
Nuclear Medicine	36095