

INFORMATION FOR PATIENTS AND FAMILIES

Living Donor Kidney Transplant

- **An overview of live kidney donation**
- **Who can be a donor**
- **What is involved in the review of a potential live donor**
- **What are some of the emotions that a kidney donor may feel**
- **Risk of the transplant patient rejecting my kidney**
- **What type of surgery is involved**
- **What to expect after surgery**
- **List of common transplant words and terms**



INTRODUCTION

Welcome to the living donor transplant program at St. Michael's Hospital. We know this may be a stressful time for you and your family. Before you agree to be tested as a possible donor, you need to know what is involved. This booklet is a guide to help you learn about being a kidney donor and the steps involved. If you have any concerns or questions, contact the live donor office at 416.867.3676 at any time.

APPOINTMENTS WITH THE LIVING DONOR TRANSPLANT TEAM

At your first appointment you will:

- Meet with the program nurse to discuss the details of this booklet
- Talk about your health history
- Sign an **Agreement to Start the Donor Work-Up Evaluation**
- Have some tests to see if you could be a kidney donor (ie. x-rays, blood and urine tests etc)
- On your next appointment you will meet with a kidney doctor (Nephrologist), Social Worker, and a Research Coordinator. You may also need to see a Psychiatrist if required.

Bring the items listed below with you to your first appointment

1. Your Health Insurance Card (OHIP)
2. Immigration Visa (if you are from out of country)
3. Your completed health questionnaire forms
4. This information booklet

INTERPRETATION SERVICES

If you are not fluent in English, contact the living donor office at (416) 867-7460 x8245 in advance so an interpreter can be present at your clinic appointments. An interpreter will translate what the donor team says to you in your language. This will help ensure you understand all of the information the donor team speaks to you about.

Please be advised that it is our hospital policy that we use an interpreter from the St. Michael's Hospital interpretation service. Family, friends, or the potential transplant patient are not permitted to translate information.

The information in this booklet is organized as follows:

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AN OVERVIEW OF LIVE KIDNEY DONATION

A. What are the advantages of Live Kidney Donation?

The transplant surgery can be arranged at a time that the donor and the transplant patient are in the best health.

FOR THE TRANSPLANT PATIENT:

- The waiting time for a transplant is shorter. Instead of waiting 6-11 years from the transplant waiting list, the transplant patient can have a transplant in a few months.
- A kidney from a living donor works better than a kidney from a deceased donor.
- The transplant patient will not need dialysis which means fewer limits on the food they can eat or fluids they can drink.
- The transplant patient has greater freedom to travel, may be able to return to work and have a more active lifestyle.
- The transplant patient's quality and length of life will improve. It is important to realize that a kidney transplant is not a cure for kidney disease but is another form of treatment.
- There is a reduced risk of kidney rejection. Also, in most cases lower doses of anti-rejection drugs are needed after transplant than with a deceased donor kidney.
- On average a live donor kidney transplant lasts about 15-20 years when compared to 10-15 years from a deceased kidney donor.
- In most cases, the transplant patient can receive a kidney transplant much earlier in the course of their kidney disease, sometimes before dialysis is needed.

FOR THE DONOR:

- Many live donors say that knowing they helped improve the health of another person is rewarding.

B. What are the other treatments available to the transplant patient aside from a live kidney transplant?

1. Dialysis treatment

Dialysis is a treatment through which a person's blood is cleaned. It takes over the work the person's kidneys can no longer do.

2. Deceased donor list

The transplant patient can be placed on the transplant waiting list to receive a kidney from a person who has died. The transplant patient has to be on dialysis and approved for transplant before going on the waiting list. The wait time for a kidney transplant from a deceased donor is long and can vary by blood group. The wait time is about 6 to 11 years.

WHO CAN BE A DONOR?

Living donors must be 18 years or older (often less than 70 years of age). Living donors must be in good general health without any health issues such as high blood pressure, diabetes, kidney disease or heart disease.

A. Types of Living Donors

Related

Living related donors include brothers and sisters, parents to children, adult children to parents as well as other blood relatives including aunts, uncles, cousins, half siblings, nieces and nephews.

Non-related

Non-related living donors are spouses, partners, in-law relatives, close friends, co-workers or members of your community.

List exchange

A list exchange may be an option when the donor is blood group (ABO) incompatible (not matched) with their intended blood group O transplant patient. The donor donates anonymously to a compatible (matched) transplant patient at the top of the deceased donor waiting list. In exchange, the transplant patient whose living donor has donated receives the next available kidney from the deceased donor list. The wait time for a kidney would be a few months instead of 6-11 years when your planned transplant patient goes to the start of the deceased donor list.

Paired exchange

Paired exchange is when two separate but willing donors are each unable to donate to their planned transplant patients due to blood group (ABO) incompatibility (mis-match) or more rarely because of incompatibility of cross match blood testing. In this program, the willing donors are matched with the other's respective transplant patient so that each transplant patient can receive a kidney with a compatible living donor. The paired exchange program is offered through Canada's transplant programs in co-operation with Canadian Blood Services (CBS). CBS is managing the waiting list computerized registry that matches suitable donor and transplant patient pairs.

Anonymous donation

An anonymous donor is a person who does not know the intended transplant patient, but donates to the top of the local waiting list or to the Canadian Blood Services paired exchange registry

Solicited donor

A solicited donor is someone who comes forward after a transplant patient makes a public request for a potential donor.

HOW DO I KNOW IF I AM A MATCH?

Blood Type and Blood Tests

There are four different blood types. In order for you to be able to donate to your planned transplant patient, you must have a blood type that is compatible with (matches) the transplant patient. The below blood types are compatible:

Transplant Patient's Blood Type				Donor Blood Type			
O	A	B	AB	O			
A				A	O		
B				B	O		
AB				A	B	AB	O

If your blood type is not the same as your transplant patient's, you may still be able to donate a kidney. There are other options to consider which are described above under types of donors (see List and Paired Exchanges).

If you do not know what your blood type is, the live donor nurse coordinator will mail you a lab requisition that you can take to any lab close to your home.

Cross Match and Tissue Typing

A blood test called cross match and tissue typing is done between the donor and transplant patient. This test has two parts. Tissue typing provides information on your genetic makeup. It is not necessary to have any genes in common with your intended transplant patient. One out of four siblings may have all six out of six antigens in common. This close a match means the kidney may last about 20 plus years and the transplant patient may need less anti rejection drugs.

The second part of the test called the cross match provides information on how your intended transplant patient responds to your blood cells. This helps predict how the transplant patient would react to your kidney, and what type of anti-rejection drugs the transplant patient would need to take. Sometimes if the blood test result is very strong, you may not be able to donate directly to your transplant patient. You may be considered for the living donor paired exchange program.

WHAT ARE SOME OF THE EMOTIONS THAT A KIDNEY DONOR MAY FEEL?

- Living donor kidney transplants work very well for most people and success rates for most can be 95% one year after the transplant. There can be a risk that the transplant patient will have problems such as infection, rejection of the donated kidney or even death. For a living donor, the news of such problems can be very upsetting.
- The donor team will talk to you about physical and/or psychological (mental) risks involved in kidney donation before you proceed as a donor
- Depression and/or anxiety can occur if the donor is rejected as a donor or is feeling pressured to donate. Sometimes donors can feel anxious or depressed after the surgery. This can occur during the healing process of surgery, along with new family demands. Sometimes donors feel that all the attention shifts from the donor onto the transplant patient. This can be the case because the transplant patient's care after surgery is more complex.
- You will have the chance to discuss your feelings, questions and concerns with the social worker. The social worker will also check to see if you will be able to handle the stress involved with being a kidney donor. You may also need to see a psychiatrist.

IS THERE A RISK OF THE TRANSPLANT PATIENT REJECTING MY KIDNEY?

- The risk of rejection is very low for kidney transplantation.
- 95% of transplants performed with live donors still have excellent function one-year post transplant.
- The average life of a living donor kidney is 15-20 years (20+ years with an identical sibling) as compared to 10-15 years with a deceased donor.
- Despite these excellent results for patients, there is a risk of loss of the new kidney function from rejection, infection or the kidney disease returning
- Although rejection of the kidney is not something we can predict, the transplant team may be able to help restore kidney function.
- If you have any questions or concerns about organ donation, it is important to discuss your thoughts and feelings with a doctor, psychiatrist/social worker and/or a live donor nurse coordinator.
- The more information you have before you make a decision, the more prepared you will be if you chose to donate.

WHAT IS INVOLVED IN THE REVIEW OF A POTENTIAL LIVE DONOR?

The Review Process

When there is more than one possible donor, the live donor team will recommend a family meeting to get information and help to determine which donor should be reviewed first for being a match. Please be advised that only one donor can be reviewed for a potential transplant patient at a time.

Before you can donate your kidney, the live donor transplant team will need to ensure that you are in good health. The live donor transplant team will need to check that you do not have any health problems that would rule you out as a donor.

Once you have agreed to be reviewed for live kidney donation, you will go through an in-depth psychological and health review. The review process is designed to answer the below questions.

1. Is your blood type compatible (match) with the transplant patient's blood type?
2. If you are not a compatible blood type, do you wish to consider list exchange or paired exchange?
3. Do you meet the medical and surgical criteria for donation?

With these goals in mind, this is how live donors are evaluated:

Step 1: Questions

- All possible donors must answer some questions about your overall health.
- These questions will be reviewed by the donor nurse. If your answers are approved, the donor program assistant will contact you to arrange for you to have your initial blood testing and consult with the donor nurse in the St. Michael's Hospital outpatient live donor clinic.
- If you live out of the province, we will arrange for you to have your blood tested locally.

Step 2: Tests, Assessments and Education

- You will meet with the nurse to review details of the live donation process
- You will complete an electrocardiogram, chest x-ray, ultrasound, blood and urine tests, and have your blood pressure checked with a 24 hour walking blood pressure cuff
- Blood tests include: HIV, Hepatitis B & C, VDRL, gonorrhea, kidney function, liver function, virus exposures, tests for anemia and diabetes.

- You will meet with the social worker for social support and to assess your psychological (mental) health.
- Once you have completed all of the testing, you will meet with the donor nephrologist (kidney doctor) to discuss your results.
- The nephrologist may need you to have more tests done.
- Please note that it is our policy that only doctors are authorized to discuss the details of your results with you.
- If the results of your tests show that you could be a donor, the next step of the review process is for you to have a spiral CT scan, cross matching and tissue typing if it has not already been done.

Additional Tests

Other tests may also be needed based on your gender, age, social history. These may include: Pap smear, Mammogram, PSA, Exercise stress test, an Echocardiogram and other tests as required. If you are a smoker, you will be advised to stop smoking to lesson your risk of problems with the surgery and anaesthetic.

Step 3: CAT scan and cross matching

Spiral CAT scan

This scan will show details about your kidneys, urinary tract, and kidney blood vessels. The CAT scan is reviewed at rounds by the nephrologists, surgeons and radiologists about a month after you had the scan. The scan will show if you can be a donor and if you qualify for laparoscopic surgery. About 90% of donors can have laparoscopic surgery and it is more common for the left kidney to be used. Sometimes donors can be turned down based on certain details about their the kidneys or blood vessels Sometimes donors can only have an open flank surgery which is a larger cut. This means it will take longer to recover after the surgery, about 8-10 weeks.

Cross Matching and Tissue Typing

Your blood will be tested for antigen match and cross match. The cross match tells whether the transplant patient's blood cells react well with your blood cells.

Live donor team meeting

Multidisciplinary Discussion (All members of healthcare team):

- Once all of your tests are completed, your results will be discussed at a multidisciplinary team meeting.
- You will be contacted by the nurse once the team has agreed that you are suitable for donation or if you need to come back for further talks with the doctor.
- The surgery date will be set as well as a date for pre admission (before surgery) testing when both the donor and transplant patient are approved for surgery.
- You will meet with the surgeon to discuss the details of the surgery, and what to expect afterwards.

WHAT TYPE OF SURGERY IS INVOLVED?

What to expect

Once your assessment is completed and the live donor team has approved you for surgery, an appointment will be made for you to meet with your surgeon. The surgeon will discuss with you the details of the surgery, the risks involved, and, what to expect after surgery. All of your questions about the surgery will be answered at that time.

In this booklet, we have provided you with some information about the surgery and what to expect so you can get ready to meet with the surgeon. **Write down any questions you may wish to ask the surgeon.**

How is the kidney removed?

There are two ways to remove a kidney: a 'Laparoscopic Donor Nephrectomy' and an 'Open Donor Nephrectomy'. A special x-ray called a CAT scan will help the surgeon decide which surgery is best for you.

Laparoscopic: The kidney is removed using special tools that are put in through 3 to 4 small (1cm or less) cuts. When the kidney is ready to be removed, it is taken out through a 7.5cm (3 inch) lower stomach cut.

- Surgery takes about 3-4 hours
- Hospital stay is about 3-4 days
- 2-6 weeks are required for full recovery but patients are advised to plan on up to 2 months off of work

- Most donors can have this type of surgery (over 90% of donors meet the standards for this type of surgery).
- The pros of laparoscopic surgery include a smaller incision; less pain and scarring, shorter hospital stay and faster return to daily activities.
- St. Michael's Hospital was the first transplant program in Ontario and the second in Canada to offer laparoscopic surgery

Open Donor: The kidney is removed by cutting through three layers of muscle in your side. When the kidney is ready to be removed it is taken out through a 20cm (9 inch) incision in your side.

- Surgery usually takes 2-3 hours
- Hospital stay is generally 4-7 days
- 8-12 weeks for a full recovery but patients are advised to plan up to 2-3 months off of work

Please note: During your surgical consult with the doctor, you will get full details of the benefits and risks of laparoscopic surgery and an open donor procedure.

What to Expect After Surgery

- You will see the surgeon about two weeks after surgery
- You will meet with the donor team (nephrologists, nurse, and social worker) about 10-12 weeks after surgery to check your health before you are discharged back to the care of your family doctor.
- You can call the donor nurse at any time if you have questions.

What are the short and long term effects of live kidney transplant surgery?

For the live kidney donor, it is shown that donation has little if any long-term effects on their health. The remaining kidney gets bigger after surgery to do the work once done by two kidneys.

The short-term risks effects in live kidney donation are directly related to the surgery done to remove the kidney. It is important to know that these risks are common to any kind of major surgery.

They include:

Minor complications (problems) and possible risks that about 15-20% donors have:

- Pain and discomfort following surgery is common, but this can be well controlled with pain medicine.
- Infection can occur at the incision site, and may slow down the healing process. Antibiotics can be given if needed to treat infections
- You will be asked to cough and breathe deeply after your surgery to decrease the risk of pneumonia, which can be as a result of the anesthetic. Coughing and deep breathing exercises following surgery can help lessen this.

Major complications (problems) and possible risks that about 2% of donors have:

- After any surgery, blood clots can form in the legs. There is a risk that these clots can then travel to your lungs. Getting out of bed and walking around as soon as possible helps to avoid blood clots.
- Since the kidney sits very close to the lungs, there is a risk of opening the space around the lung called the pleura. If this happens, a lung may collapse. Lungs can be re-inflated by inserting a tube in the chest.
- You may have an allergic reaction to anesthesia. This is usually avoided through careful screening of the donor's allergies before surgery. If you have an allergic reaction, the anesthesiologist will take immediate corrective action.
- With any major surgery there is always a risk of death, although very low, (three people for every 10,000 surgeries die).

Is there a risk of the transplant patient rejecting my kidney?

- The risk of rejection is very low for kidney transplant.
- The success rate is 95% for one-year transplant survival. This means that 95% of transplants performed with live donors still have good function one-year after transplant.
- The average life of a living donor kidney is 15-20 years (20+ years with an identical sibling) as compared to 10-15 years with a deceased donor.
- Despite these good results for patients, there is a risk that the kidney can stop working from rejection, infection or the kidney disease returning

- Although rejection of the kidney is not something that can be predicted, every effort is made to help restore kidney function.
- If you have any questions or concerns about organ donation, it is important to discuss your thoughts and feelings with a doctor, psychiatrist/social worker and/or a live donor nurse coordinator
- The more information you have before you make a decision, the more prepared you will be if you chose to donate.

What are the long term effects to my health when living with one kidney?

- In over 50 years since living kidney donation began, studies show that the long term health problems for live donors are slight.
- Most people only need about 1/3 of normal kidney function to be fully healthy after donation.
- Most donors have between 60 to 80% of normal kidney function, which is enough to be fully healthy.

Possible serious long-term health problems:

- Slight increased risk of high blood pressure
- Slight increased risk of kidney failure
- Possibility of injuring the remaining kidney
- Slight risk of developing a disease of the remaining kidney

Here are some precautions that should be taken:

- Have regular annual physical health exams with your family doctor
- Avoid rough contact sports such as football, boxing, and hockey that could damage the remaining kidney.

LIST OF COMMON TRANSPLANT WORDS AND TERMS

Blood Type Matching: The first step in the review process is to see whether or not the potential living donor has a blood type that is compatible (a match) with the transplant patient .There are four blood types: O, A, B and AB.

Cross matching: Is a blood test that is performed to tell us if the donor and transplant patient are a match. White blood cells from the donor are mixed with blood from the transplant patient. If the donor's white blood cells are attacked and killed, this is known

as a “positive” cross match and indicates that the donor and transplant patient are not compatible. A “negative” cross match, on the other hand, indicates that surgery can proceed.

Laparoscopic nephrectomy: A surgical procedure in which the kidney is removed through a small incision below the belly button. A laparoscopic nephrectomy is less invasive and involves making several 2-inch (5.08 cm) incisions into the abdomen and inserting a laparoscope and other medical tools through them.

Nephrectomy: A Latin term which means removal of a kidney.

Non-related donation Living donors are spouses, in-law relatives, and close friends, co-workers.

Anonymous donation: Living donors are not related or known by the transplant patient.

Open nephrectomy: A surgical procedure commonly used to remove the kidney. It involves an incision of about 10 inches (25.4 cm), which is made along the bottom left side of the lower rib to the middle of the stomach. The kidney is carefully disconnected from its blood supply, the veins and arteries are clamped off, and then the kidney is gently lifted out.

Paired exchange donation: Paired exchange is when two separate but willing donors are each unable to donate to their planned transplant patients due to blood group (ABO) incompatibility. In this program, the willing donors are matched with the other’s respective transplant patient so that each transplant patient can receive a kidney with a compatible blood type.

List Exchange: A list exchange is when a living donor who is incompatible with their planned transplant patient donates anonymously to a compatible transplant patient at the top of the deceased donor waiting list. In exchange, the transplant patient whose living donor has donated receives the next available kidney from the deceased donor waiting list.

Related donation: Living donors are brothers and sisters, parents, children 18 years of age and older as well as other blood relatives, including aunts, uncles, cousins, half-siblings, nieces and nephews.

Tissue Typing: Is a blood test that tells us your genetic makeup by testing the white blood cells for what is known as “human leukocyte antigens” or HLA.

LIVING DONOR TRANSPLANT TEAM PHONE NUMBERS

Living Donor Nurse Coordinator

Maureen Connelly, RN 416.867.7460 x8245

Kevin Bradley, RN 416.867.7460 x8172

Program Social Worker

Sharon Lee 416.867.7460 x4173

Program Clerical Assistant

Andrea Dedrick 416.867.3676

Living Donor Transplant Nephrologists

Dr. P. McFarlane 416.867.3702

Dr. J. Weinstein 416.867.3703

Dr. J. Zaltzman 416.867.7444

Transplant Surgeons

Dr. Honey 416.867.3705

Dr. Stewart 416.867.3686

Dr. Pace 416.867.3695

Dr. Ordon 416.867.3705

Dr. Lee 416.867.3735

Research Coordinators

Michelle Nash 416.867.3692

Lindita Rapi 416.867.7460 x8024

TRANSLATION AGREEMENT

I certify that I have translated all of the information provided in this information session and consent completely and accurately to the best of my ability.

I certify that I have asked all of the questions that the potential living donor candidate has asked through me and that I have accurately translated all of the answers.

Translator (printed name)

Agency

Daytime telephone number

Evening telephone number

Language translated

Translator (signature)

Date

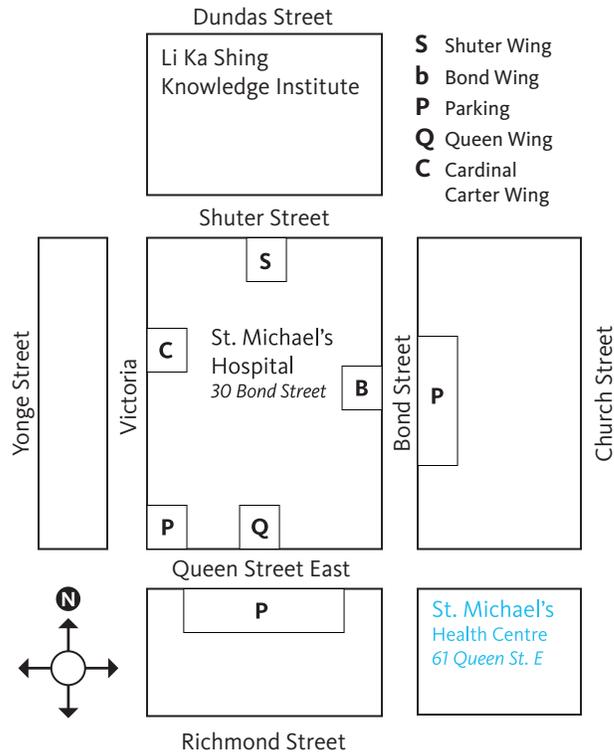
ST. MICHAEL'S HOSPITAL HEALTH CENTRE

61 Queen Street East,

Toronto, ON M5T 2C2

Renal Transplant Program 9th floor

Donor office – 7th floor, room 044



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30 Bond Street, Toronto, ON M5B 1W8 Canada
416.864.6060 stmichaelshospital.com