

# **When You Are Thinking About Donating a Kidney**

## **Information about Living Kidney Donation**

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

## When You are Thinking About Donating a Kidney

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## When You are Thinking About Donating a Kidney

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### What do I need to know if I am thinking of donating a kidney?

The decision to donate a kidney is a personal one. It should not be made lightly or under pressure. The transplant team can answer any of your questions and talk to you about your concerns. Your family doctor or health care provider is also a good resource person to talk to.

Your own needs and health are very important. You should know that all discussions between you and the transplant team and your family doctor or health care provider are kept confidential.

We want to help you make a decision that is right for you, not someone else. Kidney donation is not for everyone, but by knowing the facts, you can decide if this option is the right choice for you.

### Some words to review:

**Nephrectomy** is the surgical removal of a kidney by a transplant urologist.

**Recipient** is the person who is receiving the kidney.

**Transplant nephrologist** is a doctor who specializes in kidney function, diseases and kidney transplantation. The transplant nephrologist does a medical assessment before you can donate a kidney.

**Transplant urologist** is a surgeon who specializes in kidney transplants and other kidney related surgeries. The transplant urologist decides if you are able to have this type of surgery. The transplant urologist is the surgeon who removes your kidney and looks after you after your operation.

**Transplant coordinator** is a registered nurse who works with the transplant team to organize your donor work up assessment and provide you with information and support during this process.

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### What are kidneys and what do they do?

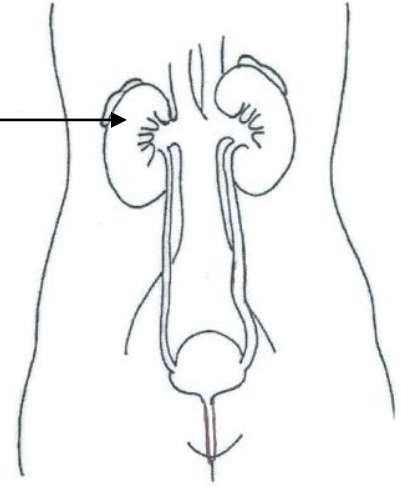
Kidneys are located at the back of the body, above the waist tucked under the lower ribs.

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 2 treatment options for kidney failure:

- dialysis
- kidney transplantation

There are 2 types of dialysis:

- hemodialysis
- peritoneal dialysis

### Hemodialysis

You are connected to a machine that cleans your blood and then returns it to your body.

### Peritoneal Dialysis

To do this, a tube is put into the abdomen where solution flows in and drains out to move the toxins out of the body.

However, dialysis cannot do all of the things a real kidney does.

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### **Kidney Transplant**

Most of the time, the best treatment is to have a kidney transplant. The success rate for a transplant is more than 90%.

The kidney can come from:

- a person who has just died called a deceased donor
- a living donor

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.

### **Deceased Donor**

Most people go on a waiting list for a deceased donor. In Ontario, adults usually wait 4 to 5 years for a kidney to become available. About 3 to 5% of people on the waiting list die waiting for a kidney each year. Kidneys from deceased donors, on average, last 10 to 12 years.

### **Living Donor**

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.

Kidneys from living donors, on average, last 12 to 20 years. There are more living donors now than deceased donors.

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### Who can donate a kidney?

Most people are born with 2 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.

### 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 report 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

Most living donors say that they would make the same choice again.

Even with the small risks and sacrifices involved, most living donors remain positive about their decision to donate and report excellent health and well being many years after.

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### **What are the risks of donating a kidney?**

Donating a kidney involves some risks that all living donors should know about. The doctor and members of your health care team will discuss the risks with you.

### **Risks from Surgery – Short Term Risks**

A kidney transplant is a major operation. Even though a living donor is in good health, there are always some risks from having surgery. The risk of any of these complications is very small.

#### **Allergic Reaction to Anesthesia:**

This occurs in less than 2%. Before surgery a complete medical history is done to assess your risk. During surgery, the health care team is ready to treat any complications that arise.

#### **Blood Clot:**

There is a less than 2% chance that a clot can form in your leg. This can happen as you do not move for several hours during the operation and move slower after. Before surgery you are taught leg and circulation exercises to practice.

After surgery you are encouraged to do these exercises every hour you are awake. When a clot forms it can break loose and travel to the heart or lungs causing a heart attack or stroke. Moving around helps prevent this risk.

#### **Lung Infection or Pneumonia:**

This can happen as you do not move for several hours during the operation and do not breathe as deep after surgery. Before surgery you are taught deep breathing and coughing exercises to practice.

After surgery you are encouraged to do these exercises every hour you are awake. Moving around also helps prevent this problem.

Antibiotic medication is used to treat this problem if it happens.

#### **Bleeding and Blood Transfusion:**

Bleeding occurs in less than 1%. The health care team is ready to assess and treat this problem if this is part of your treatment plan.

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### **Infection of incision:**

After surgery you learn how to take care of your incision and what signs of infection to watch for. Infection is managed by antibiotic medication as well as good skin care.

### **Serious risks:**

Serious risks with any general anesthetic and major surgery are extremely rare but do include a heart attack, stroke or death. This happens in less than 0.03% or 3 people in every 10,000 surgeries.

## **Risks after Surgery – Long Term Risks**

### **Future Health Problems:**

There is no evidence that living with 1 kidney puts the donor at risk for future health problems.

Within hours of removing the donated kidney, the remaining kidney takes over about ½ of the kidney function lost.

Most donors have about 65 to 75% of normal 2-kidney function for the rest of their lives.

### **Blood Pressure:**

There is evidence that blood pressure may increase by 5 mm Hg (mercury). This also happens as one grows older.

Follow-up studies have not shown this to be a serious concern.

All donors need to have blood pressure checked every year but this is a good habit for anyone.

### **Urine Changes:**

All donors develop a small increase in urine protein. There is no good evidence about how this can affect future health. All donors need to have blood and urine tests every year to monitor this.

There are rare cases of kidney failure in living donors but this risk has been reported to be the same as in the general population – 1 person in 1,000. It is not clear if donating a kidney helped cause kidney failure in the donor.



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### **Pregnancy after Donation:**

Female donors are able to have a normal pregnancy with 1 kidney, but they should wait at least 6 months after the surgery before trying to become pregnant.

### **Appointments:**

Donors need to be aware that there are many appointments before surgery to assess if they are healthy and it is safe to donate. This can mean time off work or school and travel expenses. If approved for surgery there are appointments to prepare for surgery as well as close follow-up. These all need to be considered before you agree to donate. There is more information about planning for expenses on page 11.

### **What do I do to find out if I can donate?**

As a donor, you need to know your blood type. You can find out what your blood group is by having a blood sample taken. This can be arranged through your family doctor or health care provider or the transplant coordinator.

You may already have a card from the Canadian Blood Services stating your blood type.

The following is a chart showing what blood groups are compatible (the positive and negative portion of your blood group is not important in kidney donation).

<b>Recipient Blood Type</b>	<b>Compatible Donor Blood Type</b>
Blood Group O	Blood Group O
Blood Group A	Blood Group A & O
Blood Group B	Blood Group B & O
Blood Group AB	Blood Group AB, A, B, & O

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If you are not a compatible blood group there are other ways to donate a kidney. You can talk to the transplant coordinator about these options:

- **The National 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.

### What happens if I am a compatible blood group?

There are strict criteria that you must meet to be a donor. You will complete a health questionnaire in order to determine if there are health issues that would not allow you to be a donor. Some of these medical conditions are:

- high blood pressure
- a heart condition
- certain chronic illness such as
- kidney stones

**For your safety, it is very important that you are honest about all of your health history.**

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### What if I am not sure about donating a kidney?

It is important that you take time to think about your decision carefully. You should not donate if you do not want to. You should not feel pressured by others to donate.

If you decide that donating is not the right choice for you at this time, the transplant team is available to help you deal with this decision.

The specific reason for ending a donor work up is kept confidential. The recipient is told that you are medically unsuitable for donation.

You may wish to tell the recipient yourself or you can ask the transplant coordinator to tell the recipient that your work up has been closed.

### What happens if I am sure I want to be a donor?

There are many tests and procedures you need to do after you make the decision to be considered as a donor.

All information is confidential between you and the transplant team.

### Tissue Typing and Cross Match

If your blood group is compatible with your recipient and your health history is acceptable, a blood test called a tissue typing and cross match is arranged. This test sees how similar your tissue is to the recipient's. It is also done to see if the recipient reacts negatively or positively to your tissue.

The cross match makes sure the intended recipient is compatible with you. A **negative cross match** means there is a lot less risk of the recipient's body rejecting the kidney from you.

The blood needs to be drawn in the morning at St. Joseph's Hospital Outpatient Lab.

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### **What happens when more than 1 person wants to donate a kidney to the same recipient?**

Sometimes the tissue typing and cross match results clearly show the best person to continue to be worked up as the potential donor.

There are times when more than one person is suitable to be worked up as the potential donor. When this happens, each person should think about his or her personal circumstances, work and desire to proceed.

When potential donors know each other, you can all talk about who would like to continue with the donor evaluation. The other people can then be back up donors if the first donor is medically unsuitable after testing.

If there is more than 1 potential donor each donor is told his or her results.

**It is up to the donor going forward to contact the transplant coordinator to continue the donor evaluation.**

### **What happens when the cross match is positive?**

When a cross match is positive, a blood test called cross match with titres is done to see how strongly the recipient reacts to your HLA or tissue type.

This helps determine if the HLA Desensitization Program is suitable for you and your recipient. You can ask your transplant coordinator to tell you more about this program.

### **What tests are done next?**

All tests are arranged through the transplant coordinator's office. You can let the transplant coordinator know if you have days that are better for you for any of the tests and doctors' visits. The coordinator will try his or her best to follow this. The next tests include:

- a series of laboratory and x-ray tests to screen for kidney function, liver function, hepatitis and other viruses or infections
- a 24 hour urine collection to see if your kidneys are functioning normally
- a chest x-ray and electrocardiogram (ECG) to make sure that your lungs and heart are normal
- an isotope GFR test to assess your kidney function
- other tests may be needed depending on the results of the above tests

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### Do I need to fast (not eat or drink) for the blood tests?

Fast means that you cannot have anything to eat or drink for a number of hours before a blood test.

The transplant coordinator gives you information about what blood tests you need to fast for.

### The night before the first set of tests:

- Do not eat anything after 8:00 p.m. You may have sips of water until midnight.
- Do not eat or drink anything in the morning.
- Come to the Outpatient Department at St. Joseph's Healthcare. You will have your blood tests taken here.

The Transplant Coordinator will meet with you before the blood tests are done to explain the tests and answer any questions that you may have. Your blood pressure will also be checked at this time.

### 24 Hour Urine Collection

For this test you collect all of the urine you produce for a total of 24 hours. If you are a woman, you cannot do this when you are menstruating.

### Steps to follow:

1. Keep the jug in a cool place during the whole collection.
2. Label the jug with your name, the date and time you started the collection and the date and time you finished the collection.
3. Start the collection on the first day at the time advised.  
**You must discard the first urine of the day.**
4. Put all of the urine you produce in the jug for the rest the day and night.
5. At **exactly** the same time the following morning put your first morning urine sample in the collection container.
6. Your 24 hour urine collection is now complete.
7. Bring the jug into the laboratory along with the requisition the same day you finish collecting the urine.
8. You also need to have a blood test done when you return the 24 hour urine collection.
9. If you have any questions about any testing, call the transplant coordinator's office at 905-522-1155 ext. 33161.

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### **What members of the transplant team do I meet with now?**

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.

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 1 hour. You are welcome to bring a friend or family member with you to this meeting. The recipient does not come to this meeting. The nephrologist may order more tests after this appointment.

#### **Psychiatrist**

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

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### What is the Program for Reimbursing Expenses of Living Organ Donors (PRELOD)?



The Ministry of Health and Long-Term Care has a fund to help reduce the financial stress that comes with being a living donor. This program is administered by the Trillium Gift of Life Network (TGLN).

PRELOD reimburses living organ donors for certain qualified out-of-pocket expenses and loss of income after surgery.

PRELOD helps reduce financial burdens that may prevent you from deciding to be a living organ donor. Talk to your transplant coordinator to get a PRELOAD reimbursement package.

### What happens after the transplant nephrologist clears me medically?

The transplant coordinator contacts you to arrange a Computed Tomography (CT) angiogram. This procedure is like an x-ray where dye is injected into a vein in your arm. You lie on a special table and a machine scans your body.

This angiogram allows the surgeon to look at your kidneys. It shows how many kidneys you have, (most people have 2) and how the blood is supplied to them through veins and arteries. The number of renal veins and arteries is an important part of your assessment. It also shows how the ureters drain urine from the kidneys into the bladder.

This test provides information to decide if you can be a donor and if so what kidney to use.

### Meeting with the transplant urologist

You see the transplant urologist next. This urologist is the transplant surgeon who removes your kidney. The transplant urologist reviews the CT angiogram and talks to you about the risks of surgery. You will also learn about what happens during surgery.

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### **What happens as the transplant is planned?**

The Transplant Coordinator schedules the transplant if the recipient is ready. Your work, personal obligations and schedule are taken in account to book at a time most convenient to you.

Most often, the transplant is scheduled 1 to 2 months ahead.

We contact the donor and the recipient about the best transplant date for both. We let your family doctor or health care provider know the transplant date as well.

### **How long does the whole process take?**

It takes about 6 months to 1 year to complete the donor and recipient work-up before we can schedule the transplant.

We understand this length of time is frustrating, but careful monitoring of all results is absolutely needed.

Remember, we have the donor and recipient safety in mind at all times.

### **What happens about 1 month before the transplant?**

You must come to the hospital and have some blood tests done. After this you meet with the transplant coordinator. You are encouraged to bring a family member or friend to this meeting.

We will tell you what happens when you come to the hospital for the surgery and when you can expect to go home. This meeting usually includes the recipient and interested family members. It takes about 1 hour.

### **What happens 1 to 2 weeks before the transplant?**

You come to the Pre-Admission Assessment Unit at the hospital. Your blood is taken for a final cross match. You have another ECG. You learn what to do on the day of surgery and how to plan for your hospital admission. You also see an anesthesiologist to plan your anesthesia for surgery.



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### **What happens the day of the transplant surgery?**

The morning of the transplant you come to the Day Surgery Unit. Here you are prepared for surgery. You have a thin tube called an intravenous (IV) put in a vein in your arm. The IV is used to give you fluids and medication before, during and after surgery.

You may be given a medication to help you relax about an hour before your operation. The surgery is usually scheduled at 9:00 a.m. The operation takes about 3 to 4 hours.

### **What happens after surgery in the hospital?**

#### **Post Anesthetic Recovery Unit (PACU)**

After surgery, you go to the PACU until you are fully awake. When it is safe to move, you are taken to your room on the Urology Nursing Unit. You are under the care of the transplant urologist, resident and nursing team.

#### **On the Nursing Unit**

Members of the health care team look after you and teach you how to look after yourself. They get you ready to be able to manage at home after discharge.

#### **Eating and Drinking:**

You begin sipping water and clear fluids slowly. The IV stays in until you are able to drink fluids well. You can eat a normal diet when the IV is taken out and you are able to do so.

Begin by eating small amounts throughout the day. You may also see a dietitian while you are in hospital.

#### **Urinary Catheter:**

You have a catheter tube in your bladder to drain urine. It is put in at the beginning of your surgery when you are asleep. The nurses check the colour of your urine and measure the amount. The catheter is usually taken out in about 24 hours.

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### **Pain and Discomfort:**

You will have some pain and discomfort after surgery. Pain control medication is given through the IV and a pain control pump. You learn how to use the pump and give yourself pain control medication. After a day or so, you then take pain control medication by mouth.

### **Incision Care and Hygiene:**

The incision is closed with sutures and staples. Your nurses will check your incision each day and teach you how to look for signs of infection. Your nurses will also tell you when you can have a shower and teach you how to keep your incision dry.

### **Moving Around and Activity:**

The day after surgery you get out of bed, sit in a chair and walk around. Your nurse or physiotherapist will help you at first. Take your time when you sit and stand up as it is normal to feel dizzy. You should do deep breathing and coughing exercises every hour you are awake to prevent problems such as pneumonia.

You will be encouraged to walk as much as you can over the next few days. It is easier to walk when the IV and urinary catheter are taken out.

### **Visiting:**

Visitors need to make sure that you get your rest and time to heal and recover. Visitors should not come if they have any signs of infection, rashes or cold sores. Visitors need to clean their hands when they enter and leave your room.

### **Length of Hospital Stay:**

Plan to be in the hospital 2 to 3 days.

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### What happens after surgery when you are home?

#### Follow-up:

The transplant urologist will see you in the office about 4 to 6 weeks after surgery. You will have this appointment schedule before surgery. If you do not have an appointment, call the office to make one.

If your sutures or staples have not been removed in the hospital, they are taken out at this time. You can decide to arrange for your family doctor or health care provider to do this if you want.

There may be some activities you can and cannot do for a while after surgery, talk to your transplant urologist about these at your follow-up visit.

There may be some activities you cannot do for such as contact sports for the rest of your life. Talk to your transplant urologist about this at your follow-up visit.

You should have a yearly check-up with your transplant nephrologist, including a blood pressure check, urinalysis, urea, and creatinine blood tests.

#### When you are home

You will need some help around the house when you return home. Try to make arrangements for this before you come to the hospital. You will need to take about 4 to 6 weeks off from work including the time in the hospital.

If you need any help with insurance forms please let the transplant coordinator know and he or she will have them completed by the doctor and returned to you as soon as possible.

#### Why are some people turned down as donors?

Some reasons include:

- Your blood supply to your kidneys could be complex. This would make surgery very hard to do successfully. The CT angiogram pictures are carefully reviewed by the transplant urologist, the transplant nephrologist and the radiologist to make a decision if surgery will be done or not.
- Your current health issues and risks to your personal health

It can be very upsetting to go through all of the testing and then be turned down. Please remember that the transplant team is here to listen to you, answer any questions and talk about any of your concerns.

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### **What does the recipient have to do before the transplant?**

About 1 month before the scheduled transplant, the recipient meets with the transplant coordinator. This meeting reviews what happens to the recipient before, during, and after surgery. The recipient is encouraged to bring a significant other, family, or friend to this meeting. Members of the team also meet with the donor at this time.

10 days before the transplant is scheduled, the recipient may be started on medications. The recipient will also need to have a blood test after starting the medications to check the level of medication in his or her blood. The test must be done at St. Joseph's Hospital Outpatient Department.

The day before the transplant the recipient is admitted to the Transplant Unit around 1:00 p.m. Early the next morning, the recipient is prepared for surgery and has surgery as soon as the donor's surgery is finished.

### **We are here to help**

We have a book called 'Your Kidney Transplant' that explains all about the transplant for the recipient. Ask your Transplant Coordinator for this book if you would like more information at this time. The Transplant Team is here to answer any questions you, your family or friends may have. Please feel free to call and we will try to help you.

**For any information about the Donor Program call 905-522-1155 extension 32156**

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### Where can I find more information about kidney donation?

#### **Kidney Foundation:**

The Kidney Foundation of Canada has a lot of information to offer 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](mailto:info@kidney.ca)  
Website: [www.kidney.ca](http://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](mailto:kidney@kidney.on.ca)  
Website: [www.kidney.ca/ontario](http://www.kidney.ca/ontario)

#### **Trillium Gift of Life**

To learn more about PRELOD visit the Trillium Gift of Life Network website at [www.giftoflife.on.ca](http://www.giftoflife.on.ca)

If you have any further questions or comments, please contact the PRELOD Administrator at: [www.PRELOD@giftoflife.on.ca](mailto:www.PRELOD@giftoflife.on.ca) or call: 1-888-9-PRELOD / 416-619-2342.

