



Toronto General Hospital

# Donating a Kidney

**Potential Living Kidney Donor Information**

## **An Introduction to Your Manual**

Transplantation cannot occur without the generosity of others. Most transplants occur through the kindness of strangers. Others are able to benefit from a living donor transplant. This is when someone who is living gives one of his or her kidneys to someone with end-stage kidney disease (permanent kidney failure). Your decision to be a donor is greatly appreciated not only by the patient and their family but also by the transplant program.

Members of the Multi-Organ Transplant Program of Toronto General Hospital, University Health Network (UHN) have designed this manual to provide our donors and patients with reference and resource material to help them understand, prepare for and assist them through the donation process.

We realize that there is a lot of information given to you about the donation and transplant and we hope that this manual will serve as a valuable guide.

In accordance with the Ontario Human Tissue Gift Act, The Toronto General Hospital and the Multi-Organ Transplant Program do not support or accept payment of any kind for organs for transplantation. It is against the law to buy, sell or otherwise deal in, directly or indirectly, any tissue for transplant, or any body part or parts of the body for therapeutic purposes, medical education or scientific research. If at any time you are approached by a person to purchase or sell an organ for transplantation, please immediately contact:

**Patient Relations at The Toronto General Hospital, UHN at (416) 340-4907.**

### **The Multi-Organ Transplant Program**

The Multi-Organ Transplant Program at the University Health Network in Toronto is the largest transplant program in Canada. Since 1965, over 6,500 transplant operations have been performed at the Toronto Western and Toronto General Hospitals. Many types of organs are transplanted here including the kidney, liver, pancreas, lung and heart. The Multi-Organ Transplant Unit transplants around 100 kidneys every year, of which 50-60 are transplanted from living donors.

## **Kidney Donation**

If you are reading this, you or someone you are close to is probably thinking about donating a kidney. This manual will give you information about kidney donation from a living person. This is when someone who is living gives one of his or her kidneys (donor) to someone with end-stage kidney disease (recipient). Research shows that living donation can be one of life's greatest experiences. Kidney donation is not for everyone, but by knowing the facts, you can decide if this option is the right choice for you.

There are many ways of helping a kidney transplant take place. It is important that kidney donors have an opportunity to consider all the facts about donation in order that they may decide if organ donation is right for them at this time. It is also important that potential donors discuss their desire to donate with their close family members, as donation will affect these people also.

### **Members /Responsibilities of the Living Kidney Donor Team**

The Living Donor Kidney Transplant Team is a group of highly skilled professionals who work together to help the donor and the recipient have a successful transplant and recovery. Before you are approved as a donor, each specialist evaluates your health, both physical and mental. Many tests will be performed including blood work, x-rays, and scans. The team will then decide if you are a suitable donor.

The members of The Living Donor Transplant Team include:

#### **Nephrologist**

The Nephrologist is a physician specializing in the diagnosis and treatment of kidney disease. It is necessary that you meet with the Nephrologist to make sure it is safe for you to donate your kidney. All potential donors will meet with a Nephrologist once all their testing has been completed. Your Nephrologist will meet with you again 3 months after the surgery to be sure your remaining kidney is compensating for the kidney that was removed.

#### **Nephrologists:**

Dr. Robert Richardson

Dr. Judith Miller

Dr. Melvin Silverman

Dr. Vanita Jassal

Dr. Charmaine Lok

### Urologist

The Urologist is a surgeon who specializes in the surgical treatment of kidney, bladder and urinary problems. The Urologist is also the specialist who does the kidney transplant and removes the kidney if a living donor transplant is being done. If there are any concerns with your urinary function, you may need to meet with the Urologist. All living kidney donors meet with the Urologist before their surgery.

### Urologist/Surgeon:

Dr. Michael Robinette

Dr. Anand Ghanekar

### Anesthetist

The Anesthetist is a medical doctor who will evaluate the safety of giving you the anesthetic during the operation. The Anesthetist is also a member of the Pain Management team. He/she can help you select which form of pain control is best for you.

### Transplant Assessment Coordinator

The Transplant Assessment coordinator is a Registered Nurse who works with the transplant team to organize your evaluation and provide teaching and support through this process.

### Transplant Coordinator:

Julie Cissell RN, BScN

Michael Garrels RN

Lee-Anne Hyer RN BScN

### Administrative Assistant

The role of the administrative assistant is to schedule appointments and tests. This individual is also a source of the information about the donor process. Whenever possible we will schedule appointments to suit your schedule. ***\*\*If you are unable to keep your appointments, please call the administrative assistant.\*\****

### Administrative Assistant: 416-340-4800

Diane Melo –ext. 2877

Stephanie Stewart –ext. 4848

Sherry Young –ext. 6775

Joan Lackraj –ext. 6773

Patricia Chandrapal –ext. 6595

### Social Worker

The Social Worker meets with all potential donors and their families to review each individual's situation and family supports. He/she will review how you decided to offer to donate a kidney, your understanding of donation, it's possible affects on your family and that of the recipient. He/she will work with you and your support persons to plan for the transplantation, keeping your unique needs in mind. He/she will be able to advise you about employment, financial and practical issues. In addition, your Social Worker will provide supportive counseling for you and your family, before and after the donation to address any emotional issues related to donation. If you need assistance in dealing with other agencies and institutions, the Social Worker will be able to connect you.

### Social Worker:

Brigitte Talevski MSW RSW  
Paul Rivers MSW

### Psychiatrist and/or Psychiatric Nurse

The Psychiatrist and/or Psychiatric Nurse may see you during your evaluation. These professionals specialize in helping donors and families cope with the stress of organ donation and the emotions that may go along with it.

### Psychiatrist:

Dr.Esther Elliott

### Psychiatric Nurse:

Tara Bolden

### Hospital Bioethicist

The Bioethicist is available to address any ethical issues that relate to the decision to donate any organ. The consultation process will strive to respect the wishes, beliefs and value systems of the potential donor, the family and healthcare team.

### Hospital Ethicist:

Linda Wright

## **What Do Kidneys Do?**

Your kidneys are located at the back of your body, just above your waist. When blood flows through the kidneys, waste and water are removed and the blood is cleaned. The waste is removed by your body as urine. Your kidneys need to work well to keep your bones, heart and muscles working properly. Kidneys also make hormones, which control things like your blood pressure and red blood cell production.

## **Why Someone Needs a Transplant?**

When a person has kidney failure, his/her kidneys no longer function enough to meet his/her body's needs. When this happens, the person becomes very sick. There are two treatment options for kidney failure: dialysis and transplantation. There are two types of dialysis: hemodialysis and peritoneal dialysis. In hemodialysis, a person is connected to a machine that cleans his/her blood and then returns it to their body. In peritoneal dialysis, the person uses a tube that is inserted into their abdomen where solution is inserted and then drained the help to clear out the toxins. However, dialysis cannot do all of the things a real kidney does.

Most of the time, the best treatment is to have a kidney transplant. The kidney can come from someone who has just died (called a deceased donor) or from someone who is living (called a living donor). If the transplant works, the new kidney will do all of the things a normal kidney does and the recipient will be able to live a dialysis free life. It is important to know that a transplant is not a cure, it is a treatment option. It is possible that a kidney transplant recipient may require a second transplant in the future.

## **Why Not Just Go On The Waiting List for a Kidney from a Deceased Donor?**

Most people who need a kidney transplant go on a waiting list for a deceased donor. In Ontario, adults usually wait 7-12 years (depending on the blood group) for a kidney to become available and 3-5% of people on the waiting list die waiting for a kidney each year. Advantages to living donation are that the waiting time is much shorter and the transplant date is planned allowing time for both the donor and recipient to prepare for surgery.

## **Who Can Donate a Kidney?**

Most people are born with two kidneys, but a person can live a normal life with just one, and that is why living donation is possible. Living donors may be blood relatives (brother, sister, parent, child), or genetically unrelated persons, such as spouses or friends.

## **What Are The Benefits For The Donor?**

You may experience the following benefits from donation:

- previously unidentified health issues maybe detected during your work-up
- you, like most people who donate a kidney, may feel proud and satisfied with the decision to help, and may report an improved sense of self-esteem
- You may also benefit from seeing the restored health of your recipient.

Most living donors say that they would make the same choice again. Studies have shown that donating a kidney makes donors feel good about themselves and creates stronger ties between family and friends. 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.

## **What Are The Risks in Donating my Kidney?**

Donating a kidney involves some important risks that all living donors should know about. The doctor will discuss the following risks with you in detail.

### **Risks from Surgery**

A kidney transplant is a major operation, and even though living donors are in good health, there are always some risks from having surgery.

The risk of any of these complications is very small. The risks with surgery are:

- Collapse of one lung (less than 1%)
- Bleeding requiring a transfusion (less than 1%)
- An allergic reaction to the anesthesia (1/10,000 -100,000)
- Pneumonia (infection in the lungs)
- Blood clots to the heart or lungs and
- Infection of the incision

Serious risks with any general anesthetic and major surgery are extremely rare but do include a heart attack or stroke and dying.

### **Life-Long Considerations**

There is no evidence that living with one kidney puts the donor at risk for future health problems. Within hours of removing the donated kidney, the remaining kidney takes over about half of the kidney function lost. Typical donors have about 65-75% of normal two-kidney function for the rest of their lives. All donors develop a small increase in their urine protein; There also may be a slightly higher blood pressure, but follow-up studies have not shown these to be serious concerns. Female donors are able to have a normal pregnancy with one kidney, but they should wait at least six months after the surgery before trying to become pregnant.

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

It is important that the person giving the kidney (the donor) has a blood type compatible with the recipient (the person who is going to receive the kidney). You can find out what your blood group is by having a blood sample taken. This can be arranged through your family doctor or the transplant coordinator can arrange this for you. A well, many people who donate blood will have a card from the Canadian Blood Services stating their 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).

RECIPIENT BLOOD TYPE	COMPATIBLE DONOR BLOOD TYPE
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

**\*\*\*There are options if you are not blood type compatible, ask the coordinator\*\*\***

If you are not a compatible blood group The Toronto General also has several programs to facilitate a transplant.

- NATIONAL PAIRED EXCHANGE PROGRAM in partnership with St. Michael’s Hospital. This program permits pairs of incompatible donors and recipients to donate to each other i.e. donor A gives kidney to recipient B and donor B to recipient A.
- LIST EXCHANGE PROGRAM allows a recipient to move to the top of the waiting list.
- ABO-INCOMPATIBLE DESENSITIZATION PROGRAM allows a donor to donate directly to the intended recipient. Please ask the Transplant Coordinator for more information about these options.

What Happens after it is Determined that I am a Compatible Blood Group?

The transplant coordinator will ask you to complete a health questionnaire in order to determine if there are health issues that would disqualify you as a donor. There are strict criteria that you must meet in order to be a donor. There are certain medical conditions that would exclude you as a donor such as a high blood pressure, a heart condition, certain chronic illness and kidney stones (this list is not complete). For your safety, it is essential that you make the coordinator aware of any health issues or concerns.

## **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 will be arranged. The purpose of the cross match is to determine how similar your tissue is to your recipient's as well as to see if your recipient reacts negatively or positively to your tissue. The cross match is to make sure your intended recipient is compatible with you; a **negative crossmatch** reduces the likelihood of rejection.

The tissue typing and crossmatch is a blood test that scheduled with a TGH- associated laboratory. Once the doctor has determined the results are suitable, the donor work up will commence.

**In the case of parent and child, the tissue typing may occasionally reveal the unexpected information that you are not related to one another by blood. This needs to be confirmed. If you wish to confirm this you may want to have further testing in a qualified laboratory through your family doctor. It is our practice to disclose this information to you, unless you specifically request otherwise.**

**Medically, this information does not mean you are unable to donate. Psychological support and follow up would be provided, and you can then decide if you would like to proceed with the assessment for donation. If you would rather not be informed of an unexpected result regarding your relationship to the recipient, please indicate this to the coordinator prior to the tissue typing blood test.**

**Importantly, please remember that the potential recipient will also be given this option. Their choice regarding disclosure will be respected, even if his/her preference is different from your own.**

Sometimes the tissue typing and crossmatch result will clearly indicate the most suitable person to be worked up as the potential donor. Frequently though, each of the individuals may be equally suitable to be worked up as the potential donor. Under this circumstance, each individual should take into consideration their personal circumstances, work and desire to proceed. Sometimes the donors discuss amongst themselves to determine who will undergo donor evaluation. The other individuals will then be considered "back up" donors should the initial donor be determined medically unsuitable during the evaluation

If there are multiple donors, each donor will be informed of their result. It is up to the donor going forward to contact the Coordinator to commence the donor evaluation.

## **The Cross-match is positive, what happens next?**

If the cross-match is positive a blood test called cross-match with titres will be completed to see how strongly your recipient reacts to your HLA or tissue type. This will help to determine if the HLA DESENSITIZATION PROGRAM is suitable for you and your recipient.

You may also be able to participate in the PAIRED EXCHANGE PROGRAM and a LIST EXCHANGE PROGRAM. Please ask the Transplant Coordinator for more information about these options.

**The Cross-match is negative , what happens next?**

In order to donate a kidney the donor must be assessed to determine if he/she is healthy enough to donate. The assessment requires a number of tests including blood and urine samples, medical imaging and interviews with members of the donor team. The purpose of all the testing and interviews is to make sure that the potential donor is healthy and that it is safe for both the donor and the recipient to proceed with the transplant. The donor team also wants to be certain that the donor has thought about all the aspects of donating a kidney and has been given the opportunity to have his/her questions answered by the most appropriate team member.

If, in the course of the assessment process, a potential donor is found to have a health problem, medical assessment treatment will be offered. All information gathered about the donor during the selection process is strictly confidential. Test results will not be discussed with the potential recipient. At the UHN, a different team from the recipient assesses potential donors. The donor team is there to support the potential donor and act in the donor’s best interest.

**What Tests Are Done?**

A potential donor must take many tests to make sure that he or she is healthy and that it is safe to proceed with the surgery. Below is a brief description of some of the tests. Ask your donor team for more information if you have any questions about any of them. Testing may take a number of months to complete. You may do your testing here at Toronto General Hospital or through your family doctor.

<b><u>Test</u></b>	<b><u>Purpose/Information</u></b>
Blood type (a blood test)	To see if your blood group matches the recipient's blood type.
Viral Screening (blood sample)	To make sure there are no viruses in your blood that may harm the recipient. Tests included Hepatitis B and C, HIV and syphilis. Certain times of the year you will be tested for West Nile
Liver and Kidney Function (blood sample)	To see if these organs are working properly.
Clotting Test (blood sample)	To see how long it takes for your blood to clot.
Complete Blood Count (CBC) (blood sample)	To check if the number of blood cells is normal.

Blood Sugar (blood sample)	To screen for diabetes mellitus; if there is a history of diabetes in your family you will be requested to do an additional test called a glucose tolerance test.
Electrolytes (blood sample)	To check the levels of sodium, potassium and chloride in you blood.
24 Hour Urine Test	Urine is collected for a 24-hour period. It is tested to see how much creatinine and protein is in the urine to help evaluate kidney function. <b>This must be done once.</b> (Instructions on how to do this test correctly will be provided by the Living donor kidney office)
Urinalysis	A urine sample is tested to see if there is blood or protein in your urine. <b>This must be done twice</b>
Urine Culture	The urine culture is done to determine whether or not you have an infection. <b>This must be done once</b>
Chest X-Ray (a screening x-ray)	To see if your lungs and heart appear normal
ECG	This test is done to make sure that you heart rhythm is normal
Stress Echo (usually done on persons over 40 years of age)	A treadmill walking/running test to see how your heart and body responds to stress in the form of exercise.
Abdominal Ultrasound	This lets the doctors see the kidneys and other organs to make sure they look normal.
Renal Scan (GFR)	This test determines your overall kidney function and how much function each kidney provides. You are given a small dose of a radioactive liquid.
CT Scan	This test evaluates the structure and blood supply of the kidneys; this information is used by the surgeons to decide which kidney will be removed. You are given a small dose of an intravenous contrast.

**\*NOTE: other tests may be required; the nephrologist (doctor) will determine this.**

### **What Happens If I Miss An Appointment?**

If you miss a required appointment, it will be re-booked. You will then be contacted by telephone with the new date and time. This may be done twice. If you miss the same test a second time, the transplant team will assume that you do not wish to continue with the work-up. A letter will be sent to you and if the transplant team does not receive a response within two weeks, they will consider you unable to continue with the work-up. The potential recipient will be notified that you are not a suitable candidate at this time.

## **What If I Am Having Doubts About Donating?**

It is important that you take time to think about your decision carefully. You should not donate if you do not want to, and 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 donor team will be available to help you deal with this.

The specific reason for ending a donor work up is confidential, the recipient will be informed that you are medically unsuitable for donation.

You may wish to inform the recipient yourself or you can request the coordinator to inform the recipient that your work up has been closed.

## **I have completed all the tests, what next?**

Once you have completed all of the testing and consults, an appointment will be made for you to see one of the nephrologists (kidney donor doctor). The nephrologist will review your medical history and current state of health; perform a physical examination and urinalysis. If your testing and assessments are satisfactory, the doctor will approve you to donate.

Surgery will be scheduled once the donor and recipient are approved.

## **Donor Surgery**

### When do I see the surgeon?

Once you have been cleared to donate by your team and surgery has been scheduled you will be seen by the surgeon. This appointment usually takes place about a week before surgery. During this appointment, you and the surgeon will discuss the type of surgery you will have.

### Types of Surgical Procedures

There are two types of surgery used to remove the donated kidney. The method that is right for you will be discussed with you by the surgeon.

### Modified Traditional (open) Incision

A 4-inch incision is made on your side approximately 2 inches back from the tip of the 11th rib and extending 2 inches forwards towards the front of the abdomen. Depending on the blood supply of your kidneys either the right or left kidney is removed along with its corresponding blood vessels and ureter (the tube which carries urine from the kidney to the bladder). Almost immediately, the remaining kidney begins to enlarge and assumes some of the work that was previously performed by both kidneys. Sutures are used to close the incision and the skin is closed with staples that are removed about a week later. This surgery lasts approximately 1 1/2 hours and the hospital stay is usually four to five days.

### Laparoscopic (keyhole) Nephrectomy

Three small 1 cm incisions are made in the upper left region of the abdomen to allow insertion of a small camera and operating instruments. The kidney is carefully mobilized and a television screen is used to monitor the procedure. An incision approximately 4 inches in length across the lower abdomen is made to remove the kidney once it is completely mobilized. Sutures are used to close the incisions and the skin is closed with staples. This surgery takes approximately 3 1/2 hours to complete and the hospital stay is usually four days. The surgeon will discuss with you if this procedure is appropriate for you.

### Kidney Donor Surgery

Every effort will be made to arrange the timing of surgery in accordance with your wishes. However, surgery may be cancelled if medical issues exist with the donor or the recipient. On occasion there are circumstances beyond our control that may require the donation to be cancelled or postponed.

At least one week prior to surgery you are required to repeat blood tests and appointments before surgery. Appointments also include meeting with the surgeon, nurse and anesthetist.

For your convenience the Assessment office can provide you with a list of local accommodations. The Assessment Office can also supply a letter for you to receive a reduced rate at some of these accommodations.

### What Happens During The Hospital Stay?

You will be admitted to the hospital the morning of the surgery (usually at 6:00am). An intravenous line will be started (by putting a needle into a vein in your arm) to give you fluids. Following your donor surgery you will be in the recovery room for approximately for 2-4 hours, then you will likely be admitted to the 6<sup>th</sup> floor, Clinical Services Building for the rest of your hospital stay.

### How will my pain be controlled?

There will be pain and discomfort around the site of the incision right after the surgery. Medications are given to control the pain. The incision will become less painful over the first couple of weeks, but it will take several weeks for the muscles and nerves to heal completely.

Your pain will be managed by what is called Patient Controlled Analgesia (PCA) and is given to you Intravenously or via Epidural.

### What is PCA?

Medicine for pain is called analgesia. Patient Controlled Analgesia or PCA allows you to give yourself pain medicine by pushing a button. You may use Intravenous PCA or Epidural PCA.

### **Patient Controlled Analgesia (PCA)**

A PCA pump is connected to your intravenous (IV). The pump gives you pain medicine (a narcotic like Morphine or Demerol) through your IV when you push the button.

### When should I press the button?

- When you start to feel pain.
- Before you do something that brings on the pain.
- Before breathing and coughing exercises.
- Before you start to move or turn.

The medicine will take 5-10 minutes to work. Press the button as often as you need to control your pain.

### Can I give myself too much medicine?

The PCA pump has a safety timer called a lockout. The lock out time is 5 to 10 minutes. If you press the button during the lockout time, you will not receive more medicine. There is a limit to how much pain medicine you can have in any 4 hours.

### What else should I know about PCA?

Visitors and family should NOT press the PCA button. Only you should push the button.

- Do not wait until the pain is bad before using your pain medicine.
- Do not use PCA when you are comfortable or sleepy.
- Do not use PCA for gas pain.

### Side effects and risks of intravenous PCA

The most common side effects and complications are minor and easy to treat.

They include:

- Nausea or vomiting
- Sleepiness
- Itching

- Difficulty emptying your bladder. Patients have a small tube inserted to empty urine from their bladder after surgery.
- Constipation
- Hallucinations

## **Epidural Patient Controlled Analgesia**

### What is an epidural?

An epidural is a small tube placed by the Anesthetist into the lower part of your back. The procedure is the same as the one used by women during childbirth.

### How is the epidural put in?

The epidural is usually put in before your surgery. You will either lie on your side in a curled up position, or sit up. The doctor/anesthetist will clean and freeze an area of your back. A needle is placed into your back and a small tube is placed through the needle. The needle is removed and the tube is taped to your back. Medicine is given through the tube to provide pain relief.

### What happens after my surgery?

The epidural is left in place to give you pain medicine. The medicine may make your legs feel numb, heavy, or difficult to move. Your nurse will check to see if this is a problem.

### How does epidural PCA work?

A PCA pump will be attached to your epidural and give you pain medicine continuously. You should press the button to receive more pain medicine if your pain is not under control.

### Side effects and risks of epidural analgesia

The most common side effects and complications are minor and easy to treat.

They include:

- Nausea or vomiting
- Sleepiness
- Itching
- Headache. Headaches are usually minor and respond to ordinary pain medicine. If the headache persists, there are other ways to treat it.
- Difficulty emptying your bladder. Often patients have a small tube inserted to empty urine from their bladder after surgery.
- A drop in blood pressure. This drop in blood pressure can lead to nausea or dizziness. Giving you fluids through the intravenous can treat this.
- Backache. Although some patients experience backache after an epidural this is usually short lasting.
- Very rarely the epidural could cause a neurological complication, ranging from temporary numbness up to and including weakness or paralysis.

- Other rare complications include allergic reactions, seizures or cardiac arrest. Your Anesthesiologist will be carefully monitoring you to avoid any of these complications.

\*When you meet with the Anesthetist he /she will discuss the two types of pain control in order to determine with you which method is right for you\*

#### When is PCA or epidural pain control started and stopped?

Both intravenous and epidural PCA are started before you go to the recovery room.

They are stopped when you are able to take pain medicine by mouth.

Once the PCA or Epidural is stopped, you must ask your nurse for pain pills when you need them.

#### What Happens After The Surgery?

If staples were used to close the incision, they will be removed after 7-10 days. We suggest that your family doctor removes these staples, if you do not have a family doctor or you are from out of town, please discuss staple removal with your Coordinator. You cannot do any heavy lifting (over 10 pounds), or physically demanding activity for at least 6 weeks. We recommend that patients take 4-6 weeks off work regardless of the surgical procedure. Some patients may go back as early as 3 weeks after surgery.

#### **Follow-up after surgery**

##### Surgeon

You will meet again with the surgeon who performed the surgery, either with Dr. Robinette at six weeks or with Dr. Ghanekar at four weeks to determine how well you are recovering.

##### Nephrologist (Kidney Doctor)

Three months after the surgery, you will see the kidney donor doctor for a check up. You will be sent requisitions to do lab work one week before the scheduled appointment date and again at six months after donation.

The donor team will be available to discuss any concerns or answer any questions that you might have throughout the donation process.

##### Family Doctor

Following the six month appointment you will be discharged back to the care of your family physician. It is suggested that you see your family doctor for a yearly blood pressure check, serum (blood) creatinine level, and a urinalysis.

## Important Points to Remember

- A kidney transplant is the best form of treatment for kidney failure for most patients
- Although we try our best, sometimes kidney transplants are not successful. If this happens, it will be very disappointing for you and others involved. All members of the donor team are here to support you in the unlikely event that this happens.
- You should be aware as a potential donor that a living donor kidney transplant on average lasts for 15-20 years and that some recipients may need another transplant later on in life. Certain conditions may be more likely to reoccur in the transplanted kidney and the doctor will discuss this with you.
- You must complete all the testing before being seen by the nephrologist and the nephrologist will determine if you are suitable to donate. You may be turned down as donor if you are found to be medically or psychological unsuitable
- Surgery may be delayed if there is change if the recipient's or donor's condition
- If you are not sure or feel uncomfortable about donating let the transplant coordinator know. You may change your mind or back out at anytime
- The only information that will be shared with your recipient is information you give us permission to share

## Statistics from Kidney Transplant Program at The Toronto General Hospital, UHN

Chart Below refers to the kidney transplant recipient

	<b>Kidney Survival at one years</b>	Kidney Survival at five years
Identical Live donor Match (6/6)	<b>95%</b>	<b>90%</b>
Non-identical Live donor Match (0/6 to 5/6)	<b>95%</b>	<b>87%</b>
1 <sup>st</sup> Deceased Donor Transplant	<b>90%</b>	<b>80%</b>
<b>2<sup>nd</sup> or &gt; Deceased Donor Transplant</b>	<b>85%</b>	<b>75%</b>

## **West Nile**

To reduce the risk of spreading the West Nile Virus (WNV) to your potential recipient, we ask that you follow the precautions we have outlined. At certain times of the year, West Nile is more prevalent and therefore you will be tested for this about a week before surgery. If your test comes back positive, the surgery will have to be delayed. We will be tested about once a week until the test comes back negative and then the surgery can be rescheduled.

We ask that you follow certain protection measures for 2 weeks before the surgery, which, are outlined in the section below “What can people do to reduce their risk of WNV infection?” In addition, for the two weeks before surgery we ask that you avoid high-risk activities like camping, cottaging and similar activities, where prolonged exposure to mosquitoes may occur.

### **What is West Nile Virus?**

West Nile Virus belongs to a family of viruses called Flaviviridae. Mosquitoes that have fed on the blood of an infected bird spread it.

### **How do people get infected with West Nile Virus?**

The evidence shows that most people infected with West Nile Virus got it from the bite of an infected mosquito. Recently, it has been discovered that people could be infected with West Nile Virus in other ways, including blood transfusions and organ/tissue transplants. The risk of getting WNV this way is considered to be quite low. There is no evidence to suggest that people can get WNV by touching or kissing someone who is infected.

### **What are the symptoms of West Nile virus infection?**

Many infected people have no symptoms and do not get sick or have only mild symptoms. People with weaker immune systems, such as transplant recipients, are at greater risk for serious health effects. The extent and severity of symptoms vary widely from person to person. In mild cases, there may be flu-like symptoms, including fever, headache and body ache. Some individuals may have infections that are more serious, including meningitis and encephalitis. Meningitis is inflammation of the lining of the brain or spinal chord. Encephalitis is inflammation of the brain itself. These conditions can be fatal. In such cases, symptoms could include the rapid onset of severe headache, high fever, stiff neck, nausea, difficulty swallowing, vomiting, and drowsiness, and confusion, loss of consciousness, lack of coordination, muscle weakness and paralysis.

### What can people do to reduce their risk of WNV infection?

You can further reduce your chances of becoming ill by protecting yourself from mosquito bites. To avoid mosquito bites:

- Apply insect repellent containing DEET to exposed skin whenever you are outdoors.
- When possible, wear long-sleeves, long pants and socks when outdoors. Treating clothes with repellent containing permethrin or DEET will give extra protection, since mosquitoes may bite through thin clothing. Do not apply repellents containing permethrin directly to skin. Do not spray repellent containing DEET on the skin under your clothing.
- The hours from dusk to dawn are peak mosquito biting times. Consider avoiding outdoors activities during these times—or take extra care to use repellent and outdoors activities during evening and early morning.
- Mosquitoes lay their eggs in standing water. Limit the number of places around your home for mosquitoes to breed by getting rid of items that hold water.

### When should I use mosquito repellent?

Apply repellent when you are going to be outdoors and will be at risk for being bitten by mosquitoes.

### What time of day should I wear mosquito repellent?

Mosquitoes are especially likely to bite around dusk and dawn. If you are outdoors around these times of day, it is important to apply repellent. The safest decision is to apply repellent whenever you are outdoors.

### How often should repellent be reapplied?

Follow the directions on the product you are using in order to determine how frequently you need to reapply repellent. Sweating, perspiration or getting wet may mean that you need to reapply repellent more frequently. Repellents containing a higher concentration of active ingredient (such as DEET) provide longer-lasting protection.

### Which mosquito repellent works the best?

The most effective repellents contain DEET, which is an ingredient used to repel pests like mosquitoes and ticks. DEET has been tested against a variety of biting insects and has been shown to be very effective. The more DEET a repellent contains, the longer time it can protect you from mosquito bites. A higher percentage of DEET in a repellent does not mean that your protection is better - just that it will last longer. DEET concentrations higher than 50% do not increase the length of protection.

How does the percentage of DEET in a product relate to the amount of protection it gives?

Based on a recent study:

- A product containing 23.8% DEET provided an average of 5 hours of protection from mosquito bites.
- A product containing 20% DEET provided almost 4 hours of protection.
- A product with 6.65% DEET provided almost 2 hours of protection.
- Products with 4.75% DEET and 2% soybean oil were both able to provide roughly 1 and half hours of protection.

Choose a repellent that provides protection for the amount of time that you will be outdoors. A higher percentage of DEET should be used if you will be outdoors for several hours while a lower percentage of DEET can be used if time outdoors will be limited. You can re-apply a product if you are outdoors for a longer time than expected and start to be bitten by mosquitoes.

## **Mentorship Programs for Transplant Patients & Their Families**

### What is a mentor?

A living donor or post-transplant patient who volunteers to share his/her transplant experience with you.

### Who is the program for?

- Patients and candidates for transplant
- Their families and support people

### Why may you want a mentor?

- You may want to meet another person who has had the experience of kidney transplant and can share these experiences with you. You may have questions about transplant and would like to hear from another patient.

### About mentors

- All mentors are post-transplant patients or the support people of post-transplant patients. Mentors can be either transplant recipients or living donors who are interested in helping others now facing the same experience they have had.
- They are trained volunteers of the Multi-Organ Transplant Services.
- Mentors will respect the principles of confidentiality, in accordance with hospital policies.
- Mentors are supported in their volunteer work by transplant staff. The professional staff of the Kidney Foundation of Canada also assists kidney mentors.

### How does the program work?

- The program is strictly voluntary. No one needs to see a mentor unless he/she wishes to do so.
- Mentors are available to talk to patients at their request.
- The patient will decide what the focus of the contact will be.
- Together, the mentor and the patient decide how they will meet, how often and for how long. Some people want only one or two meetings. Others would like longer, more ongoing contacts. Contact may be by telephone or a visit.

### How do I obtain a mentor?

- The names and numbers of staff contacts are listed below.
- Simply give your contact staff a member a call and a peer support volunteers will be found for you.
- To obtain the services of a peer support volunteer, please call the following staff contact: **Roselyn Liadsky at 416-340-4800 Ext. 3821 of The Kidney Foundation of Canada**

### Where Can I Get More Information?

If you have any questions about anything in this booklet or need more information on living kidney donation, there are people and places that can help. Here a few suggestions there are many more on the Internet.

#### The Kidney Foundation of Canada- Central Ontario Branch

Telephone: 416-445-0373

Website: [www.kidney.ca](http://www.kidney.ca)

#### The National Kidney Foundation (USA)

Website: [www.kidney.org](http://www.kidney.org)