



Donating a Kidney

**Information for potential living
kidney donors**

An introduction to your living kidney donor manual

Transplantation cannot occur without the generosity of others.

Most organ transplants occur through the kindness of strangers. Other recipients are able to benefit from a living donor transplant. This is when a living person gives one of his or her kidneys to someone with end-stage kidney disease (permanent kidney failure). Your decision to consider being a donor is greatly appreciated.

Members of the Multi-Organ Transplant Program of Toronto General Hospital, University Health Network (UHN), have designed this manual to help you understand, prepare for, and assist you through the whole donation process.

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

The Multi-Organ Transplant Program at University Health Network

The Multi-Organ Transplant Program at University Health Network in Toronto is the largest transplant program in Canada. Since the start of the program, over 4,000 kidney transplant operations have taken place at the Toronto Western and Toronto General Hospitals, of which more than 1,200 are from living kidney donors. Many types of organs are transplanted here, including the kidney, liver, pancreas, lung and heart. The University Health Network transplants approximately 140 kidneys every year, of which 70 to 80 are transplanted from living donors.

Organ Donation, transplantation and the law

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 call the Patient Relations department right away:

UHN Patient Relations
Tel: (416) 340- 4907

Part A: Living 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 the living kidney donation process. This is when someone (the “donor”) who is living gives one of his or her kidneys to someone with end-stage kidney disease (the “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 in the process of a kidney transplant. It is important that kidney donors have a chance to consider all the facts about donation before deciding if organ donation is right for them at this time. It is also important that potential donors talk about their desire to donate with their close family members, as donation will affect these people also.

Members of the living donor kidney 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 team member evaluates your health, both physical and mental. Many tests will be done, including blood work, x-rays, and scans. The team will then decide together with you if you are a suitable donor.

The members of the Living Donor Kidney transplant team include:

Transplant Assessment Coordinator: _____

The transplant assessment coordinator is a Registered Nurse (RN) who works with the transplant team to set up your evaluation and provides teaching and support throughout the donation process.

Administrative Assistant: _____

The role of the administrative assistant is to schedule your appointments and tests. This person is also a source of information about the donation process. Whenever possible, they will schedule appointments to suit your schedule.

****If you are unable to keep your appointments, please call the Administrative assistant. ****

Social Worker: _____

The social worker meets with all potential donors and their families to talk about each individual's situation and to provide family support.

- He or she will go over with you how you decided to offer to donate a kidney, your understanding of donation, and its possible effects on your family and that of the recipient.
- He or she will work with you and your support persons to plan for the transplantation, keeping your unique needs in mind.
- He or she will be able to advise you about employment, financial, and practical issues.
- Your social worker will offer supportive counseling for you and your family, before and after the donation, to talk about any emotional issues you may have related to donation. If you need help to deal with other agencies and institutions, the social worker will be able to connect you.

Psychiatrist or Psychiatric Nurse: _____

The psychiatrist 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.

Hospital Bioethicist: _____

The bioethicist can talk with you about any ethical issues that relate to your decision to donate an organ. The bioethicist will make sure that the wishes, beliefs, and value systems of the potential donor, the family, and healthcare team are respected.

Nephrologist: _____

The nephrologist is a doctor 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.
- The nephrologist you meet with is not a member of the transplant team that evaluates and manages potential recipients before and after the transplant. This ensures that there is no conflict of interest involved in your evaluation as a potential kidney donor.
- All potential donors will meet with a nephrologist once all their testing has been completed to review and ensure you are aware of the benefits and risks of donation.
- Your nephrologist will meet with you again 3 months after the surgery to be sure your remaining kidney is working well.

Transplant Surgeon: _____

The transplant surgeon may be either a urologist or general surgeon who specializes in kidney transplantation. They will perform the kidney transplant surgery and will remove the kidney if a living donor transplant is being done. Sometimes, a potential donor may need a special evaluation by one of their local urologists to ensure there will be no problem proceeding with kidney donation. All living kidney donors meet with one of the transplant surgeons before their surgery.

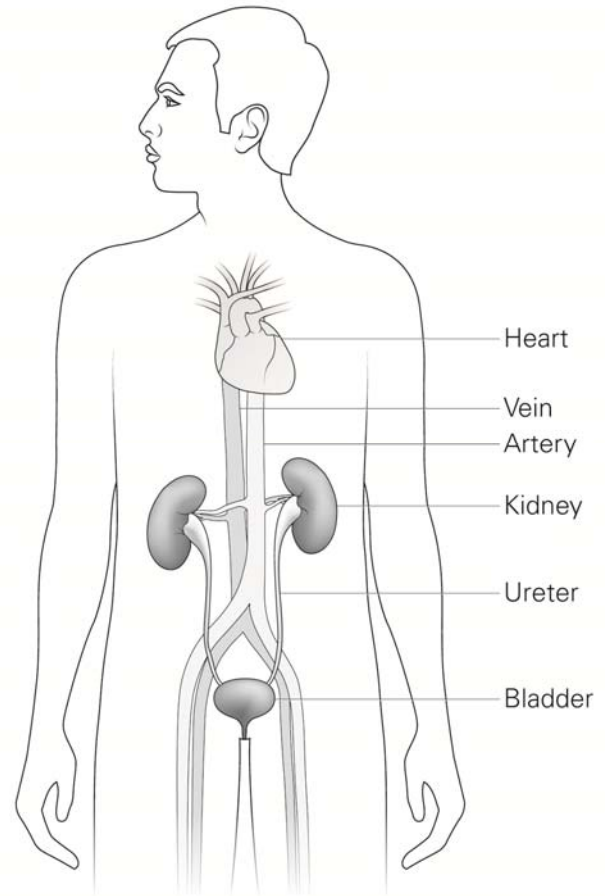
Anesthetist: _____

The anesthetist is a medical doctor who will assess the safety of giving you anesthetic (medication that puts you to sleep) during the donation surgery. The anesthetist is also a member of the pain management team. He or she can help you select which form of pain management will be best for you after your surgery.

Part B: Beginning the Process

What do the kidneys do?

- Your kidneys are found at the back of your body, just above your waist.
- 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 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.



General human anatomy diagram

Why would someone need a kidney transplant?

When a person has kidney failure, his or her kidneys no longer work well enough to meet his or her body's needs. When this happens, the person becomes very sick.

There are two treatment options for kidney failure: dialysis and transplantation.

Dialysis:

There are two types of dialysis:

- Hemodialysis: a person is connected to a machine that cleans his or her blood and then returns it to their body

- Peritoneal dialysis: a person has a tube inserted into their abdomen where fluid (dialysate) is inserted and then drained to help clear out the toxins from the blood

Dialysis cannot do all of the things a real kidney does.

Transplantation:

- Most of the time, the best treatment for kidney failure 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 need 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 kidney.

- In Ontario, adults usually wait 7 to 12 years (depending on their blood type) for a deceased donor kidney to become available.
- Unfortunately, 3 to 5 out of 100 people on the waiting list die waiting for a kidney each year.
- There are many advantages to a living kidney donation over a deceased kidney donation. For one, the waiting time is much shorter and the transplant date is planned ahead, allowing time for both the donor and recipient to get ready for the surgery. Furthermore, a kidney removed from a living donor is generally healthier than one removed from a deceased donor, and usually begins to function right after the transplant operation. This contributes to a better long-term success rate than deceased donor kidney transplants.

Who can donate a kidney?

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

Living donors may be blood relatives (a brother, sister, parent, child) or genetically unrelated persons, such as husbands and wives or friends. People can also donate a kidney when they do not know the person who needs one. The hospital gives these kidneys to people on the kidney transplant waiting list.

What are the benefits for me if I donate my kidney?

If you decide to donate your kidney, you may experience the following benefits:

- Like most people who donate a kidney, you may feel proud and satisfied with the decision to help, and may report an improved sense of self-esteem.
- Any health issues that you did not know about already may be found during your work-up. If this is the case, this may mean that you will be able to get any help that you may need for these conditions earlier than you otherwise would have.
- You may 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. Most living donors remain positive about their decision to donate and report excellent health and well-being many years afterwards.

What are the possible risks to me if I donate my kidney?

As a potential living donor, you should know about some of the risks that can be linked to donating a kidney. Your doctor will discuss the following risks with you in detail.

Risks from surgery

Kidney donation is a major operation, and even though living donors are in good health, there are always some risks related to having surgery.

Some of the risks are:

- Temporary partial collapse of one lung (less than 1 person out of 100 people) that is recognized during surgery and the lung is simply re-expanded.
- Bleeding requiring a blood transfusion (less than 1 person out of 500 people)
- An allergic reaction to the anesthesia (1 person out of 10,000 -100,000 people)
- Pneumonia (infection in the lungs) or small areas of mucous plugs in the lung tissue (called atelectasis). This rarely occurs because patients are encouraged to walk after 24 hours and are given special exercises to keep the lung airways clear.
- Blood clots in the heart or lungs is also a rare complication because of the use of mini-dose heparin (blood thinner) after surgery.
- Infection of the incision is also rarely seen as a result of the use of a single dose of intravenous antibiotic given in the operating room just before the surgery.

**** It is important to know that the risk of any of these complications for donors accepted into our program is very small. ****

Serious risks with any general anesthetic and major surgery are extremely rare, but may include heart attack, stroke, or death.

You should learn all you can about the risks of a kidney donation. Talk with your doctor or other members of the healthcare team to make sure that you have all your questions answered.

Life-long considerations

In addition to the risks of surgery, kidney donors live the rest of their lives with a single kidney. There have been many studies of kidney donors to try and find out whether the risks of living with a single kidney are important.

Fortunately, most of the studies that have looked at donor outcomes from many different countries are reassuring:

- Kidney function after donation is between 65 and 70% of the level before surgery.
- The decrease in kidney function after donation does not affect how donors feel and does not require any change in diet or physical activity.
- Kidney function declines with age at the same rate as it does in the general population.
- There is typically a small increase in protein loss in the urine after donation which does not require any treatment.
- Blood pressure may increase by a small amount after donation, but rarely enough to require treatment.
- We know from a study of more than 2000 Ontario kidney donors, that donors have no increase in major cardiovascular disease such as heart attack or stroke after donation.
- The risk of a kidney donor developing serious kidney disease which might require dialysis or a kidney transplant is less than in the general population.
- If donors develop kidney disease or kidney damage after donation, they may have a slightly higher risk of developing kidney failure than if they did not donate because they have only one kidney.
- Women who have donated a kidney may have a successful pregnancy but are encouraged to wait at least 6 months after surgery before becoming pregnant.

In order to ensure good outcomes for kidney donors after surgery, the living kidney donor program at UHN recommends the following:

- An appointment with your donor surgeon will be arranged one month after surgery.

- An appointment with your donor nephrologist will be arranged 3 months after surgery. At this visit your blood pressure will be measured and kidney function will be tested with a blood creatinine level.
- At 6 months after donation you will have a 24 h urine collection and blood test to accurately measure your kidney function and protein loss in the urine, but you do not need to see the nephrologist. If the results of these tests are satisfactory, no further follow-up with the living donor program at UHN is necessary. If any of the results are abnormal, follow-up with your donor nephrologist will be arranged.
- After testing at 6 months, the living donor program recommends that you see your family physician annually for the rest of your life. The reason for this is that if you did develop any sign of kidney disease or high blood pressure you should be properly assessed and treated in order to prevent kidney failure. Annual testing would consist of measurement of blood pressure, blood creatinine, and urinalysis.

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

The initial steps in determining if you are able to donate involve examination of your health history and determining your blood type. It is important that the donor has a blood type that is compatible (well-matched) with the recipient. You can find out what your blood type is by having a blood sample taken. This can be set up with your family doctor or your transplant coordinator. As well, many people who donate blood will have a card from the Canadian Blood Services stating their blood type. This information will help in the donation process.

My blood type is _____

The following is a chart showing what blood types are compatible (the positive and negative portion of your blood group is not important in kidney donation). It should be noted that although compatible blood types provide the recipient with the greatest benefit, there are alternatives for incompatible blood types (see below).

Compatible donor blood types (My blood type)	Recipient blood type
If your Blood Group is O	You can donate to a recipient whose Blood Group is O, A, B, or AB.
If your Blood Group is A	You can donate to a recipient whose Blood Group is A or AB
If your Blood Group is B	You can donate to a recipient whose Blood Group is B or AB
If your Blood Group is AB	You can donate to a recipient whose Blood Group is AB

***** There are options if you and your potential recipient are not blood type compatible. These options are explained later in this section as part of Toronto General Hospital's Incompatible Transplant program. *****

What happens after I find out that my blood type is suitable to donate?

The transplant coordinator will ask you to fill out a health questionnaire in order to find out if you have any health issues that would disqualify (ban) you as a donor.

There are strict criteria that you must meet in order to be a donor. This means that there are certain medical conditions that would not allow you to be a donor, such as if you have high blood pressure, a heart condition, a certain chronic illness or multiple kidney stones (this list is not complete).

For your safety, it is essential that you make sure you tell your transplant coordinator about any health issues or concerns you may have.

HLA Testing: HLA Typing and Crossmatching

If your blood group is compatible with your recipient AND your health history is acceptable, blood tests called “HLA typing and crossmatch” will be done.

- The purpose of the HLA typing is to find out how similar you’re your cells are to your potential recipient’s cells
- The crossmatch tests if your recipient’s immune system does not demonstrate an immediate reaction to your cells (also known as a ‘negative crossmatch’).
- If you have a **negative crossmatch**, this means that there is a lower chance that the recipient’s body will reject your donated kidney right away.
- No test is available that can guarantee that the recipient will not reject a donated organ.

You will be informed if these results are suitable to proceed with kidney donation.

This test may also give some information about the biological relationship between you and your recipient, but it is not being performed to determine this relationship. Therefore, you will not be given information about this aspect of the test result. If you wish to have testing done to determine your biological relationship to your recipient, you will be referred to your family doctor.

The results of your test will be reported on the recipient’s chart in order to compare them with the recipient’s results and to ensure that it is safe to proceed with the transplant. You will be asked to give written consent for the crossmatch test (along with other tests) and for your results to be visible in the recipient’s report and record.

Once your doctor has decided that the results are suitable, the donor work up will begin.

If multiple donors are interested in donating to the same recipient, a crossmatch test will be conducted for each individual. Sometimes the HLA typing and crossmatch result will suggest a more preferable donor among many potential donors. More, frequently however, each of the individuals interested in donating may be equally suitable to be 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 further 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 transplant coordinator to commence the donor evaluation.**

The crossmatch is positive. What happens next?

If the crossmatch is positive, an additional blood test called “crossmatch with titres” will be completed to see how strongly your recipient’s immune system reacts to the donor cells. If you are a living donor that is crossmatch positive or blood type incompatible with your intended recipient, you can still be a living donor. The Toronto General Hospital's Incompatible Kidney Transplant Program has several options that make a transplant for your recipient possible:

- **The Living Donor Paired Exchange (LDPE) Registry** works in partnership with Canadian Blood Services. This program permits a donor of an incompatible pair to donate to another recipient in Canada, to whom they are compatible, while their original recipient receives a kidney from a different living donor in the program that is compatible with them. In this program, a donor will only donate a kidney if their original intended recipient receives a kidney from within the program at the same time.
- **The Desensitization Program** allows you to donate directly to your intended recipient. The recipient will require a series of treatments before the transplant to treat their immune system reaction to your cells.
- **The List Exchange Program** allows your recipient to move to the top of the deceased donor waiting list. This is done when you donate to another patient that is at the top of the deceased donor waiting list.

Please ask your transplant coordinator for more information about these options. If none of these programs are suitable, another potential donor may be evaluated.

The crossmatch is negative. What happens next?

In order to donate a kidney, the donor must be assessed to find out if he or she is healthy enough to donate.

- This assessment requires a number of tests including blood and urine samples, medical imaging, and interviews with members of the living kidney donor transplant 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 living kidney donor transplant team also wants to make sure that the donor has thought about all the aspects of donating a kidney and has been given the opportunity to have his or her questions answered by the most appropriate team member.

If you, as a potential donor, are found to have a health problem, medical care will be offered or you will be sent to your family physician for follow up.

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, separate teams assess the recipient and potential living donors so that your information is kept private from the recipient. The living kidney donor transplant team is there to support the potential donor and act in the donor's best interest.

What tests are done to find out if I can donate my kidney?

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 list of some of the tests.

<u>Test</u>	<u>Purpose of this test</u>
Blood type (a blood test)	To see if your blood group type matches the recipient's blood type.
Infection screening (blood sample)	To make sure there are no viruses or other infections in your blood that may harm the recipient. Tests included Hepatitis B and C, HIV, syphilis, and sometimes West Nile virus.
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 your 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 asked to do another test called a "glucose tolerance test."
Electrolytes (blood sample)	To check the levels of sodium, potassium, and chloride in your blood.
24 Hour urine test	You will be asked to collect your urine for 24-hours. It is tested to see how much creatinine and protein is in your urine to help look at your level of kidney function. This must be done once. (Instructions on how to do this test will be given to you by the living donor kidney office).
Urinalysis	A urine sample is tested to see if there is blood or protein in your urine. This must be done twice.
Urine culture	A urine culture is done to find out whether or not you have an infection. This must be done once.
Chest X-Ray (a screening x-ray)	To see if your lungs and heart appear normal.

ECG	To make sure that your heart rhythm is normal.
Stress echo (if age above 40)	A walking and running test done on a treadmill to see how your heart and body responds to stress while exercising.
Renal scan (GFR)	This test looks at your overall kidney function and the function each kidney provides. You will be given a small dose of a radioactive liquid.
CT scan	This test assesses the structure and blood supply of your kidneys. This information is used by the surgeons to decide which kidney will be removed. You will be given a small dose of an intravenous contrast dye.

Ask your donor team for more information if you have any questions about any of the tests. Testing may take a number of months to complete. You may do your testing at Toronto General Hospital or through your family doctor.

**** NOTE: Other tests may be needed depending on your medical history and the results of your tests. Your Nephrologist will let you know about any other tests you may need. ****

What happens if I miss an appointment?

If you miss a required appointment, it will be re-booked. You will be called by telephone with the new date and time. This will be done twice.

- If you miss the same test a third 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 get a response from you within 2 weeks, they will consider you unable to continue with the work-up.
- The potential recipient will be told 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.

If you decide to end a donor work-up process, the specific reason for ending your work up will be kept confidential. The recipient will only be told that you are medically unsuitable for donation. You may wish to tell the recipient of your choice yourself or you can ask your transplant coordinator to tell 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 consultations, an appointment will be made for you to see one the nephrologists (kidney donor doctor). The nephrologist will review your medical history and your current state of health, and will do a physical examination and urinalysis. If your testing and assessments are satisfactory, the doctor will approve you to donate.

Your surgery will be scheduled once both the donor and recipient are approved.

Part C: Donor Surgery

When do I see the transplant surgeon?

Once you have been cleared to donate by your team and your surgery has been scheduled, you will be seen by the transplant surgeon. This appointment usually takes place about 1 week before your surgery. During this appointment, you and your surgeon will talk about the type of kidney donation surgery you will have.

Types of Surgical Procedures

There are two types of surgical procedures used to remove the donated kidney. Your surgeon will talk with you about the method that will be right for you.

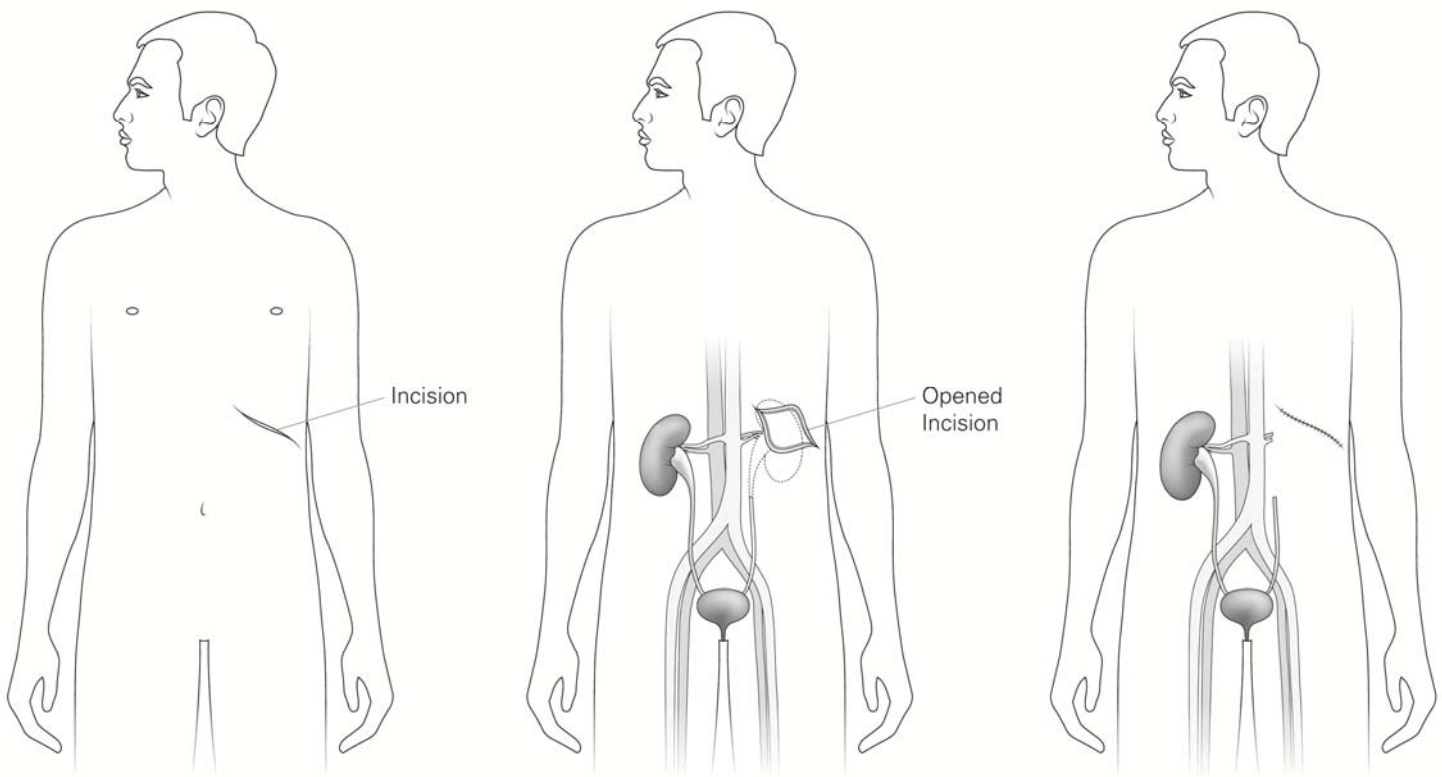
1. Modified Traditional Mini-Incision (open)

A 4-inch incision (cut) is made on your side about 2 inches back from the tip of the 11th rib and extending 2 inches forward towards the front of the abdomen.

Depending on the blood supply of your kidneys, either the right or left kidney is removed along with all its blood vessels and its ureter (the tube that carries urine from the kidney to the bladder).

Almost immediately the remaining kidney will begin to enlarge and take on 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 about 1 1/2 hours and the hospital stay is usually 4 to 5 days.



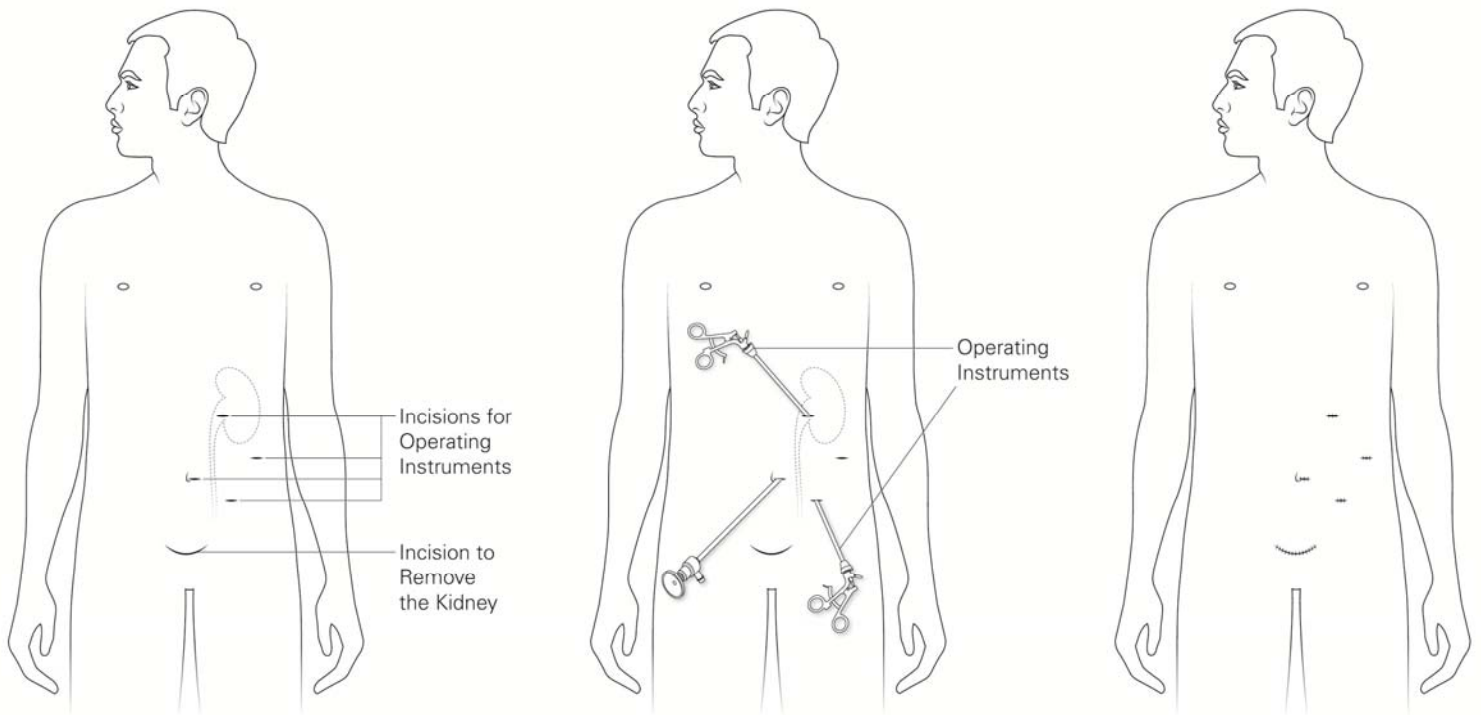
Modified traditional mini-incision diagram

2. Laparoscopic Nephrectomy (minimally invasive)

Three or four small 1/2 inch incisions are made in the upper left part of the abdomen to allow insertion of a small camera and operating instruments.

The kidney is carefully dissected free of its attachments and a television screen is used to monitor the procedure. An incision about 4 inches in length in 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 Steri-strips. This surgery takes about 3 1/2 hours to complete and the hospital stay is usually 4 days.



Laparoscopic nephrectomy diagram

Kidney donor surgery

Every effort will be made to arrange a date and time for your surgery that is best for you. However, surgery may be cancelled if medical issues exist with the donor or the recipient. Sometimes, there are circumstances beyond our control that may require the donation to be cancelled or postponed.

At least 1 week prior to your surgery you are required to repeat the blood tests and appointments. Appointments also include meeting with the surgeon, nurse, and anesthetist. To make it easier for you to get all these tests and appointments done, the Assessment office can provide you with a list of local accommodations (hotels) near the hospital. The Assessment office can also supply a letter for you to give to the hotel staff to get a reduced rate. You should know that many, but not all, of the local hotels offer a discount rate for TGH patients.

What happens during the hospital stay?

You will be admitted to the hospital the morning of your surgery (usually at 6:00 a.m.). An intravenous line (IV) (a needle into a vein in your arm) will be started to give you fluids.

Following your donor surgery, you will be in the Post Anesthetic Care Unit (PACU) or recovery room for about 2 to 4 hours, and then you will be admitted to the 6th, 7th or 10th floor, Peter Munk Building, depending on the method used for your kidney removal.

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). You will be allowed to control the number and timing of the medication doses (but not excessively to avoid an overdose). The medication will be given to you intravenously.



PCA machine

What is Patient Controlled Analgesia (PCA)?

Medicine for pain is called “analgesia.” Patient Controlled Analgesia or PCA allows you to give yourself pain medicine by pushing a button. You will use Intravenous 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 to 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 medication. There is a safety limit to how much pain medicine you can have in 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 (bowel) pain.

Side effects and risks of intravenous PCA

The most common side effects and complications of IV PCA are minor and easy to treat. They include:

- Nausea or vomiting

- Sleepiness
- Itchiness
- Difficulty emptying your bladder following removal of your urinary catheter (This is inserted in the operating room after you have been anaesthetized and is left in place for the first couple of days following your surgery to help empty urine from your bladder during and after surgery)
- Constipation
- Hallucinations

When is PCA pain control started and stopped?

Intravenous PCA is started before you go to the PACU or recovery room.

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

Once the PCA 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 7 to 10 days after the surgery.

- 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 talk about your staple removal with your transplant 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 to 6 weeks off work regardless of the surgical procedure. Some patients, particularly those who are self employed, return to work as early as 3 weeks after surgery regardless of whether the kidney was removed laparoscopically or using the mini-incision approach. Patients who work for a company and who are given time off usually take off 6-8 weeks, regardless of the method of kidney removal.

Part D: Follow-Up After Surgery

Surgeon

You will meet with the surgeon who performed the surgery 4 to 6 weeks after your surgery to determine how your incision is healing and how well you are recovering.

Nephrologist (kidney doctor)

Three months after your surgery, you will see the nephrologist who assessed you pre-operatively for a check-up. You will be sent requisitions to do blood and urine tests 1 week before the scheduled appointment date and again at 6 months after donation.

The donor team will be on hand to talk about any concerns or answer any questions that you might have throughout the donation process.

Family Doctor

Following your 3-month check-up 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 should happen.
- You should know as a potential donor that a living donor kidney transplant usually lasts 15 to 20 years and therefore 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. It is the nephrologist who will decide 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 any change in the recipient's or donor's condition.
- If you are not sure, or feel uncomfortable about donating, let your 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.

Kidney donation survival from the Kidney Transplant Program at the Toronto General Hospital, University Health Network

Greatest survival occurs in living donor kidney transplants where there is a complete match.

The chart below refers to the kidney transplant recipient:

Type of Kidney Transplant	One-Year Kidney Survival	Five-Year Kidney Survival
Identical Living Donor Match (6/6)	95%	90%
Non-Identical Living Donor Match (0/6 to 5/6)	95%	87%
1 st Deceased Donor Transplant	90%	80%
≥ 2 nd Deceased Donor Transplant	85%	75%

Part E: Precautions

During the time before your donation surgery, you will need to protect yourself. By protecting yourself, you will decrease the risk of harm to the recipient.

West Nile Virus

To reduce the risk of spreading the West Nile Virus (WNV) to your potential recipient, we ask that you follow these precautions:

- At certain times of the year, the WNV is more widespread. You will be tested for this about 1 week before surgery.
- If your test comes back positive, the surgery will have to be delayed.
- You 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 the protection measures listed below for 2 weeks before the surgery. In addition, for the 2 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 and how do people get infected?

WNV belongs to a family of viruses called flaviviridae. Mosquitoes that have fed on the blood of an infected bird can spread it.

There is proof that shows that most people infected with WNV got it from the bite of an infected mosquito. It has been discovered that people could be infected with WNV in other ways, including blood transfusions and organ or tissue transplants. The risk of getting WNV this way is considered to be quite low. There is no proof 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 people may have infections that are more serious. In such cases, symptoms could include a severe headache that comes on quickly, high fever, stiff neck, nausea, difficulty swallowing, vomiting, drowsiness, confusion, loss of consciousness, lack of coordination, muscle weakness, and paralysis.

What can I do to reduce my risk of WNV infection?

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

- Apply insect repellent containing DEET to exposed skin whenever you are outdoors.
- Whenever 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.
- The hours from dusk to dawn are peak mosquito biting times. Consider avoiding outdoor activities during these times—or take extra care to use repellent when outdoors during the 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.
- 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. A higher percentage of DEET in a repellent does not mean that your protection is better - but it will last longer, which will be convenient for longer trips outdoors.

Other Viruses

Viruses can be transmitted from the kidney donor to the recipient through the blood at the time of surgery.

- To find out if you can donate your kidney, you will be tested for Hepatitis B, Hepatitis C, and HIV.
- You will also be tested for viruses that are common in our population such as CMV, EBV, and varicella (chicken pox).
- You will be tested for sexually transmitted diseases such as syphilis.

You are tested for the presence of these infections when your initial blood tests are done and these tests are repeated within 30 days of the transplant surgery.

Additional Precautions

There is a risk that a donor can carry or become infected with a virus after the time of final blood testing and just before the transplant surgery. Donors are asked to reduce the risk of viral transmission at the time of transplant by taking the following measures:

- Do not have any body piercings, tattoos, acupuncture or electrolysis once you have come forward as a potential donor.
- Practice safe sex. Reduce the risk of sexually transmitted disease through the use of condoms.
- Tell your transplant coordinator about any accidental incidents, such as a needle stick injury.
- Do not use any illicit drugs (“pot”, “crack” etc.) before your surgery.

It should be noted that the results of viral testing for viruses like the Epstein-Barr virus (EBV) and cytomegalovirus (CMV) will be shared with the recipient team for safety reasons. If there are, however, viral illnesses that are discovered, the donor will be asked for consent prior to this information being shared with the recipient team. Without sharing this information, the kidney donation cannot occur.

Part F: Mentorship programs that provide support for transplant patients & their families

What is a mentor?

During your transplant living donation experience, 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. A mentor is a living donor or kidney transplant recipient who volunteers to share his or her transplant experience with you.

Who is the program for?

- Patients and candidates for transplant
- Families and support people of transplant and donation patients

About our 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 follow our hospital policies and respect the principles of privacy and confidentiality.
- Mentors are supported in their volunteer work by our transplant staff. The professional staff of the Kidney Foundation of Canada also assists kidney mentors.

How does the program work?

- The program is voluntary. No one needs to see a mentor unless he or 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 personal visit.

How do I find a mentor?

- Simply give your contact staff member a call and a peer support volunteer will be found for you.
- Staff contact:
 - Belinda Karahalios of The Kidney Foundation of Canada
 - 905-278-3003 Ext. 4949

Part G: Where can I get more information?

If you have any questions about anything in this booklet or you need more information on the kidney or living kidney donation, your transplant coordinator is an invaluable resource.

There are additional sources of information that you may find useful:

Internet:

The Kidney Foundation of Canada - Central Ontario Branch

Telephone: 416-445-0373

Website: www.kidney.ca

The National Kidney Foundation (USA)

Website: www.kidney.org

Toronto General Hospital Patient & Family Library

Peter Munk Cardiac Centre Lobby, First floor Norman Urquhart (next to Tim Horton's)

Hours: Monday to Friday 8:30 a.m. to 4:30 p.m. Closed weekends and holidays.

Telephone: 416-340-4800 Ext. 5951

Email: tgpen@uhn.ca

Web : www.uhnpatienteducation.ca

Services:

- Information about many different diseases and health conditions, treatments, and tests in different languages
- Over 250+ books, manuals, guides, DVD's and VHS's for loan
- Free Internet access and wireless Internet access
- Help to search the Internet for information that is valid and up to date
- Trained library staff and volunteers to help you find the information you need free of charge

Part H: My questions and notes

Acknowledgements

Special thanks given to Stacey Konidis for revisions, Galina Gheihman for edits, Segun Famure for directing, and Dr. Robinette, Dr. Cole, Michael Campbell, Michael Garrels, Dr. Richardson, Dr. Ghanekar, Dr. Tinckam, Dr. Schiff, and Lee-Anne Hyer for their updates.