

# Living Kidney Donor Guide



Transplant Manitoba  
Gift of Life



Health Sciences Centre  
Winnipeg

An operating  
division of



Winnipeg Regional  
Health Authority  
Caring for Health

Office régional de la  
santé de Winnipeg  
À l'écoute de notre santé

# Living Kidney Donor Guide

## Introduction

The decision to donate a kidney is very personal. There is no right or wrong choice. Transplant Manitoba – Gift of Life’s living donor team is here to support you and the choice you make, whether it is a yes or a no. Our mission is to provide you with the information you need to make the decision that is right for you, and to help you through this process if you decide to go ahead.

To help you make an informed decision, this guide provides answers to many kidney donation questions.

**The goal of this guide is to help you understand:**

- **what it means to donate one of your kidneys**
- **the risks involved**
- **what to expect before and after donation**

Resources are also available from other members of the healthcare team including the:

- nurse coordinator
- social worker
- kidney doctor (nephrologist)
- surgeon

For more information, you can go online at [www.transplantmanitoba.ca](http://www.transplantmanitoba.ca) or email [livingkidneydonation@hsc.mb.ca](mailto:livingkidneydonation@hsc.mb.ca).

### Take note

Manitoba is a leader in kidney transplantation. The Transplant Manitoba – Gift of Life team at HSC Winnipeg has been committed to providing transplant services since 1969.

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## Understanding kidney failure

Kidneys are vital organs that serve as the body's main filter. Most people are born with two kidneys. These fist-sized organs (located on either side of the spine just under the lower ribs) do many things including:

- removing waste from the blood
- controlling water and mineral balance
- regulating blood pressure
- making red blood cells
- helping maintain healthy bones

Kidneys can fail for a number of reasons. Sometimes this happens suddenly and the kidneys do not recover. Kidneys can also fail gradually over months or years.

Common diseases that damage kidneys are:

- diabetes
- uncontrolled high blood pressure
- glomerulonephritis (disease that damages kidney filters)

There is no cure for chronic or long-term kidney failure. When kidney function decreases to around 10%, a person needs treatment such as dialysis or a kidney transplant to stay alive.

## Treating kidney failure

### Dialysis

Dialysis cleans the blood by removing wastes and excess water. There are two ways to do this:

- **Hemodialysis**

During this process, blood is removed from the body and passed through an artificial kidney machine or filter. This cleans the blood and returns it to the body. Patients generally require four hours of treatment, three times per week. This is often done in a dialysis unit in a hospital and can sometimes be done at home with special training.

- **Peritoneal Dialysis**

During this process, blood is cleaned using special dialysis fluid put into the belly (peritoneum) using a catheter tube. The fluid stays in the belly for several hours. During this time waste products, extra water and salts from the body move into the dialysis fluid. The fluid is drained into a bag and more fresh fluid is put in. This can be done at home or work. The fluid needs to be changed several times during the day. It can also be done overnight using a machine.

People can live on dialysis for many years as long as they stay healthy, however they may not have the same freedoms (employment, travel) as people who are not on dialysis.

## Kidney transplant

Kidney transplantation is the best treatment for kidney failure. It is better than long-term dialysis because with a kidney transplant a person will likely:

- remain healthier
- live longer
- enjoy better quality of life

Kidneys become available for transplant in two ways:

### Deceased donor

A deceased donor is a person who dies in a way that makes organ donation possible. Though everyone has the potential to be an organ donor, the opportunity to donate is small. Only 2-3% of deaths offer the possibility of providing the gift of life to someone else.

Potential organ donors are patients who have died of brain death because of traumatic brain injuries, or an intracranial hemorrhage, stroke or aneurysm.

Donation after cardiac death becomes an option when a family decides to remove life support after a physician has determined that there is no hope for recovery.

Kidneys from a deceased donor can be transplanted into two different people.



## Living donor

A living donor is a very healthy person who has decided to donate a kidney to help someone living with kidney failure. There are important advantages to getting a kidney from a living donor rather than a deceased donor.

These include:

- people may have to wait a long time on the transplant waiting list to receive a kidney from a deceased donor, while a kidney transplant from a living donor can happen much sooner
- kidney transplants from living donors tend to last longer
- people who receive kidney transplants from living donors tend to live longer

### Take note

**There are no guarantees as to how long a transplant will last.**

Many transplants from a living donor may last 20 years or more. Kidneys from a deceased donor usually don't last as long.

Some transplants can fail right away and some may last a lifetime. When transplants fail, people can go back to dialysis or they can talk with their doctor about another kidney transplant.

### Take note

People may have to wait 5-9 years on dialysis to receive a kidney from a deceased donor.

## Deciding to donate

When a loved one is sick, being worried about their health is natural. Knowing you may be able to help can make the decision even more difficult. While people living with kidney failure can benefit from living donation, it is very important to make the decision that is best for you.

When you think about donation, ask yourself:

- What are your beliefs about organ donation?
- Who will support you throughout this process?
- How will you manage your responsibilities (family, work, financial) now and during your recovery?

## Who can be a living kidney donor?

Living donors are healthy people with good kidney function. They cannot have diabetes or high blood pressure. The testing of each donor is specific to that person. This is to make sure it is safe for them to donate.

Sometimes, compatibility testing (matching) may reveal one donor is better suited than the others. Compatibility tests are confidential and only you will find out your own result. This way, no one feels pressured to continue with further testing.

It is also possible that compatibility testing will not identify a best donor. If this happens, donors may be asked to decide among themselves who will go forward. Everyone is asked to speak to each other and decide who will proceed further with testing. Some things to consider in the conversation are sick benefits, family, and financial responsibilities.

Donating a kidney involves risk for the person donating. Donors need to understand and carefully consider the risks involved.

There are two types of risks:

- **surgical risks**
- **long-term risks of living with one kidney**

### Take note

Your own feelings, not the feelings of others, are the best guide when deciding if donation is right for you.

### Take note

Anything that pierces the skin – acupuncture, ear or body piercing, electrolysis, injections, microblading, and tattooing – can cause a delay of up to a year because of the risk of diseases like hepatitis or HIV. If you have undergone a procedure in the last 12 months or plan to, please discuss it with your nurse coordinator.

## Risks of becoming a kidney donor

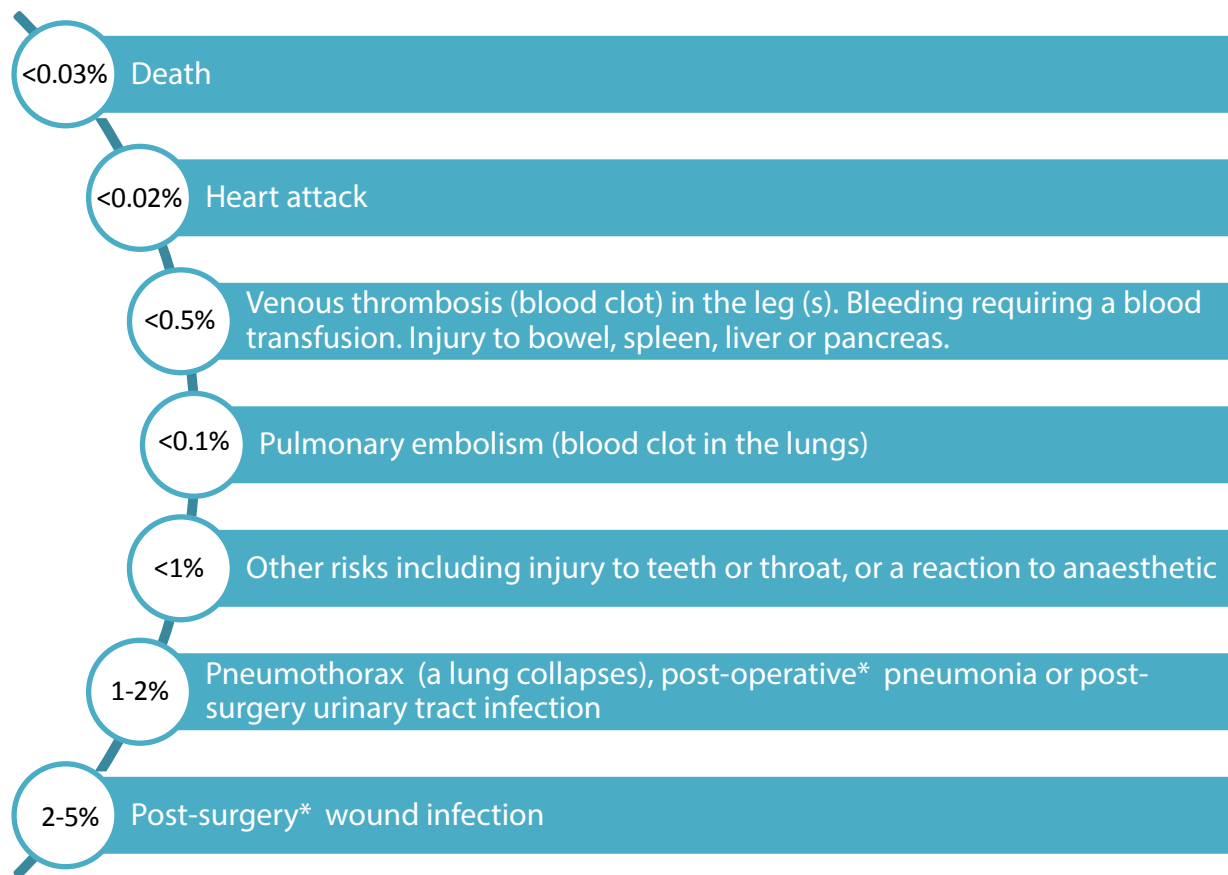
### **Surgical risks**

Risks of kidney donor surgery are reduced by choosing only healthy people. However, any surgery will have a risk of some complications.

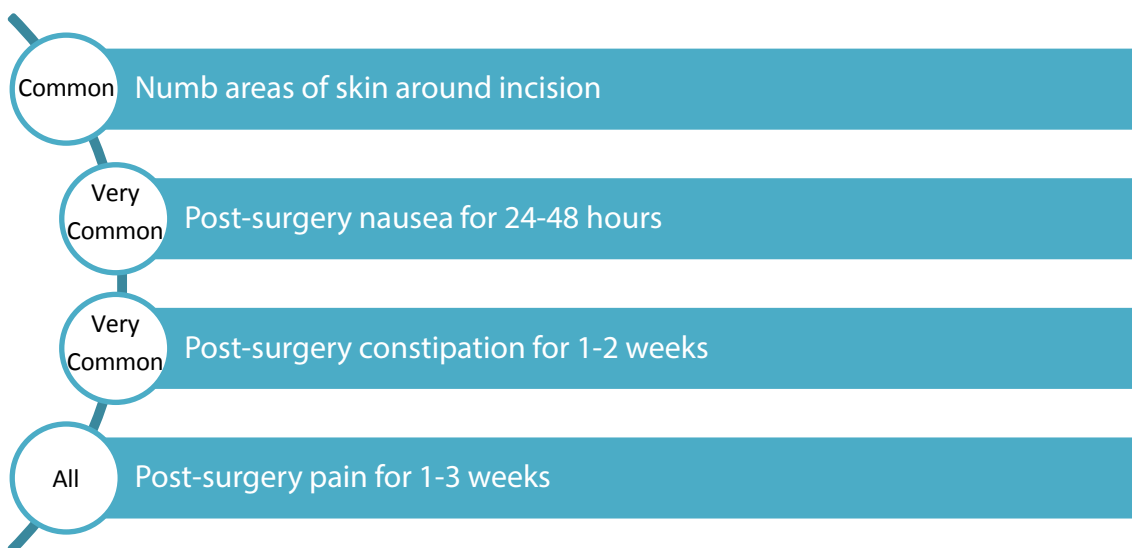
Fewer than one in 20 donors (less than 5%) will have complications from the surgery. Most of these complications are minor and the risks are small. There is a very small chance of a serious complication happening with any surgery. This can result in long-term problems or even death. The risk of dying while donating a kidney is roughly one in 3000 cases or less than .03%.

You need to consider all the risks during your decision-making. The following list includes many, but not all, of the complications that could occur. Talk to your nurse coordinator about any of your concerns.





\* Post-surgery means the risk could take place in the hours, days or weeks following surgery.



## Long-term risks of becoming a kidney donor

It is also important to understand the long-term risks of living with only one kidney.

A number of studies have followed living kidney donors for many years. In general, donors are carefully chosen individuals and remain healthier than the general population in the future.

A donor's overall kidney function will be slightly less for the rest of their lives. Immediately after surgery, kidney function drops by 50%. Over the coming weeks and months, the remaining kidney adapts and works more.

Most donors will have between 70-80% of the kidney function they had before the donation. This is a healthy level of kidney function and donors do not feel any different. However there are some uncommon long-term risks and after-effects of a donating a kidney.

### Long-term risks of living with one kidney include:

- **High blood pressure**  
Some donors may develop high blood pressure as they get older. It is common to develop high blood pressure with age, but kidney donors may be at a higher risk of developing high blood pressure than those who have not donated a kidney. High blood pressure may require medications to control it, more medical follow-up, and can lead to heart disease and kidney disease if it is not treated.
- **Kidney problems**  
Some donors develop small amounts of protein in the urine over time. This may indicate the remaining kidney is filtering more than it used to. Protein in the urine needs to be monitored over time. Increasing protein in the urine may carry a risk of slowly losing some kidney function.
- **Kidney failure**  
It is important to understand that everyone has a risk of getting serious kidney disease or kidney failure in their lifetime. Even though donors are carefully chosen, some studies suggest donors may be at slightly higher risk of developing kidney disease or kidney failure in the future. The additional risk of a donor getting kidney failure because of donation is very low.

#### Take note

The Transplant Clinic at HSC Winnipeg can see donors every one to two years for a kidney check-up. This does not replace regular family doctor visits.

## Minimizing long-term risks

- **Follow-up care**  
Donors need to maintain a healthy active lifestyle and get regular follow-up with a family doctor once every year or two. Simple blood pressure and kidney function tests may find any problems early on.

## Other considerations

- **Pregnancy**

Pregnancy after donation is a concern for young women thinking about donation. Having a single kidney does not seem to interfere with a woman's chance of becoming pregnant or delivering a healthy baby. However, getting pregnant in the first six months after donation is not recommended. The body needs to recover and heal after the donation surgery. Women who are pregnant are not suitable to donate until six months or more after the baby is born.

- **Preeclampsia**

This is also known as high blood pressure in pregnancy. This is an uncommon complication in pregnancy, but may occur slightly more often in women who become pregnant after donating a kidney. Preeclampsia increases the risk of a mother having to deliver a baby early.

If a woman becomes pregnant after donation, she should tell her doctor/obstetrician that she donated a kidney.

- **Insurance**

Life insurance and disability insurance rates should not be affected if the donor's overall kidney function is still normal. We recommend all potential donors consider looking into obtaining insurance before looking into become a living donor.

- **Active living**

There are no special long-term restrictions for donors after they donate. Donors are encouraged to be physically active and to return to recreational activities enjoyed before donation including jogging, skiing, snowboarding, running, and team sports like soccer, hockey, rugby, etc.

There are a few activities that may be considered high risk for someone with one kidney including boxing, competitive martial arts and highly competitive or professional contact sports. If you have any concerns regarding activity or future plans, please talk to the nurse coordinator, your transplant surgeon or nephrologist.

## When making your decision, ask yourself:

What are my feelings and beliefs about organ donation?

What are the risks and benefits of donating?

Do I feel well-informed about donating?

How will donation affect my relationship with the recipient or other family members?

How would I manage my work, family and financial responsibilities while I am recovering after surgery?

How would I feel if the evaluation process rules me out or uncovers a health issue?

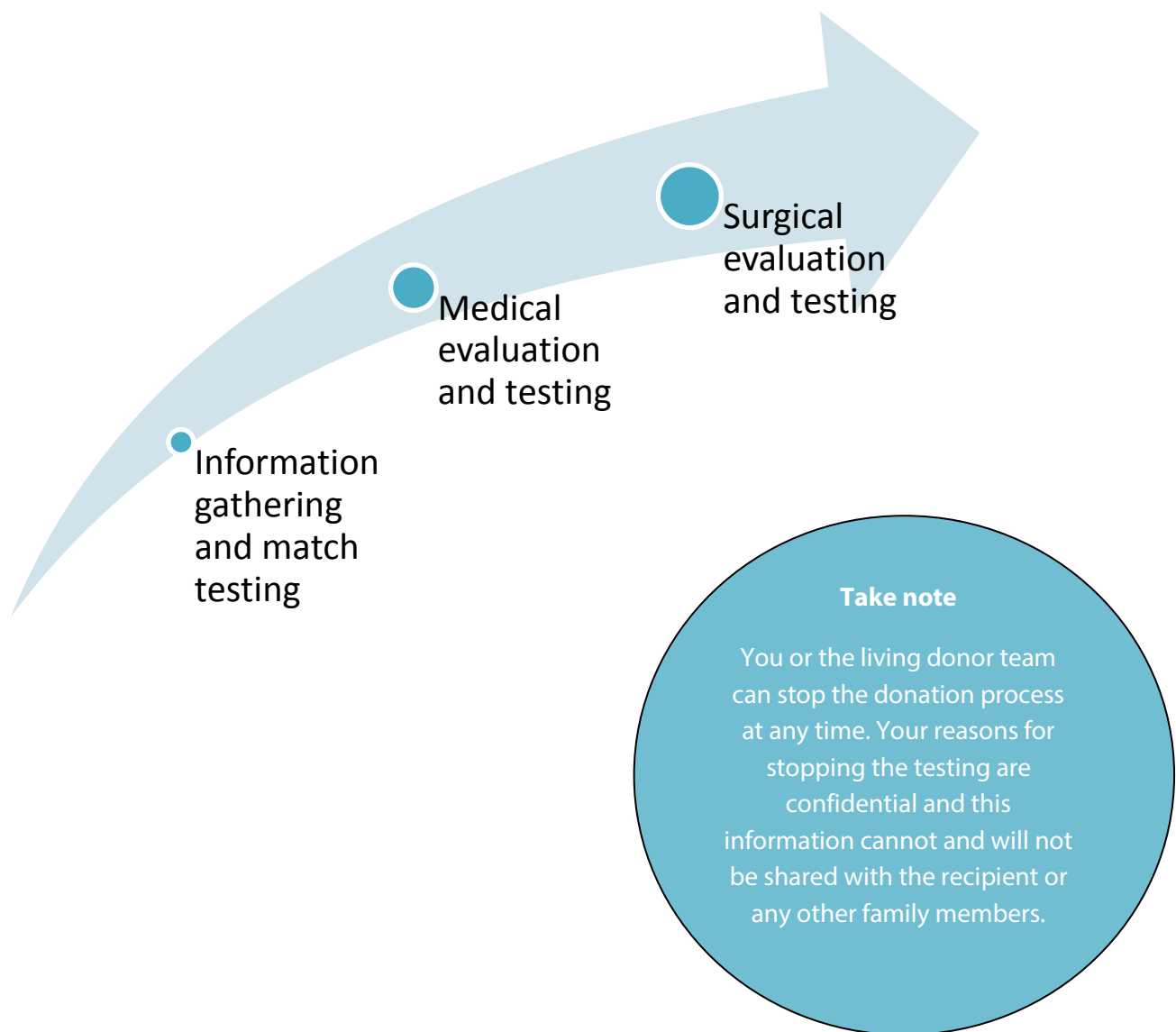
Who would be my support network to help me through this process?

## Donor testing

Testing to see if you can become a donor is done using a series of steps. The testing process can take six to 12 months to complete. This is because of the number of tests a donor has to do. It can be a lengthy process.

All testing is confidential. Outside of the living donor team, you and your family doctor are the only ones to receive your results. Test results are not discussed with the recipient or any family member without your permission.

### The three phases of donor testing



## Phase 1 – Information gathering and match testing

- **Step 1: Make the call**

If you have decided to start the process, you need to contact the donor program by telephone.

Call:

- **204-787-2323** locally
- **1-877-499-8774 ext 72323** for toll free long distance

During the call, you will be asked for your:

- Name
- Date of birth
- Address
- Health card numbers
- Name of your recipient
- Your recipient's date of birth

**Please have this information ready when you call the donor program.**

- **Step 2: Screening questionnaire**

Information and a screening questionnaire will be mailed to you. Complete the questionnaire as best you can. Sign and date it, and return it to the donor program.

We will review your questionnaire. You will be contacted by the nurse coordinator or an appointment letter will be mailed to you.



- **Step 3: Blood group compatibility testing**

Determining whether your blood group is compatible with your recipient is important. To find out what your blood group is, blood will be drawn. At the same time, a blood sample is taken for Human Leukocyte Antigen (HLA) typing. This sample will be stored until it is needed.

You can donate to	If you have blood group				
		O	A	B	AB
	O	✓			
	A	✓	✓		
	B	✓		✓	
	AB	✓	✓	✓	✓

- **Step 4: Donor information session**

This is an appointment with the Living Kidney Donor clinic at HSC Winnipeg. You will watch an informational presentation given by the nurse coordinator. The benefits, process and risks of living kidney donation will be reviewed.

This presentation will be followed by a meeting with a **nephrologist** (kidney doctor). The doctor will follow all the testing if you decide to continue. The doctor will also review important information about donating a kidney with you, including:

- the risks of donating a kidney
- your overall health
- the benefits of a living donor transplant

You can ask the doctor any questions you have. Write them down ahead of time so you don't miss any. At the end of this appointment, the doctor will:

- ask if you want to go ahead
- ask if you need time to think and call us back
- explain if lifestyle changes are needed (weight loss, quitting smoking for example)
- explain if it is not safe for you to be a donor

- **Step 5: HLA compatibility typing**

If you are cleared to move forward, HLA compatibility testing is next. These additional tests are important in determining if you and your recipient are compatible and how good the match may be. Results take four to six weeks.

**Take note**

If you are not a match for your recipient, the nurse coordinator will discuss other options with you, such as Kidney Paired Donation (KPD). Information on KPD is provided in the last section of this guide.

### Multiple potential living donors

If more than one person comes forward as a possible living donor, each potential donor will go through compatibility testing. Compatibility testing may identify a best potential donor, however sometimes a preferred donor is not identified and donors must choose among themselves who will proceed further with testing.

### HLA Typing

This blood test identifies genetic markers called Human Leukocyte Antigens (HLA) found on cells throughout the body, including the kidney. The recipient's immune system can recognize differences in these markers, and over time, these differences may cause their body to reject the kidney.

Eight different markers are used to determine the degree of match. The more markers that are shared between you and your recipient, the better the match. The best matched kidney is an eight out of eight. This type of match should last longer than a zero out of eight match. However, zero matched kidney transplants are routinely done and last for many years.

### Virtual Crossmatch

Your HLA markers are also used to check if the recipient's immune system may strongly reject your donated kidney. This test is called a Virtual Crossmatch. For this prediction, your HLA markers are compared against the HLA antibodies in the recipient's blood. HLA antibodies are proteins that can attack a donor kidney and cause rejection. We need to make sure the recipient has no HLA antibodies against you.

If the Virtual Crossmatch is negative, your work-up continues. If it is positive, it means you are not a match for the recipient and cannot donate to them. The nurse coordinator will advise you of other options including Kidney Paired Donation (see below).

### HLA Crossmatch

The next step is the HLA Crossmatch. This is an actual blood test, not a prediction like the Virtual Crossmatch. It confirms the recipient has no HLA antibodies in their blood that could attack the kidney as soon as it is transplanted.

- A **negative crossmatch** means there are no antibodies and the process can continue.
- A **positive crossmatch** means the transplant cannot be done.

HLA Crossmatch testing is done twice. The first is done early during testing to confirm the results of a virtual crossmatch. The last test is done about one week before the transplant surgery. Repeat testing makes sure the result is still negative and no new antibodies to your kidney have developed.

## Phase 2 – Medical evaluation and testing

You will be scheduled for a number of medical tests over the following weeks. These tests assess your kidney function and your overall health to see if you are healthy enough to donate a kidney. You will also meet with our psychiatrist and social worker to talk about how donation may affect your job, family life and finances. Appointments will be mailed to you, or the clinics completing your testing will contact you.

If test results show that donating a kidney would put you at high risk, either to your health or during surgery, donation will not be possible. If any results raise concerns, you will be informed.

## Phase 2 Tests

- Females only:
  - schedule a Pap test with family doctor
  - mammogram (aged 50 and up)
- ultrasound
- chest x-ray
- electrocardiogram or ECG – heart tracing
- height and weight assessment
- Health Canada questionnaire (reviewed with nurse coordinator)
- tuberculosis testing (four visits)
- blood work
- serology (hepatitis, HIV, etc.)
- glucose tolerance test (diabetes screening)
- crossmatch with recipient (direct donation)
- urine testing (two samples – one week apart)
- 24 hour urine collections (at least two collections and blood taken with each)
- urinalysis
- microalbumin/creatinine ratio
- blood pressure (one sitting and one standing - each arm)

## Other considerations

### **Acupuncture, piercing, electrolysis, and tattooing**

Anything that pierces the skin – acupuncture, ear or body piercing, electrolysis, injections, microblading, and tattooing – can cause a delay of up to a year because of the risk of diseases like hepatitis or HIV. If you have undergone a procedure in the last 12 months or plan to, please discuss it with your nurse coordinator.

## Phase 3 – Surgical evaluation and testing

At this step, you will be sent for a CT scan. This test maps out your blood vessels and takes detailed pictures of each kidney. The surgeon uses this information to decide which kidney will be donated. The surgeon will meet with you at a later appointment and explain what happens during surgery and tell you which kidney has been chosen.

Finally, once more your nephrologist reviews all your test results and the information you have shared to decide if donation is possible. The nurse coordinator will contact you and let you know your evaluation is complete.

## What if I am not a match?

### **Kidney Paired Donation**

Some donors find out that they are not compatible with their recipient and cannot give them a kidney. Kidney Paired Donation (KPD) is a national program run by Canadian Blood Services. The program searches for recipient and donor matches among the many other pairs across Canada who do not match each other. When a match is found, pairs may be able to anonymously donate so that each recipient can get a good kidney transplant. The nurse coordinator or your donor nephrologist, will advise if KPD is an option for you and your recipient to consider. For more information, please visit [www.blood.ca](http://www.blood.ca), click on the Organs and Tissues tab, then Living Kidney Donation.