

Your Kidney Transplant

Information for kidney transplant recipients,
their families and supports



Kidney Urinary Program
St. Joseph's Healthcare Hamilton

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Introduction

Members of your Transplant Care Team wrote this book so you, and your family members and friends will know what to expect before and after a kidney transplant. Try to read this book a few times to get ready.

Telephone numbers at the back. Feel free to talk to any member of the health care team if you have any questions.

Who will I meet on the Transplant Team?

There are many members on your transplant team. Each person has a special role in your care. All the members of the team work closely together with you, your family and other support people.



The **Transplant Coordinator** is someone you will get to know well. He or she will guide you through all the preparations. The coordinator organizes your tests and helps you with appointment times. He or she reviews instructions with you and explains what will happen. The coordinator is experienced and understands any fears you may have.

Your transplant coordinator will meet with you and your family. This will help you get an idea of what will happen when you are admitted to the hospital. You will be able to talk about questions and concerns with your transplant coordinator.

Transplant Doctors are Nephrologists with experience in transplantation. We have many transplant doctors at St. Joseph's Healthcare so you will meet more than one while you are here. Transplant doctors are responsible for your care while you are in the hospital and after you go home. They work closely with the rest of the transplant team. You will still see your family doctor or health care provider regularly after your transplant.

Residents are experienced doctors who are learning to be specialists. They are also responsible for your day to day care. Residents are supervised by our transplant doctors.

Transplant Surgeons are Urologists. You will meet an urologist before your transplant. This may not be the surgeon who operates on you.



You will meet the **Transplant Unit Nurses** after you are admitted to the hospital for your transplant. Your nurses will help you prepare for surgery and take care of you during your hospital stay. While you are in the hospital, your nurses will help you learn how to get ready to go home.

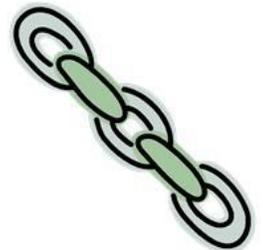
You will get an 'After Your Kidney Transplant' patient education binder with information about your care after transplant. This will include information about the medication you will be taking, how to take your own blood pressure, how to keep a record book and much more. You will need to learn all about your new lifestyle.



Transplant Clinic Nurses monitor your care after you go home with your new kidney. You will come to the Transplant Clinic often and learn about your new kidney and how to continue to look after yourself.

Your **Social Worker** will meet with you before your transplant. Together, you will talk about how you feel, your family, your work and any other issues you feel are important.

Your social worker is an important link between you and your community. He or she can help you with drug benefit plans, community resources and work adjustments. Your social worker can help you adjust to living with your new kidney. Everyone having a transplant has concerns, worries, and doubts.



Your Kidney Transplant – Information for Kidney Transplant Recipients

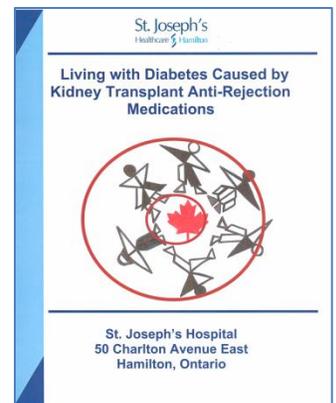
You and your social worker can talk about any problems that you may have. Your social worker can also arrange family meetings if you wish them to be involved in your care. Your social worker is your link to community resources. The social worker can help your family with places to stay overnight if they are from out of town.

The social worker will also review medication coverage. Medications after transplant are very expensive. If you do not have a drug plan or 100% coverage, the social worker will advise you on how to apply for more coverage.



The **Diabetes Educator** can help you manage your lifestyle after the transplant if you have diabetes or develop diabetes.

Sometimes people develop diabetes caused by kidney transplant anti-rejection medications. If this happens, the diabetes educator will help you learn how to manage your lifestyle with diabetes. You will also get a book called 'Living with Diabetes Caused by Kidney Transplant Anti-Rejection Medications' to learn about this and how to manage your care.



The **Dietitian** will help you choose your diet to help keep you healthy. A kidney transplant, time on dialysis and medications all affect your nutrition. Some of the medications you need may have side effects. These may include increased appetite, weight gain, high potassium and high blood sugar.

Your dietitian will work with you to find a diet that is right for you. This will help your body get all the nutrients it needs to become healthy and work properly. You will be able to stay healthy while enjoying the foods you eat. A proper diet can help you maintain a healthy weight and control some medication side effects.



The **Physiotherapist** will come to see you after your surgery. He or she will show you how to do deep breathing exercises and how to cough to keep your lungs clear.

The **Spiritual Care Specialist** can help you, your family and friends with any spiritual concerns you may have. He or she can also help you maintain contact with your own clergy while you are in hospital, if you wish.

The **Peer Support Program** offers one to one help to those whose lives have been affected by renal disease. Through their own experience, these trained volunteers understand what you are going through. If you want to talk to someone, call the Kidney Foundation Hamilton Chapter and ask for the Peer Support Program.



Will I be involved in research?

Research helps St. Joseph's Healthcare offer the best care and results for our patients. Research projects are often going on. You may be asked to be in a research study. All research is carefully screened and approved. Before you agree or refuse, the study will be explained to you so that you can understand what it is all about. You will never be in a study without knowing about it.



Remember:

- **Most of our current success in transplants is because patients and families have agreed to be in research projects.**

Before Your Transplant – Getting Ready

What do I do if I want to have a transplant?

Your nephrologist will arrange an appointment with the transplant nephrologist for you. The transplant nephrologist will meet you and ask you many questions about your past health history. The transplant nephrologist will do a complete physical exam.



The transplant nephrologist will then discuss what a transplant means to you and what it involves. You can bring a family member or friend with you as having a transplant involves them also.

This appointment takes at least 1 hour.

Where would my kidney come from?

Patients can get a new kidney from:

- a living donor **or**
- a deceased donor

Living Donors

A living kidney donor is a person who gives one of his or her kidneys to someone who has renal failure. Family members, spouses, close friends, anonymous people and others can be a living kidney donor.

Generally, a living donor must be healthy. There are many medical tests that the donor needs to complete before becoming a living donor.

The next section describes 4 types of living donors:

- List exchange living donor
- Paired exchange living donor
- Altruistic anonymous living donor
- ABO incompatible living donor

List Exchange Living Donor

A list exchange living donor is a person who gives one of his or her kidneys to a person on the waiting list designated by the Transplant Program. In exchange, the intended recipient is given priority status on the deceased donor transplant list.

For example, a husband would like to donate a kidney to his wife. His wife's blood does not match his blood type. The husband then gives one of his kidneys to a person on the waiting list that matches his blood type. In return his wife is put at the top of her blood type waiting list.

Paired Exchange Living Donor

This happens when a living donor and kidney recipient have blood types that do not match. They are paired with another living donor and kidney recipient who do match.

For example, 2 living donors each want to give a kidney to a person they love but their blood types do not match. The 2 donors switch recipients so each recipient gets a kidney that matches their blood types.

Altruistic Anonymous Living Donor

This happens when a person gives his or her kidney to someone they do not know. This type of donation is made purely out of selfless motives.

ABO Incompatible Living Donor

This happens when a living kidney donor's blood type does not match the kidney recipient's blood type. Since there are medications and treatments that decrease the risk of kidney rejection this type of donation is now a standard option of care at St. Joseph's Healthcare Hamilton.

Deceased Donors

A deceased donor is a person who is close to dying or has died and has indicated that he or she would like to donate kidneys. A person's Substitute Decision Maker is involved in this decision as well.

The next section describes 3 types of deceased donors:

- Heart beating deceased donor
- Non heart beating deceased donor
- Expanded criteria deceased donor

Heart Beating Deceased Donor

This donor is a healthy person who has an irreversible brain injury. For example, this can happen after a motor vehicle accident, heart attack or stroke.

Non Heart Beating Deceased Donor

This is when a kidney comes from a person who is pronounced dead after his or her heart stops beating. The kidney must meet special criteria before it can be used.

Many research studies support using a non heart beating donor kidney. The outcomes are similar to using a heart beating deceased donor kidney.

Expanded Criteria Deceased Donor

Donors can now include older people and people who have certain medical conditions or other factors that are linked with decreased kidney function. For example, a kidney can come from a person with diabetes or high blood pressure.

Research studies have shown that getting this type of kidney is better than waiting a long time for an ideal donor kidney.

If you would like to read more about living kidney donation, ask a member of the team for the book called 'When You Are Thinking About Donating Your Kidney'.

What tests will I need to have done before having a kidney transplant?

You will need to have several tests done. If you have any questions, please feel free to talk to the transplant coordinator. Your nephrologist will arrange some of the testing before your appointment with the transplant nephrologist.

Blood Tests:

Blood tests such as blood group and type are done to gather all of the information needed to plan your treatment.



Abdominal Ultrasound:

This test is done to check for gallstones and any other problems in your abdomen. This test uses sound waves and is painless. It is done in the Diagnostic Services Department.

You must not eat or drink the night before the test and you cannot have any breakfast until the test is done. The test takes about 1/2 hour. If the test shows that you have gallstones or other problems, your nephrologist may arrange treatment.

Chest X-ray:

A chest x-ray is done to check if your heart and lungs are healthy. It is very important that you have this test done at St. Joseph's Healthcare in Hamilton. It will be done in the Diagnostic Services Department.



Cystoscopy:

This test is done to make sure that your bladder is working properly. Your Urologist does it. A soft, thin tube, about the size of a pencil, will be placed through your urethra and into your bladder. This will let the doctor see inside your bladder. It is important to have a healthy bladder, so that it will work properly after your transplant.

After the test, both men and women may feel a bit of irritation and have pinkish urine when urinating. This will only last a few days at the most.

Echocardiogram:

This test is done to check your heart using sound waves. It is a painless test done in the Electro-Diagnostic Service Department. It takes about 1/2 hour.

Electrocardiogram (ECG):

The electrocardiogram test is also called an ECG and is done to check the health of your heart. It shows the pattern of your heartbeat. Small pads are placed on your chest to pick up your heartbeat and the pattern is printed on paper. The ECG is painless and takes about 15 minutes. If there is a problem with your heart pattern, you may need to see a heart specialist called a cardiologist.



Stress Test:

This test checks your heart and is done if you are being assessed to go on the transplant waiting list. It is done in the Nuclear Cardiology Department. You are given an injection in your arm. Pictures of your heart are then taken. You then wait and have more pictures taken. This test takes about 6 hours to complete. Your transplant coordinator will give you more details if you are going to have this test.

Skin Test for Tuberculosis (TB):

This skin test is done to check if you have been exposed to tuberculosis. You will get a small injection under the skin of your arm. It will be checked in 48 hours. It will be repeated again within 1 to 3 weeks. During either testing, if your arm swells, you have been exposed to TB. If this happens to you, you will see one of our specialists. You will also get special medication after your transplant to protect you from TB.

Who will arrange these tests?

If you live in Hamilton, your nephrologist will arrange the first set of tests such as a chest x-ray and ultrasound. Your transplant coordinator will arrange the rest of your tests.

If you live outside the Hamilton area as many tests as possible will be done in your dialysis centre. Some tests still need to be done in Hamilton and the transplant coordinator will send you a letter with these instructions.

What is the transplant waiting list?

The transplant waiting list is made up of people from our region including the Hamilton, St. Catharines, and Kitchener areas. These people have chosen to have their transplants at St. Joseph's Healthcare Hamilton.



After all your tests are done, your transplant nephrologist and transplant coordinator review the results. If everything is stable you will be placed on the waiting list. When this happens you will receive a letter from your coordinator.

For most people the date of listing on the transplant list is the date they started on dialysis.

How long will I have to wait?

Every year the waiting time is longer as more people who have kidney disease are healthy enough to receive a transplant. In 2012 for example, the waiting time was 3 to 5 years. The waiting time depends on many factors.

What happens when a kidney becomes available?

Your transplant coordinator keeps a list of telephone numbers where you can be reached. This may include family and friends.



When you have changes in telephone numbers or addresses, please let the coordinator know. It is very important that we are able to contact you at any time.

When you have been called to get a kidney, do not eat or drink anything. Do not put on any nail polish or make-up. This will save time once you get to the hospital.

Remember:

- **It is your responsibility to make sure you have drug coverage.**
- **Do not wait to apply for coverage, because when you go on the transplant waiting list, you can be called to receive a kidney at any time.**

What do I bring to the hospital?

- new toothbrush and toothpaste
- comb and personal equipment
- short length housecoat for safe walking
- non-slip slippers with full backs for safe walking
- list of allergies
- current list of medications and the doses you take



Bring all medications that you are taking in the containers they came in.

Remember:

- **Leave all valuables at home.**

Where do I go?

When you arrive at the hospital, go to the Bed Booking area. Ask the location at the Information Desk.

After you are admitted you will go to the Transplant Unit. Your transplant team will assess you. A transplant nurse will take your blood pressure, temperature, pulse, respirations, weight, and record your medical history and do a quick physical assessment.

Your doctor will then take your medical history and do a physical exam.



What tests will I need to have done now?

You will have many blood tests to make sure you are healthy for the operation. If you have a fistula or graft, do not allow anyone to take blood from your access arm without written permission from the doctor.

After the results of your blood tests are back, you may need to have dialysis or other treatments before surgery.

If you are able to pass urine, a sample will be sent to the lab. Your nurse will take some swabs from your skin, nose and rectum for culture.

You will also have a chest x-ray. These tests are done to make sure that you are infection free. If you do have an infection, your kidney transplant will have to be cancelled.

You will also have an electrocardiogram or ECG test to check the health of your heart.

Do I sign any consent forms?

You will sign these forms:

- consent to the surgery to receive a kidney
- consent for a central venous catheter (CVC) to be put in



The CVC is a tube that the Doctor puts into a vein in your neck. The catheter monitors the amount of fluid you get after the transplant. It is also used to give you medications, monitor the pressure in your heart, and take blood. Your doctor puts the catheter in right before your surgery starts in the operating room. The catheter can be stitched to your skin and you will be able to walk around with the catheter in. It stays in 7 to 10 days or until you go home.

Is there anything else before surgery?

A nurse will come to start an intravenous called an IV in your hand or arm.

You will have a general anaesthetic for the surgery.

This means that you will be asleep. Because of this,

you must not eat, drink or smoke for at least 8 hours before your surgery.



You will be asked to leave your dentures, eyeglasses and any jewellery on the Transplant Unit. Your nurse will help you put on a hospital gown.

A porter will then take you to the operating room on a stretcher or bed.

What happens during surgery?

The doctor will tell you before surgery what will be done. The kidney transplant is placed in your lower abdomen. The new kidney has an artery and vein. These carry blood into your kidney and out to the rest of your body. The kidney's vein and artery are joined to blood vessels your body already has.

The ureter is transplanted together with your new kidney. It is connected to your bladder. The ureter is a tube that carries urine from your kidney to your bladder.

During surgery, a catheter will be put into your bladder. The catheter drains away the urine you produce. It is put in while you are asleep and will be there when you wake up.

How long is the surgery?

The surgery takes about 3 to 4 hours including 1 hour of preparation time at the start of the surgery.

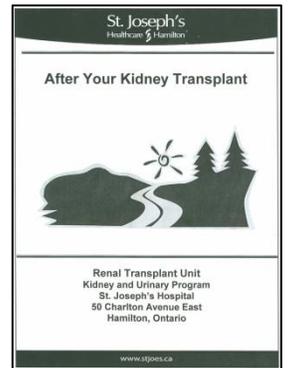
While you are in surgery your family and supports may wish to wait in the surgical waiting room. They can also go to the hospital chapel, gift shop, coffee shop or cafeteria.

If your family prefers to wait at home, they may call the Transplant Unit at anytime for a progress report.



After Your Transplant

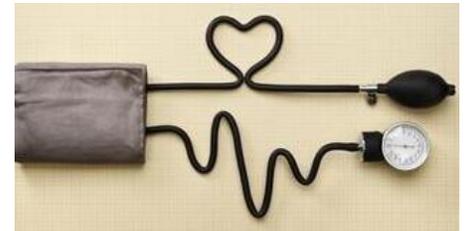
This section is included to help you know what will happen. After surgery, you will get a patient education binder called 'After Your Kidney Transplant' with more information. Members of the health care team on the Transplant Unit will help you learn what you need to know. You will also have the binder at home to refer to.



What happens when the surgery is over?

When the surgery is over, you go to the recovery area. A transplant nurse and recovery nurse will be there. They will look after you while you wake up. Your doctor will talk to your family to tell them how you are doing.

The nurses will check on you until you are fully awake. They will take your blood pressure, pulse, and check your breathing. Some blood samples will be taken as well. You will have an oxygen mask on. You will be given pain control medication while you are in the recovery room.



You may wake up very thirsty because of the medications you have been given. It is not safe, however, for you to drink at this time. You would be in danger of choking. Later, you will be able to have ice chips.

The ultrasound technician will come to your bedside. He or she will do an ultrasound of your new kidney. This is done by placing a probe on the skin above the kidney with a cool gel. This will help the doctor to see the kidney. Your stay in recovery will be about 2 hours.

After you are awake you will be taken back to the Transplant Unit. A nurse will be with you in the room most of the time for the first 24 hours after surgery. The resident will also be close by.

Where will the incision be?

Your new kidney will be put into your pelvis. The incision is about 25 centimetres (10 inches) on the left or right side of your lower abdomen.

How do I know my kidney is working?

You may make urine as soon as your new kidney is connected. Most people take time to adjust to the new kidney and do not produce urine for hours or days after surgery.

When you do begin to produce urine, the nurses will measure it. A record will be kept of the amount you make.

At first, your urine may be a little bloody due to the surgery. This is normal, so do not worry.

As your new kidney starts to work, it will clear waste products from your blood. Creatinine is a waste product your body makes. Measuring the creatinine level in your blood shows how well your kidney is working.

Your blood creatinine level will go down. If your creatinine level goes up, do not worry. This often happens. You may need dialysis treatments for a short while, until your new kidney is working well.

Hemodialysis can be done in your room on the Transplant Unit.



What else can I expect after my surgery?

The urine catheter will drain all the urine from your bladder. The urine will collect in a bag attached to the catheter. It will be measured every hour and a record will be kept. Your nurse may have to flush the catheter at times to make sure it does not get blocked.

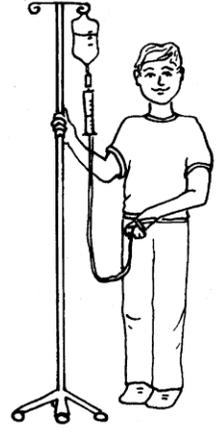
You may have some spasms or pain while the catheter is in your bladder. Tell your nurse if this happens. You will be given medication for the pain.

How much pain or discomfort will I have?

After the surgery, your incision will be painful. You will receive medication as needed to control pain and discomfort.

At first you will not be able to have anything by mouth. You will be given medication through your IV and control the amount of pain control medication you take by using a pump. Later, you will be given medication in pill form.

At first, it is a good idea to have some pain control medication about 1/2 hour before your physiotherapist comes to see you.



Can I have visitors?

When you return to the unit, your nurses help you to settle in and make sure you are stable. You will need some time to wake up. You need to rest to recover from your surgery.

You may have 1 close friend or relative visit on the day of the surgery. On the day after, your close family can visit.

Try not to have too many visitors. This is important to make sure you do not get an infection.

Remember:

- **No one with an infection should visit you. This includes runny noses and cold sores. You should tell all your friends and family about this for your safety.**

All visitors should wash their hands before coming into your room. The nurses will also explain any other precautions visitors may need to take when they arrive.



When will I begin moving around again?

You need to start moving around as soon as you can for a healthy recovery. Moving around helps your circulation, prevents constipation, prevents breathing problems and keeps your muscles strong. The day after your surgery, your nurse will help you get up. At first, you may feel dizzy, but this will pass. You can sit on the side of your bed and dangle your legs. You may also sit in a chair.

Moving may be uncomfortable at first. Your nurse will help you and show you the best way to move. Moving will get easier each day. You should also exercise while lying in bed. You can move your toes up and down, circle your feet and bend your knees.

Your urine catheter and IV may still be in place. These tubes should not stop you from getting up. A few days after surgery, the physiotherapist will help you climb stairs. This will help keep your leg muscles strong.

When do I do my breathing exercises?

Your nurse and physiotherapist will help you with your coughing and deep breathing exercises. They will go over the steps with you. You will practice together.

You should practice your exercises every hour you are awake, for at least 3 days after surgery. You may find it easier to cough if you hold a pillow against your incision. You may also find it easier if you are sitting up.

What complications should I know about?

About 25% of patients have to be readmitted after their transplant. It is common to come to a Post Transplant Clinic visit and be admitted to the hospital. Bring a small overnight bag with you to your first few Post Transplant Clinic visits in case you have to come back into the hospital for treatment.



These are the main problems that can happen after a kidney transplant:

- delayed kidney function
- CMV
- rejection

We carefully monitor for these problems and they can be treated.

What is delayed kidney function?

Delayed kidney function is called Acute Tubular Necrosis or ATN. This happens when your new kidney is in shock or sleeping. It is a painless condition and usually temporary.

ATN means that your new kidney is taking time to get used to your body. It may take a little while for you to begin to produce urine. This happens in 5 to 10% of transplant patients.



What is CMV?

As a transplant patient, you are on many medications to prevent rejection. These medications may leave you with less defence against viruses and other illnesses. CMV is Cytomegalovirus. This is a virus that can make you quite ill with flu like symptoms.

There are treatments to prevent a CMV infection if you are at risk.

There are also treatments for CMV if you are affected by it. You will take medication for 3 months after your transplant to prevent CMV infection.

What is rejection?

Your body often works to fight things that do not belong. This includes bacteria and germs. These things come from outside your body. They are called foreign.

Rejection happens when your body thinks that your new kidney is foreign. It tries to fight your new kidney and prevent it from working.

It may take some time for your body to get used to your new kidney.

Rejection happens to about 20% of transplant patients.

What are the signs of rejection?

It is important to be on the look out for signs of rejection. You may be rejecting your kidney if your kidney area feels tender.

Other signs of rejection are:

- an increase in temperature
- an increase in weight
- an increase in creatinine levels
- changes in blood pressure
- a decrease in amount of urine
- anxiety and restlessness

What medications will I be taking to prevent rejection?

You may be taking several different medications. Your doctors and nurses will explain what they are and how they work. They will also explain side effects. You must always take your medications exactly as directed. This means you must take the right dose at the right time for each one.

It may take a while for you to get to know your medications. The 'After Your Kidney Transplant' patient education binder describes all of these medications.

When do I go home?

You can plan to be in the hospital for about 1 to 2 weeks. This will give you time to learn about your new kidney and how to take care of yourself.

When you go home, you will have to take your patient education binder for you, your family and supports to refer to any time.



What happens to my dialysis access?

A graft may become clotted with blood after surgery. It may be cleared or your doctor may decide to leave it alone.

A fistula may also clot after surgery and may need a revision. A fistula needs to work in case you need dialysis after the transplant.

A peritoneal catheter or permacatheter is capped off. It is kept functional for about 3 months after your transplant in case your kidney fails. This tube needs to be flushed weekly at your dialysis centre to keep it clear. Before you go home from hospital, make sure you have weekly appointments booked for flushing at the Peritoneal Dialysis Unit.

Before you go home

You should be given an appointment with the Transplant Clinic and know when to have your blood tests done next.

We are here to help

Your transplant team cares about you and your family. We want you to get home as soon as you can and start living with your new kidney. We are always here to help you.

We hope this book has answered some questions you had about having a kidney transplant. Please feel free to talk to any member of the transplant team if you have more concerns. We are here to help you get ready. We hope your wait is a short one.

Your Kidney Transplant – Information for Kidney Transplant Recipients

Contact Information: St. Joseph’s Healthcare Hamilton: 905-522-1155

Transplant Coordinators	ext. 33161
Transplant Clinic	ext. 33780
Transplant Unit	ext. 34048

Departments:

Diabetes Services	ext. 34999 or 34985
Diagnostic Imaging	ext. 36074
Electro-Diagnostic Services	ext. 36082
Firestone Chest and Allergy Clinic	ext. 36000
Nutrition Services	ext. 33115
Nuclear Cardiology	ext. 36073
Occupational Therapy	ext. 33306
Physiotherapy	ext. 33246
Social Work	ext. 33101

Kidney Foundation:

Hamilton Chapter	905-318-8627
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Transplant Coordinators:

Maria Roberts/Tricia Gill	ext. 33236
Ron DeNardis	ext. 34289
Tracy Hamilton	ext. 33193
Melodie Jansen	ext. 33136

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St. Joseph's Healthcare Hamilton: 905-522-1155

Nephrologists:

Dr. Gangji	ext. 33261
Dr. Ludwin	ext. 33323
Dr. Ribic	ext. 33261
Dr. Russell	ext. 33679
Dr. Treleaven	ext. 33261

Urologists:

Dr. Kapoor	ext. 33218
Dr. Piercey	ext. 34987
Dr. Whelan	ext. 34988