

2014

Your Kidney Transplant

Prepared by:

Kidney Transplant Program

Queen Elizabeth II Health Sciences Centre

Capital Health, Halifax, Nova Scotia



Capital Health

This guide will help you learn about what happens before, during, and after transplant.

The transplant process can be long and challenging. You and your family will be our partners in this process. Remember that transplantation is a treatment, not a cure, for kidney disease. It is important for you to know what is expected of you. You will be the lifelong caretaker of your new kidney. We will be here to help you with your new responsibilities.

Important phone numbers

We want you to become an independent member of your community. Your local doctor and health care workers can answer many of your questions.

Local numbers

Hospital _____

Pharmacy _____

Family doctor _____

Friend or family to contact in an emergency _____

Queen Elizabeth II Health Sciences Centre, Halifax

Transplant Coordinator 902-473-2609

Transplant Clinic 902-473-4190

Transplant Social Worker 902-473-5180

QEII Switchboard - If after hours, ask for the kidney transplant doctor on call

902-473-2222

QEII Outpatient Pharmacy 902-473-7986

Transplant Unit Manager/ Transplant Clinic Manager 902-473-7008

Patient Representative 902-473-2133

Introduction

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Kidney transplantation is a treatment for kidney failure. A healthy kidney from one person (donor) is placed (transplanted) into another person (recipient). New medications make this a very successful treatment.

Remember - a kidney transplant is not a cure but a treatment. You must take medication for the rest of your life.

Some people find waiting for a transplant very stressful. The team members will help you and your family members cope with any stresses before, during, and after transplant.

History of kidney transplants

The Atlantic region has had a Kidney Transplant Program since 1969 when the first successful transplant was done at the Victoria General Hospital. All kidney transplants in this region are done at the Victoria General Site, Queen Elizabeth II Health Sciences Centre (QEII) in Halifax. There are 85-100 kidney transplants done at the QEII each year.

Thirty percent of the kidneys used for transplant come from living donors. Most non-living (deceased) kidney donations in the Atlantic provinces go to the patients on the wait list for the Atlantic area. When a kidney cannot be used here, it will be offered to someone else in Canada. Sometimes, kidneys from other parts of Canada are transplanted at the QEII.

Using Your Kidney Transplant guide

We believe *Your Kidney Transplant* will help you and your family members learn about your transplant. This guide is yours to keep and read whenever you feel like it. You do not have to start at the beginning. You do not need to read it all at once.

There is a lot of information in this guide and you will not be able to remember it all.

Although you can learn a lot by reading, no booklet can replace your healthcare team who will discuss the material with you.

You will need to review this guide before and after your operation. **Remember to bring this guide with you when you are admitted for your kidney transplant.** We hope you will check on some things in this guide many months after your transplant.

The last section will give you some tips on how to avoid and detect problems early so you can seek medical attention. It also introduces some lifestyle changes that you may need to make. **You will be the lifetime caretaker of your new kidney.**

If you have any questions or concerns, please call your transplant team. All your questions are important.

Together we can learn and discover.

Words to know

Antibody

The body makes this protein when a foreign substance (antigen) invades the body. Antibodies help destroy the foreign substance.

Antigen

This substance is not normally present in the body. It stimulates the body to make antibodies.

Catheter

A hollow tube used to carry fluids to or from your body.

Creatinine

This waste product is found in blood and urine. Your kidney is not working well if you have high levels of creatinine.

Cross match for transplant (tissue typing)

This blood test finds out if your body will accept the kidney. Your blood is mixed with the donor's blood cells. If your blood destroys the cells then the test (cross match) is positive and you would reject this kidney immediately. If your blood does not destroy the donor cells then the test is negative and the chances of rejection are much less.

DCD

Donation after cardiac death.

Deceased donor

A person who died suddenly and his/her family donate organs for transplantation.

Delayed graft function/acute tubular necrosis (ATN)

Acute tubular necrosis (ATN)/delayed graft function is when the kidney does not work right away. It may take the kidney several days or a few weeks before it starts to work. Dialysis may be needed until the kidney starts to work.

ECD

Expanded criteria donors. Older donors or donors with medical problems such as high blood pressure or diabetes.

Graft

This is the transplanted kidney.

Immune system

A network of cells and tissues (spleen, lymph glands) that fight foreign bodies such as a virus, bacteria, or someone else's organ.

Immunosuppressive medication

This is a medication used to turn down your body's immune system. It is also called an anti-rejection medication.

Live donor

A living person who donates a kidney for transplantation. A donor may be related by blood (such as mother, brother, sister, uncle) or unrelated by blood but emotionally connected (friend, spouse).

Lymphocele

After surgery, fluid may collect near the kidney. It can become large enough to block the ureter. This will prevent urine (pee) from flowing into the bladder. It may have to be drained.

Obstruction

The ureters carry urine from the kidneys to the bladder. Urine will not be able to flow if the ureter becomes blocked or kinked.

Rejection

The body's immune system identifies the transplanted organ as foreign and tries to destroy it (see 'Rejection and infection' in the "Your Transplant" section of this guide).

Renal scan

This test measures the blood flow to the kidney, the function of the kidney, and the drainage of urine to the bladder. A small amount of radioactive substance is injected into your arm. The movement of the substance is detected by a scanner (large metal device) placed over your kidney.

Renal biopsy

Freezing is injected. A small piece of tissue is removed from your new kidney with a long thin needle. This test helps your doctor to find out how the kidney is working or why it is not working.

Ultrasound

This machine bounces sound waves off your kidney. It measures your kidney blood flow and makes sure the flow of urine is not blocked.

Learning about your kidneys and kidney disease

How do healthy kidneys work?

The kidneys clean the blood and control the amount of water in your body. As blood passes through the kidneys, water and wastes are removed. This ensures that the chemicals and water in your body are balanced correctly.

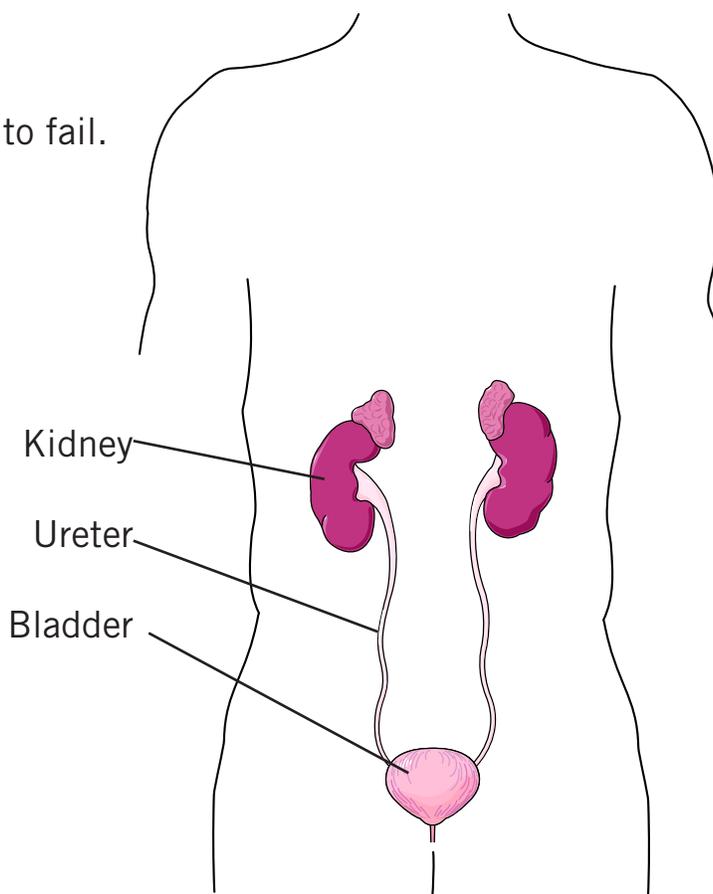
The kidneys also make hormones to keep the body healthy.

Kidney diseases

Many diseases can cause the kidneys to fail.

Some of these diseases are:

- Diabetes
- Glomerulonephritis
- High blood pressure
- Polycystic kidney disease
- Infection
- An obstruction in the urinary tract



If you do not know why your kidneys failed, ask your doctor. There are many ways that you can learn about kidney disease. The Kidney Foundation may be helpful. You can find the Kidney Foundation of Canada online at www.kidney.ca.

Treatments for end stage kidney disease

When your kidneys first began to fail, you may only have needed to change your diet and to take some medications. We would like you to learn about dialysis. You may need dialysis if your kidney function continues to fail. Many people waiting for kidney transplants need dialysis treatments. Dialysis cleans the blood and removes the extra fluid.

Hemodialysis and peritoneal dialysis

Health professionals with special training do hemodialysis. The blood passes through an artificial kidney with the help of a machine. A hemodialysis treatment takes about 4 hours and is needed about 3 times a week.

A person can learn to do his/her own peritoneal dialysis. The abdominal cavity is filled with dialysis fluid. The fluid is left in the cavity for several hours. Wastes and excess fluid are passed from the blood to the fluid in the cavity. The dialysis fluid is then drained and replaced by fresh dialysis fluid. These fluid exchanges are done about 4-5 times each day. Each exchange takes about 30 minutes.

The benefits and risks of the treatments used for end stage kidney disease

When you are trying to decide if you want to have a kidney transplant, you should weigh the benefits and risks of surgery over dialysis. You are only ready to make a decision after everything has been discussed with your doctor and family.

Transplant

The benefits of a transplant

- Free from dialysis

Anyone who has a working transplant will not need dialysis. After transplant, 1 out of 10 kidney transplants do not function right away. This is due to the shock of moving the kidney from one person to another. It is called acute tubular necrosis (ATN). Dialysis may be needed while the kidney recovers.

- A better quality of life

A person who has a working kidney transplant will have more energy and a better appetite.

- Live longer

There is some evidence that people who have functioning transplants may live longer than if they had stayed on dialysis. This is not true for everyone. About 4% of people receiving a transplant will die within the first year. This may be due to pre-existing medical problems, but can be due to immunosuppression medicine.

The risks of transplant

The first risk facing anyone who has a kidney transplant is the operation. The risk differs for each person based on his/her own health and if there are any serious problems after the operation. Someone who is quite healthy may have problems if he/she has a severe rejection episode or if the kidney transplant does not work right away.

About 1 out of every 3 people will have a rejection episode. This can be treated with high dose steroids or other medications. These medications carry some risk, but rejection can usually be reversed.

A kidney can be lost from chronic rejection. The disease that caused the original kidney problem can also return. Kidneys are often lost if medications are not taken properly.

Returning to dialysis can be emotionally difficult if the kidney fails.

You will need medications to prevent rejection after transplant. Some common side effects of these medications are:

- A high risk of heart disease, diabetes, high blood pressure, and high cholesterol levels. Prednisone may cause diabetes, high blood pressure, and high blood cholesterol levels.
- One out of 10 people receiving a transplant will develop diabetes. This occurs more often in older people. Insulin injections may be needed.
- An increase in the risk of infection.
- Skin cancer is a big risk. Staying out of the sun and using sun block can lower this risk.
- Lung and bone cancers occur more often.
- Cataracts, hair growth, liver inflammation, and other problems can occur.

Despite these side effects, people on these medications still live longer than if they were on dialysis.

Dialysis

The benefits of dialysis

Staying on dialysis may be the safest choice for anyone who has serious heart, lung, or liver disease and infections that cannot be cured. The anti-rejection medications needed after a transplant can aggravate cancer or an infection.

The risks of dialysis

Anyone who has been on dialysis is very aware of the problems. People on dialysis have a very high risk of heart disease. This may be due to the years of high blood pressure, high cholesterol levels, and other problems that occur with chronic kidney failure.

Some people on dialysis have low blood counts. Aranesp®, iron, or a blood transfusion may be needed. Blood transfusions are safer now than in the past but there is still a very small risk of catching a virus. Blood transfusions can also increase your risk of developing antibodies.

The complications of hemodialysis and peritoneal dialysis are different. With hemodialysis, there is a high risk of infection in the blood stream. There is a risk of infections in the abdomen with peritoneal dialysis. These problems are rare for an individual with a functioning transplant.

Deciding to have, or not to have a kidney transplant needs careful consideration. Talk about it with your family and doctors. Working with you, we will plan the best treatment for you.

Meet your health care team

You, the patient, and your family are the most important members of the team. Many other members of the health care team will be involved with your care.

Your **nephrologist** (kidney doctor) and **transplant surgeon** will work together to direct your care before and after transplantation. Before your surgery, you will see the nephrologist for visits. After surgery, you may see the nephrologist or transplant surgeon during your Transplant Clinic visit.

The **transplant coordinator** will place you on the wait list and guide you through the whole transplant process. He/she also monitors your health, arranges your tests and appointments, and keeps your file up to date until your transplant.

Your **family doctor** will receive frequent letters from the Clinic. This is to keep him/her updated about your condition and treatment. You will need to visit your family doctor regularly.

Other specialists (infectious disease, cardiologists, dermatologist, and others) may be asked to assist in your assessment and treatment if special problems occur.

Nurses on the inpatient unit will prepare you for surgery and care for you after your transplant. They will help you learn about your medications and how to care for your new kidney.

The **transplant fellow** is a specialist in training who assists the surgeons and nephrologists in your care after transplant.

The **nurses** in the **Clinic** help care for you after you leave the hospital. In the beginning a person is followed (monitored) in the Halifax Transplant Clinic for 2-4 weeks. If you are from mainland Nova Scotia or PEI, the nurses in the Transplant Clinic will continue to follow you for the life of your kidney. If you are from NB, NL, or Cape Breton you will be followed in these areas at a transplant clinic for the life of your kidney.

Research nurses follow patients who have chosen to take part in a study. They are available 24 hours a day for any matters about the study.

A **social worker** can help you and your family members adjust to the changes in your lifestyle. He/she can counsel and support you and your family and help you contact other resources within the community. You can speak to a social worker at any time.

Care for patients from NB and PEI is arranged by **liaison nurses**.

Your **dietitian** will help you prepare an eating plan before and after your transplant. After surgery, the dietitian will see you in the Transplant Clinic for follow-up visits.

Spiritual care workers will serve your spiritual needs. Someone is available to you and your family members during your hospital stay. There is always a worker on call. Speak with your nurse if you want to see a member of the Spiritual Care Department.

You may need to work with a **physiotherapist** to improve your strength and flexibility.

The **patient representative** works with all departments on your behalf. He/she can help you with concerns or questions not resolved by other staff members (see pamphlet provided).

Getting Ready for Transplant

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Getting Ready for Transplant

Types of kidney transplants

- **From a non-living donor (deceased)**

This kidney is from someone who has died and his/her family has donated the kidney. The donor's death is usually due to an injury or stroke. A transplant from a non-living donor lasts about 10 years. This is only an average and outcomes are hard to predict.

- **From a living donor**

The donor is usually a family member, spouse, or close friend who wishes to donate a kidney. On average, a kidney from a living donor lasts 10 to 15 years. Again, this is only a prediction.

Donating a kidney

A potential live donor must be in very good health and offer to donate one of his/her kidneys. There is a risk involved in donating a kidney, as there is with any major surgery. The donation of a kidney should be voluntary - there should be no feelings of pressure or guilt.

If someone is interested in donating a kidney, he/she should call the live donor coordinator who will start the process.

- Several blood tests will be needed to see if the donor's blood group is compatible with yours. Tissue typing and the cross matching are done to see if your body would accept his/her kidney. If these tests show that the potential donor may be acceptable, he/she will be contacted.
- A complete medical checkup and a number of other tests are also needed to ensure the donor is in perfect health.
- The surgeon and the nephrologist will carefully review the results of the tests. In consultation with you, they will make the final decision.
- We will try to arrange your surgery at a time that is best for the donor and you.

Please see the booklet provided about live donation.

Live Donor Paired Exchange Registry

A national registry which can help match an incompatible donor for you with another donor in the country. Please see pamphlet provided.

Your medical condition

Cancer, some types of kidney disease, heart disease, or other medical conditions may make a transplant too high a risk for you.

Tests you will need

A number of tests are needed before you can be placed on the kidney transplant wait list.

You will need:

- A letter from your nephrologist (kidney doctor)
- A chest X-ray
- Electrocardiogram (EKG)
- Blood tests
- Your urine checked for infection
- Pap test for women over 18
- Mammogram for women over 40
- Prostate level for men over age 50 (PSA)
- TB skin test
- Ultrasound or CT abdominal scan
- Dental evaluation
- Stool occult blood test if over age 50
- Glucose tolerance test (only if you are not a diabetic)

Your health will determine if other tests are needed.

You will need blood tests for:

Your blood group

The 4 basic blood groups are: A, AB, B, and O. You cannot receive a kidney from a donor whose blood group is not compatible with yours.

Viruses

We must know if you have hepatitis virus, cytomegalovirus (CMV), or HIV in order to help us plan the best care for you.

Tissue typing

Antigens are bits of genetic material that we inherit from our parents. We receive half from our mother and the other half from our father. This test allows us to compare your antigens with a donor's antigens.

Cytotoxic antibodies

The antibodies in your blood are measured. You may have antibodies if you had a blood transfusion, a previous transplant, or if you have ever been pregnant. Antibodies could cause you to reject a kidney from certain donors. Anyone with high antibodies is harder to match. He/she may have to wait longer for a kidney than someone who does not have any antibodies. There is a national registry for patients that have high antibody levels.

Extra tests

These may be needed if you have cardiovascular disease and/or diabetes.

Heart disease can cause major problems at the time of transplant. A person who has irreversible heart disease may not have a kidney transplant.

These tests may include:

Exercise stress test: An exercise stress test is a special type of electrocardiogram (EKG) that compares your heart's electrical activity at rest and under exertion. The test is painless. An EKG is done while the patient is exercising in a controlled environment.

Dobutamine stress test: This type of stress test can be done if you are not able to exercise. It helps the doctor measure the reaction of the heart to exertion. A drug is given that causes the heart to act as if it were exercising, even though you are at rest.

Echocardiogram: This is a painless and safe test of the heart. It shows the size, shape, movement of the heart, and the flow of blood to the heart. Sound waves (ultrasound) are used to get a picture of the heart which is then viewed on a monitor. The pictures are saved to be studied by the doctor later. The doctor can check the heart valves, the wall of the heart, and look for diseases and fluid around the heart.

Thallium scan (MIBI): This test looks at how the heart is working or if there is any disease in the heart's vessels. It may be done along with an exercise stress test. A cardiac catheterization may be needed if this test shows any disease.

Cardiac catheterization: Your heart's blood vessels are checked. Catheters (long thin tubes) are placed in the blood vessels of your groin. Dye is injected into the blood vessels feeding your heart. If the vessels are narrowed, they can sometimes be opened up by an operation such as angioplasty or cardiac bypass surgery.

If these tests are needed, they must be completed before the transplant team can place your name on the transplant waiting list.

The wait list

After the tests and interviews are finished and your chart is reviewed by the transplant committee, the Transplant Team will talk about your test results with you. You and your doctor will talk about the best treatment for you. If transplant is recommended, you may want to talk this over with your family. If you decide to have a transplant, you will be placed on a wait list.

When you meet the requirements for the transplant list, your information is placed into our computer in the Transplant Program.

You now begin a period of waiting. This time can be difficult. People have many different emotions during this time. At first, you may be quite excited and hopeful that you will receive a new kidney quickly. After a while, you may begin to wonder if you will ever get a new kidney. You may find that you begin to feel guilty if your new kidney depends upon the death of someone else. These feelings are normal. The average time a person is on the wait list is 2-3 years. It may be less and it could be more.

The computer matches donors with people on the wait list. Deciding who will receive a kidney is based on many things. The cross-match between you and the donor must be negative. A computer program is used to help choose the right person for the transplant. The computer compares how well your tissue typing matches with the donor's tissue typing. How long you have been waiting is another consideration. The nephrologist and surgeon make the final decision.

Getting on the list is only the first step. We will work hard to see that you stay on the list, but we need your help. You must try to stay as well as possible. Follow the advice of your healthcare team.

You can get a donor match at any time, so it is important to be ready!

Some information from your Social Worker

It is just as important to prepare financially for a kidney transplant as it is to prepare emotionally and physically. Any preparation patients and families can do before surgery may ease the recovery process.

Patients and families are caught off guard when they receive “the call” from the transplant coordinator. Many people have said, “I never thought it would happen so I never prepared.”

We have listed some of the costs patients and families can expect before and after transplant:

- Patients are responsible for medication costs upon discharge from hospital. Bring all of your medications from home when you come to Halifax. You will need them while you are staying in Halifax. Depending on your drug plan, some of these medications may be covered. If you have a private plan, call the company to see if the medication is covered. If it is, you may have to pay part of the cost and your percentage of the co-payment. It is possible that the medication is covered only for certain health problems. The doctor may need to complete a special authorization or “exception status” form before you will know if your plan will cover the medication.
- All NS Pharmacare programs cover the same medications, but the amount you pay depends on the type of program you have. To register for NS Pharmacare, call 1-877-330-0323 or check www.nspharmacare.ca.
- New Brunswick and PEI have provincial Pharmacare programs. They also have Liaison nurses available to provide information and answer questions.
- Patients covered by Newfoundland Prescription drug coverage should bring medications with them. Newfoundland has a Medical Transportation Assistance Program through which NL patients can receive partial reimbursement for medical travel expenses. Call 1-877-475-2412 or check www.health.gov.nl.ca for more info.
- Most patients will spend about 2-3 weeks at Point Pleasant Lodge (PPL) upon discharge from hospital.

- Patients do not pay for lodging while staying at PPL; however, family members will have to pay for their own lodging unless they are approved as an “essential escort”. If a spouse, sibling, or friend plans to stay at PPL while a patient is recovering after transplant surgery, then money must be available to help with this cost.
- Lodging at PPL will cost \$45 + tax a night. A family member may be asked for a \$100.00 security deposit to be paid by either a credit card or cash. See www.pointpleasantlodge.com for details.
- Patients from NS and NL receive two \$5.00 meal tickets per day from the Clinic while at PPL. These can be used at PPL or in the hospital cafeteria. This is a small subsidy and will not cover all meal costs. Family members will have to pay for their own meals. Patients from NB and PEI receive a meal credit of approximately \$25.00 + tax available for use at Point Pleasant Lodge only.
- Travelling arrangements and costs also need to be considered.
- Loss of income during the hospitalization and follow-up period after transplant can be a concern. Try to explore options such as sick leave and Employment Insurance.

Some patients receive financial support from fundraising activities. Financial worries can cause stress and decrease the joy of the transplant experience. The transplant social worker will contact workers for patients on income assistance if this is needed.

We strongly encourage anyone awaiting an organ transplant to set money aside in advance. Please prepare for the day even though you think it will never arrive.

If you have any questions or concerns you would like to talk about with a social worker, please tell your transplant coordinator, or call the social worker directly at 902-473-5180.

Your responsibilities

Here are some things that you must do.

Blood must be taken for:

- **Antibodies every month. If we do not have a fresh tube of blood, you may miss your chance for a transplant.**
- CMV, Hepatitis B and Hepatitis C tests every 6 months.
- HIV test once a year.
- Cardiac update yearly (if needed).
- EKG and Chest X-ray yearly.
- Pap test for women over 18 yearly.
- Mammogram for women over 40 yearly.
- PSA levels for men over 50 to check the prostate yearly.

Your coordinator or nurse will notify you when you need these tests.

Remember, these tests are your responsibility. If we do not receive this information, you cannot be matched against a kidney donor.

Keep your team updated. Call if you:

- Have a blood transfusion. This can cause a rise in antibodies. We will need a fresh blood sample for cross matching and to check antibodies.
- Have any illness that might keep you from having a transplant such as an infection or pneumonia.
- Plan to move, take a trip, or change your phone number. The transplant coordinator must know how to find you within a few hours when a kidney becomes available. **Keep your coordinator updated!**

Stay as healthy as possible

- **Do not smoke**
- **Have dialysis if needed on a regular basis**
- **Take your medications**
- **Follow your kidney diet**
- **Limit or avoid alcohol**
- **Keep your transplant coordinator informed of any important changes**

If you no longer wish to be on the list, please call your transplant coordinator.

You may be placed on hold if:

- You have an infection and need antibiotics. For example, if a patient has peritonitis he/she will be put on hold until the infection has cleared.
- You are waiting for other surgery.
- You had a heart attack in the last 6 months.

Being placed on hold is only temporary. If you are only on hold for a short period of time, you will still accumulate time on the wait list. When you are better, you will be matched against all donors.

Your Transplant

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Your Transplant

A kidney is available

When a kidney is available, the transplant coordinator will phone you. She/he has a few hours to find you and will not give up on the first try. If she/he cannot reach you at the first number, she/he will try the other numbers you have given.

We have used the RCMP to find a patient when a kidney is available.

It is very important to keep the coordinator informed about where you are and any change in your address or phone number.

The coordinator will ask:

- Are you in good health and free from infection?
- How will you travel?
- When do you expect to arrive at the hospital?
- When was your last dialysis?
- Have you had a blood transfusion lately?

If you had a recent transfusion, you will need to have a cross match repeated. If this test is positive, we would be unable to do the transplant.

Remember, there are still a number of things that can prevent a transplant. If you are unwell, be honest with yourself and the Team. It can be very dangerous to receive a transplant when you have an infection.

You will be given time to collect your thoughts and make travelling arrangements. Many people and their families have said that they worry about being able to respond properly when they get the call. They feel that they will freeze up or be too excited or anxious to do what needs to be done.

Although many people have felt this way, this has never occurred. You are likely to feel excited and relieved that a donor has been found. You may feel some sadness for the donor family and some anxiety about the surgery. Your main task is to get to the hospital safely.

Some reminders

- **Do not eat or drink anything**
- **Bring these with you:**
 - › **Provincial Health Care Card**
 - › **Medications (insulin) if needed**
 - › **Blood glucose monitor and strips**
 - › **CPAP – if needed**
 - › **This binder**
- **Leave valuable items (jewelry, credit cards, cash) at home**
- If you are on peritoneal dialysis, bring your portable equipment and fluid for at least 1 exchange to the hospital. Also bring dressing supplies including exit site cream/ointment to last approximately 2 weeks while staying in Halifax.

Your family

Your family may go to the Transplant Unit with you. They will be able to wait in the **family room** while you are having your operation. **Please try to limit the number of family members to 1-2.** It is important to understand that family members can only stay on 6B **while you are in surgery.** They will need to find a place to stay at while they are in Halifax with you. They cannot sleep in the family room or at your bedside.

If they want to find a place to stay overnight, they can try the places listed below. Remember that this will be at their own expense.

- Point Pleasant Lodge: 902-421-1599 - There is a shuttle service to the VG.
- Westin Hotel, Hollis Street: 902-421-1000 - There is a shuttle service to the VG.
- Lord Nelson Hotel, South Park Street: 902-423 -6331
- Atlantica Hotel, Robie Street: 902-423-1161
- Halifax Haven: 902-421-1650
- Garden Inn Bed and Breakfast, South Park Street: 902-492-8577 or toll-free 1-877-414-8577

The above are close to the VG and/or have reasonable rates.

Arriving at the Victoria General site

The map on the back of this binder shows you the Victoria General (VG) site, off South Park Street, and the main doors to the hospital.

If you arrive between:

7 a.m. to 5 p.m.

- Use the main entrance off South Park Street. Go to Admitting on the 10th floor Victoria Building. From there, you will go to 6B.

5 p.m. to 7 a.m.

- Go to the security entrance in the Dickson Building. This building is attached to the main hospital. Staff will direct you to the Transplant Unit on the 6th floor of the hospital.

Your hospital stay

Just before your surgery

You will be cared for on 6B, VG site.

Many things have to be done before your transplant. You may feel rushed. Please stop us and ask questions at any time.

A nurse and a doctor will help you get ready for surgery.

You will have:

- Blood work and urine tests
- EKG
- Chest X-ray
- Swabs of your groin and nose for MRSA (if required)
- Intravenous (IV) medications or an IV infusion given to you (depending on your doctor's orders)
- Teaching of what to expect for the next few days

One of our research nurses may invite you to take part in a study. If you wish to be in a study, she will explain the study in detail and answer your questions. Your care will not change in any way if you decide not to take part in a study.

Surgery

- Nurses in the Operating Room (OR) will meet you.
- An anesthetist will assess you and put you to sleep.
- Once asleep, a catheter will be inserted into your bladder and a large IV line put into your neck.
- Your surgeon will make an incision (cut) in your lower abdomen and insert a kidney. The transplanted kidney is connected to your own bladder. Your own kidneys will not be removed.
- Your operation will take several hours.

After your surgery

You will be in a special unit for a couple of hours as you recover from the anesthetic.

When you return to 6B, you will be cared for in a special 4-bed unit for at least 24 hours. This is called IMCU (Intermediate Care Unit).

Men and women are together in this unit.

- You will get oxygen.
- You will get help with deep breathing and coughing exercises every hour.
- There will be an intravenous (IV) line in the side of your neck to give you fluids and to check your fluid balance. This line and an IV in your arm will be needed for about 4 days.
- The nurse will remove the dressing on your abdomen the day after your operation. If there is drainage, a new one may be reapplied and changed as needed. The incision (cut) will be closed with staples. They will be taken out 10-14 days after surgery.
- A catheter will drain your urine for at least 4 days. The amount of urine you are making will give us an idea of how well your transplanted kidney is working. Your urine may have a reddish colour in the beginning.
- A drainage tube may be used to drain any fluid that collects around the kidney for a few days. It is taken out the day after your catheter or when the fluid draining slows down.
- Your blood pressure, temperature, oxygen levels, and pulse will be checked often.
- You will not be able to drink until your nurse hears bowel sounds. You could become sick to your stomach if you drink before your bowels are active. Bowel sounds usually return within 12 hours. You may use sterile water when you take your medications and rinse your mouth.

People recover at different rates from their surgery. Sometimes people become anxious if they are not recovering as fast as other people they have met or heard about. While it can be useful to hear about other peoples' experiences, it is not a good idea to compare yourself to others. Everyone is different. The average hospital stay varies. It is about 5-10 days if everything goes well. It can be up to 30 days. Complications can occur during your hospital stay or after you go home.

- Blood will be taken early every morning to check your kidney function and your medication levels. **Do not take any medications before your blood is taken.**
- The amount of anti-rejection medication is measured in your blood. Your dose may need to be changed depending on the level (this is normal).
- Urine samples will be checked twice a week.
- The doctors will visit you twice a day. Make a list of your questions.
- About 24 hours after your surgery, you will be up in a chair. Within a day, you will be up walking with help. Being active will help to prevent pneumonia and blood clots in your legs.
- **Learning about your medications is one of the most important things you need to do so you can care for your transplanted kidney.** Within 2 days of surgery, you will begin to learn about your medications. You will learn why you need these medications, when you should take them, and possible side effects. With help, you will learn to take your medications on your own during your hospital stay. It is important to check with your nurse every day as your dosage may be changing often. Write down your actual dose on your record sheet. You should use it at home. See the next page.
- Your diet may change after surgery. Your dietitian will see you in the Transplant Clinic after discharge.
- A social worker is available to you and/or your support people.
- If you have a fistula in your arm, it will not be removed. Call your doctor if it becomes swollen or painful.
- Your peritoneal dialysis catheter may be taken out if your kidney was from a living donor. If you receive a kidney from a deceased donor (donor who died), the catheter may be left in up to 3 months.

Your medications can cause you to have some emotional ups and downs. As the medications are adjusted, the emotional ups and downs will lessen.

Possible problems after surgery

Cytomegalovirus (CMV)

This is a common virus. Most adults who have been exposed to this virus do not develop CMV disease. A healthy immune system can keep the virus quiet. The virus can become active if a person's ability to fight infection is reduced. The medication you are taking to prevent rejection can prevent you from fighting this virus.

Call your family doctor if you have:

- Fatigue (tiredness)
- High temperature
- Aching joints
- Headaches
- Cough and/or phlegm

Herpes

The herpes viruses may cause:

- Cold sores
- Chicken pox
- Shingles or genital herpes

Precautions:

- Keep sore areas clean and dry.
- Wash your hands with soap and water after touching the sore.
- Do not kiss anyone who has a cold sore.
- If you have never had chicken pox, call your family doctor right away if you are exposed to chicken pox or shingles.

Rejection and infection

The immune system helps the body fight against disease and infection. It also protects the body against anything that is foreign. After transplant, your body sees your new kidney as foreign and tries to reject it. Medications called immunosuppressants (anti-rejection) protect your new kidney by turning down your immune response. The cells involved in the immune response have a memory. They will always recognize the new kidney as foreign and you will always need medication to protect you from rejection.

One of every 3 patients will have a rejection episode. Rejection usually occurs within the first 3 months after surgery but can occur at any time. This does not mean you will lose your new kidney. **Changing or adjusting your medications can control most rejection.** The best way to prevent rejection is to always take your medications.

Call your doctor if you have any of these signs of rejection:

- Flu-like symptoms (chills, fever, fatigue, and aches)
- Pain or tenderness around the transplant
- Swelling of eyelids, hands, or feet
- Less urine
- Rapid weight gain
- Cough or shortness of breath

The medications you are taking to prevent rejection also lower your body's ability to fight infection. The risk of infection is higher in the first few months after surgery. You are more likely to be taking larger doses of anti-rejection medications at this time.

Some common infections that may occur are wound, bladder, or pneumonia.

Call your doctor if you have:

- A sore that does not heal
- Burning or a funny smell when you pee
- Fever and chills
- Cough and sputum (phlegm)

Planning for discharge

- **A transplanted kidney brings new responsibilities. You are now the lifetime caretaker of this kidney.**
- Many people are anxious about leaving the hospital. They worry that something will happen to their transplanted kidney. They feel safe with the “experts” at the hospital, and worry that people outside the hospital will not be able to help them with their problems. These feelings are usually quite short lived and often disappear with the first breath of fresh air outside the hospital.
- Discharge plans must be made well in advance.
- Before you go home, your nurse will discuss the Clinic with you. He/she will also arrange a tour of the area for you.
- If you have any concerns about your discharge, please speak with a member of your Transplant Team as soon as possible. We would be pleased to help in any way.
- Follow-up visits are very important if you are to stay healthy. If you are not from the Metro area, we will arrange for you to stay at Point Pleasant Lodge in Halifax.

Remember, you must take your medications as directed. If you don't, you or your transplanted kidney can be damaged, which may result in you losing your kidney or having poor kidney function.

A letter to the donor family

This is a very exciting time in your life. To receive such a gift is very precious to you, but it is also a time of loss for others. You and the donor must remain unknown to each other to protect you, the donor, and the donor's family.

However, you may write a letter of thanks to the members of the donor family for having a new chance at life. Your transplant coordinator can give you a pamphlet on how to write this letter. The coordinator will review your letter and then mail it to the family.

The Transplant Clinic

The nurses in the Clinic on the 4th floor of the Dickson Centre will help you plan your care. The Clinic is open Monday to Friday, 7:30 a.m.-3:30 p.m., and their phone number is 902-473-4190. It is closed on holidays and weekends. You may leave your name and number on the answering machine and someone will call you back during clinic hours. If you can't keep an appointment, call the Clinic.

Your clinic visit

- Bring your Provincial Health Care Card to all appointments.
- Do not take your anti-rejection medications before you have your blood taken, unless you receive other instructions.
- Bring your medications and medication list to the Clinic.
- Your medications may need to be changed.
- Make sure you get your next appointment in the Clinic.
- Mark down your appointments in a book or calendar.

The doctors in the Clinic change every day so you may not see the same one. You may see the transplant fellow who took care of you in hospital.

During your visit, the staff will review your medications and discuss any problems. The dietician, pharmacist, and research nurses are available to talk about any of your concerns.

Anyone staying at the Lodge will probably be able to return home after 14 days depending on his/her progress. A transplant doctor will make this decision.

We will still need to monitor your progress. We will arrange for you to have blood taken at your local hospital. The results will be sent to the Clinic, usually by fax. The Transplant Team will review your blood tests. As you progress, you will need blood work less often.

During the first 3 months, you will need to visit the Clinic often. At first the visits are 3 times a week, but over time they will drop to twice a week, once a week, once every 2 weeks, and then every month. Your doctors will arrange the number of visits. You will continue to be followed in the clinic for the life of your kidney.

There are clinics in Sydney, NB, NL, and PEI. Check the Satellite Telephone Numbers list in the Staying Healthy at Home section of this guide. We will send your file to a specialist in your area for your follow up. Most patients from these areas will need to spend about 3 weeks in Halifax after their transplant. You will then return home and will be followed by that clinic for the life of your kidney.

Your Medications

The medications you need in your particular case may not match this list exactly, and all medication info sheets may not be included in your Transplant binder.

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The self-medication program

Introduction

You need to learn about your medications. During your hospital stay, you will start to take your own medications. The nurse will help you with this by making out a medication sheet for you to follow. This helps you get ready to take your medications at home. Be sure to let your nurse know if you have a vision, hearing, or memory problem.

Your nurse will help you learn:

- The name of each medication that you are taking
- Why you need to take each medication
- When and how to take each medication
- The side effects that can happen with each medication
- How to get your supply of each medication

A supply of your medications and a medication record will be given to you. You will start to get your own medications ready and take them at the right times. During your hospital stay, your nurses will check how you are doing each day.

Reminders

- **You will need to take anti-rejection medications all of your life.**
- Take your medications as directed by your doctor.
- Do not stop taking any medication without asking your doctor.
- Take your medications at the same time each day.
- If you forget a dose of your anti-rejection medication:
 - › **Medications you take twice a day:** if you miss a dose and remember it before the halfway point between the 2 doses, take the medication. Otherwise skip this dose and take the next dose at the regularly scheduled time.
 - › **Medications you take once a day:** take your dose as soon as you remember it.

- If you are vomiting, you are probably bringing up your medications. If you vomit within 1/2 hour of taking a dose of anti-rejection medication, repeat that dose of medication after your stomach settles. If it is longer than 1/2 hour, unless the pills are visualized, do not repeat that dose. Take your usual dose at the next regular scheduled time. Do not double dose. If your nausea continues, contact your doctor.
- If you have diarrhea that lasts more than a couple days, contact the Team, as well as your family doctor.
- Make sure you have enough medication. **Do not run out.** Get your refills while you still have **at least a 2-week supply of medications left.**
- Tell your dentist, pharmacist, and family doctor about the medications you are taking.
- Carry a list of your medications with you at all times in your purse or wallet.
- **Some over-the-counter medications may affect the level of your anti-rejection medications.** Do not take medications such as cold medications without speaking with your doctor or pharmacist.
- Do not take any other medications such as large doses of vitamins or herbal remedies without asking your doctor or pharmacist.

How to get your anti-rejection medications

- If you live in PEI, NS, or NL your anti-rejection medications are provided to you through a government-funded program. They are not available in the local drug store.

You will be given instructions on how to get your medications before you leave the hospital.

- If you live in NB, you can get your anti-rejection medications from your local drug store. Before your discharge, please make sure that you know how to get these medications.

Storing your medications

- Keep medicine out of the reach of children.
- Do not store in damp areas such as the bathroom.
- Do not store in direct sunlight.
- Do not store pills or tablets in the fridge.
- Any medication that is in a foil package should not be removed from the package until you are going to take them.
- Do not keep old medicine or medicine that you no longer need. Take these to your local drug store which will get rid of them safely.
- Do not share your medicines with anyone.

Your medications

After your transplant, your medications will include some of the following: acyclovir, mycophenolate mofetil, mycophenolate sodium, prednisone, ranitidine, sirolimus, sulfamethoxazole/trimethoprim, tacrolimus, valganciclovir.

You may take other medications to prevent infection, to control high blood pressure or diabetes, as well as medications that you took before transplant, such as thyroid medication.

Information on your medications can be found on the following pages.

Acyclovir

Generic name: Acyclovir

Brand name: Zovirax®

What is acyclovir?

- Acyclovir is a drug used to treat or prevent infections caused by viruses.
- It is prescribed to treat or prevent viral infections such as chicken pox, shingles, and cold sores.

How do I use acyclovir?

- Do not stop taking acyclovir on your own - talk to your doctor first.
- Acyclovir can be taken with or without food.
- Acyclovir can cause problems if you take it with other medicine. Talk to your doctor, pharmacist, or transplant nurse before taking any other medicine, including prescription/non-prescription medicine, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, talk to your transplant clinic nurse or your pharmacist.
- If you have started taking new medicine and worry it might have an effect on acyclovir, or you forgot to take your medicine and are not sure what to do, talk to your transplant clinic nurse or your pharmacist .
- Store acyclovir at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to a healthcare professional if you do not feel well while taking acyclovir. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Blood problems:** Acyclovir can lower red blood cells, white blood cells, and a part of the blood (platelets) which helps make blood clots. This can make you feel tired, increasing your risk of infections, bruising, and/or bleeding problems. The Transplant Team will watch closely for these problems and will change the amount of your medicine if needed. Please talk to your transplant clinic nurse, your pharmacist, or your doctor about any tiredness, bruising, or infections.
- **Kidney problems:** Rarely, acyclovir can cause kidney problems. The Transplant Team will watch closely for these problems and will change the amount of medicine you take as needed.
- **Rash:** Contact a healthcare professional or the Transplant Clinic should you develop a rash.

Mycophenolate Mofetil

Generic name: Mycophenolate Mofetil (MMF)

Brand name: CellCept®

What is MMF?

- MMF is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is prescribed to prevent your body from rejecting your transplanted organ.

How do I use MMF?

- Do not stop taking MMF on your own - talk to your doctor first.
- Take MMF at the same time each day.
- MMF can be taken with or without food though it is best absorbed on an empty stomach. Be consistent with how you take your medicine each day.
- MMF can cause problems if you take it with other medications. Talk to your doctor, pharmacist, or transplant nurse before taking any other medications, including prescription/non-prescription medications, natural products, and/or supplements.
- Your blood counts will be monitored regularly. The amount of MMF you take may have to be adjusted because of the results of your blood count.
- If you are not sure how much medication to take, or if you think you may be experiencing any side effects, talk to your transplant clinic nurse or your pharmacist.
- Leave MMF in its packaging until you are ready to take it.
- If you have started taking new medication and worry it might have an effect on MMF, or you forgot to take your medication and are not sure what to do, talk to your transplant clinic nurse or your pharmacist .
- Store MMF at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side-effects can happen with all medicines. Talk to your healthcare professional if you do not feel well while taking MMF. Below is a list of side effects to be aware of:

- **Higher risk of infection:** Report the first signs and symptoms of an infection (such as fever, sore throat, chills, fast pulse, etc.) to your doctor **immediately**.
- **Higher risk of developing cancer:** Report any lumps or changes in skin color and moles to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting and diarrhea:** These symptoms often occur early in treatment and should go away. **Talk to your doctor or pharmacist before taking any over-the-counter medications to treat these symptoms.**
- **Headache, light-headedness, dizziness, and weakness:** If these symptoms continue, or if you experience any fainting, see your doctor right away.
- **Blood problems:** MMF can lower red blood cells, white blood cells, and platelets (the part of the blood which helps make blood clots). This can increase your risk of infections, bruising or bleeding problems, and tiredness. You will be carefully monitored for any signs of these blood problems and the amount of MMF you take may need to be adjusted due to these problems. Please report any extreme tiredness, bruising, or infections to your transplant clinic nurse, pharmacist, or your doctor.
- **If you are a woman of child bearing age:** Pregnancy should be avoided while you are taking MMF as it can cause harm to an unborn child. Ask your doctor or pharmacist for help in choosing the right birth control method for you. If you are planning to get pregnant, talk with the Transplant Team months beforehand as some of your medicines may need to be changed.

Mycophenolate Sodium

Generic name: Mycophenolate Sodium

Brand name: Myfortic®

What is mycophenolate sodium?

- Mycophenolate sodium is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is prescribed to prevent your body from rejecting your transplanted organ.

How do I use mycophenolate sodium?

- Do not stop taking mycophenolate sodium on your own - talk to your doctor first.
- Take this medicine at the same time each day.
- Mycophenolate sodium can be taken with or without food though it is best absorbed on an empty stomach. Be consistent with how you take your medicine each day.
- Mycophenolate sodium may cause problems if you take it with other medicines. Talk to your doctor, pharmacist, or transplant nurse before taking any other medicine, including prescription/nonprescription medications, natural products, and/or supplements.
- Your blood counts will be monitored regularly and the amount of medicine you take may have to be adjusted because of the results of your blood count.
- If you are not sure of how much medicine to take, or if you think you have any side effects, talk to your doctor.
- If you have started taking new medicine and worry it might have an effect on mycophenolate sodium, or you forgot to take your medicine and are not sure what to do, talk to your transplant clinic nurse or your pharmacist .
- Store mycophenolate sodium at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to your doctor if you do not feel well while taking mycophenolate sodium. Below is a list of side effects to be aware of:

- **Higher risk of infection:** Talk to your doctor **immediately** when you see the first signs and symptoms of infection: fever, sore throat, chills, fast pulse
- **Higher risk of developing cancer:** Report any lumps or changes in skin color and moles to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting and diarrhea:** These symptoms often happen early in treatment and should go away. **Talk to your doctor or pharmacist before taking any over-the-counter medications to treat these symptoms.**
- **Headache, light-headedness, dizziness, weakness:** If these symptoms continue, or if fainting happens, see your doctor immediately.
- **Blood problems:** mycophenolate sodium can lower red blood cells, white blood cells, and platelets (the part of the blood which helps make blood clots). This can cause fatigue, higher risk of infection, and bruising or bleeding problems. Your doctor will watch closely for these blood problems and will change the amount of medicine you take if needed. Please talk to your transplant clinic nurse, your pharmacist, or your doctor if you have any unusual fatigue, bruising, or infections.
- **If you are a woman of child bearing age:** Pregnancy should be avoided while you are taking mycophenolate sodium as it can cause harm to an unborn child. Ask your doctor or pharmacist for help in choosing the right birth control method for you. If you are planning to get pregnant, talk with the Transplant Team months beforehand as some of your medicines may need to be changed.

Prednisone

Generic name: Prednisone

Brand name: none

What is prednisone?

- Prednisone is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is taken to prevent your body from rejecting your transplanted organ.

How do I use prednisone?

- Do not stop taking prednisone on your own - talk to your doctor first.
- Prednisone can be taken with or without food.
- Prednisone may cause problems if you take it with other medicines. Talk to your doctor, pharmacist, or transplant nurse before taking any new medicines, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, talk to your transplant clinic nurse, your pharmacist, or your doctor.
- If you have started taking new medicine and worry it might have an effect on Prednisone, or you forgot to take your medicine and are not sure what to do, talk to your transplant clinic nurse, your pharmacist, or your doctor.
- Store prednisone at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to your doctor if you do not feel well while taking prednisone. Below is a list of side effects to be aware of:

- **Mood changes:** Prednisone can change your mood. Some people may become depressed, while others may feel extremely happy or energetic. Prednisone can also make psychiatric disorders worse. If you have a psychiatric illness and think it is getting out of control, or if you think you may be having mood problems, contact your healthcare professional immediately.
- **Higher risk of infection:** Talk to your doctor **immediately** if you experience any signs and symptoms of infection: such as fever, sore throat, chills, or a fast pulse.
- **High blood pressure/cholesterol:** prednisone can make your blood pressure and cholesterol levels higher. Eating well and exercising can help.
- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Fluid retention:** prednisone can make your body hold onto fluid causing edema (puffiness). If you think you are retaining fluid and becoming “puffy”, contact the Transplant Clinic.
- **Weakened bones:** prednisone can weaken bones over time and may cause osteoporosis. Make sure you have enough calcium in your diet to help cut down on the risk of this side effect.
- **High blood sugar:** prednisone can make your blood sugars higher and some people will develop diabetes. Eating well and exercising can help.

Ranitidine

Generic name: Ranitidine

Brand name: Zantac®

What is ranitidine?

- Ranitidine is a type of antacid that lowers the amount of acid the stomach makes.
- It is taken to prevent heart burn, stomach upset, and stomach ulcers.

How do I use ranitidine?

- Do not stop taking ranitidine on your own – talk to your doctor first.
- Ranitidine can be taken with or without food.
- Ranitidine can cause problems if you take it with other medicine. Speak to your doctor, pharmacist, or transplant nurse before taking any new medications, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, contact the Transplant Clinic or your pharmacist.
- If you have started taking new medicine and worry it might have an effect on ranitidine, or you forgot to take your medicine and are not sure what to do, contact the Transplant Clinic or your pharmacist.
- Store ranitidine at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Contact a healthcare professional if you do not feel well while taking ranitidine. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Blood problems:** Rarely, ranitidine can lower white blood cells and a part of the blood (platelets) which helps make blood clots. This can cause a higher risk of infection and bruising or bleeding problems. Your doctor will watch closely for these blood problems and change how much medicine you take if needed. Please report any unusual bruising, bleeding, or infections to your transplant clinic nurse, your pharmacist, or your doctor.
- **Rash:** Contact the Transplant Clinic (see contact numbers at the end) if you get a rash.

Sulfamethoxazole/Trimethoprim

Generic name: Sulfamethoxazole/Trimethoprim

Brand names: Septra®, Bactrim®, cotrimoxazole, Sulfatrim®

What is sulfamethoxazole/trimethoprim?

- Sulfamethoxazole/trimethoprim is an antibiotic which is used to treat or prevent infections caused by bacteria.
- It is taken to either treat or prevent different bacterial infections including one caused by PneumoCystis (jirovecii) Pneumonia or “PCP”.

How do I use sulfamethoxazole/trimethoprim?

- If you have an allergies to “sulfa drugs” or to sulfonamides, tell your doctor before you start taking sulfamethoxazole/trimethoprim.
- If you are glucose-6-phosphate dehydrogenase (G6PD) deficient, contact the Transplant Clinic before you start taking sulfamethoxazole/trimethoprim.
- Do not stop taking sulfamethoxazole/trimethoprim on your own – contact the Transplant Clinic first.
- Sulfamethoxazole/trimethoprim can be taken with or without food.
- Sulfamethoxazole/trimethoprim can cause problems if you take it with other medicine. Speak to your doctor, pharmacist, or transplant clinic nurse before taking any new medications, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure of how much medicine to take or if you think you may be experiencing any side effects, contact your transplant clinic nurse or pharmacist.
- If you have started taking new medication and are worried it might have an effect on sulfamethoxazole/trimethoprim or you forgot to take your medicine and are not sure what to do, contact the transplant clinic nurse or your pharmacist.
- Store sulfamethoxazole/trimethoprim at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Contact a healthcare professional if you do not feel well while taking sulfamethoxazole/trimethoprim. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medicine with food may help prevent stomach upset.
- **Blood problems:** sulfamethoxazole/trimethoprim can lower red blood cells, white blood cells, and a part of the blood (platelets) which helps make blood clots. This can cause fatigue, a higher risk of infection, and bruising or bleeding problems. Your doctor will watch closely for these problems and change the amount of medicine you take if needed. Please report any unusual fatigue, bruising, or infections to your transplant clinic nurse, your pharmacist, or your doctor.
- **Kidney problems:** Rarely, sulfamethoxazole/trimethoprim can cause kidney problems. Your doctor will watch closely for these problems and change the amount of medicine you take if needed.
- **Electrolyte problems:** sulfamethoxazole/trimethoprim can cause potassium levels to go up. Rarely, this can lead to heart problems, especially if your body has difficulties getting rid of potassium. Your doctor will watch closely for these problems change the amount of medicine you take if needed.
- **Rash:** Contact the Transplant Clinic (see contact numbers at the end) if you get a rash.

Tacrolimus

Generic names: Tacrolimus, FK506

Brand names: Advagraf®, Prograf®

What is tacrolimus?

- Tacrolimus is an immunosuppressant or anti-rejection drug that weakens the immune system in your body.
- It is taken to prevent your body from rejecting your transplanted organ.

How do I use tacrolimus?

- Do not stop taking tacrolimus on your own – contact your doctor first.
- Take tacrolimus at the same time each day.
- Tacrolimus can be taken with or without food though it is best taken on an empty stomach. Be consistent with how you take your medication each day.
- Your doctor will test your blood regularly. How much tacrolimus you take may be changed because of the results of these blood tests.
- Do not take tacrolimus before your blood tests. Bring it with you so you can take it just after your blood test is done.
- Tacrolimus can cause problems if you take it with other medications. Talk to your doctor, pharmacist, or transplant nurse before taking any drugs, including prescription/nonprescription drugs, natural products, and/or supplements.
- If you are not sure how much medicine to take, or if you think you are experiencing any side effects, contact your transplant clinic nurse or your pharmacist.
- If you have started taking any new medication and are worried it may have an effect on tacrolimus, or you forgot to take your medication and are not sure what to do, contact your transplant clinic nurse or your pharmacist.
- Store tacrolimus at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Contact a healthcare professional if you do not feel well while taking tacrolimus. Below is a list of side effects to be aware of:

- **Higher risk of infection:** Report the first signs and symptoms of infection (such as fever, sore throat, chills, or fast pulse) to your doctor **immediately**.
- **Higher risk of developing cancer:** Report any lumps or changes in skin color and moles to your doctor.
- **Stomach upset, loss of appetite, nausea, vomiting, diarrhea:** These symptoms often happen early on in treatment and should go away. **Talk to your doctor or pharmacist before taking any over-the-counter drugs to treat these symptoms.**
- **Headache, light-headedness, dizziness, weakness:** If these symptoms keep happening, or if you experience any fainting, see your doctor immediately.
- **Higher blood pressure, blood sugar, or cholesterol levels:** Your doctor will check for these possible effects. If you experience any of these symptoms, your doctor may change the amount of medicine you take to deal with these side effects.
- **Toxic effects on the kidneys:** tacrolimus can be toxic to the kidneys. It is important that you get your blood tested regularly so this side effect can be checked.
- **Slight hand trembling:** This usually depends on the amount of tacrolimus in your blood. The trembling tends to go away with time as the concentration of the dose decreases.
- **If you are a woman of child-bearing age:** Pregnancy should be avoided while you are taking tacrolimus as it may cause harm to an unborn baby. Ask your doctor or pharmacist to help you choose the right birth control for you. If you are planning to become pregnant, talk with your Transplant Team months in advance, as some of your medications may need to be changed.

Valganciclovir

Generic name: Valganciclovir

Brand name: Valcyte®

What is valganciclovir?

- Valganciclovir is an antiviral drug used to treat or prevent infections caused by viruses.
- It is taken to treat or prevent different viral infections such as one caused by Cytomegalovirus or “CMV”.

How do I use valganciclovir?

- Take valganciclovir according to your doctor’s directions.
- Do not stop taking valganciclovir on your own – talk to your doctor first.
- Valganciclovir can be taken with or without food.
- Valganciclovir may cause problems if taken with other medications. Contact your doctor, pharmacist, or transplant nurse before taking any medications, including prescription/nonprescription medications, natural products, and/or supplements.
- If you are not sure of how much medicine to take, or if you think you may be experiencing any side effects, contact your transplant clinic nurse or your pharmacist.
- If you are taking new medication and are worried it may have an effect on valganciclovir, or you forgot to take your medication and are not sure what to do, contact your transplant clinic nurse or your pharmacist.
- Store valganciclovir at room temperature away from heat, light, and moisture.

What are the side effects? (Please note this is not a complete list of all possible side effects.)

Side effects can happen with all medicines. Talk to a healthcare professional if you do not feel well while taking valganciclovir. Below is a list of side effects to be aware of:

- **Stomach upset:** Taking this medication with food may help prevent stomach upset.
- **Blood problems:** valganciclovir can lower red blood cells, white blood cells, and platelets (the part of the blood which helps make blood clots). This can cause tiredness, higher risk of infection, and bruising or bleeding problems. Your doctor will watch closely for these problems and change the amount of your medicine if needed. Please contact your transplant clinic nurse, pharmacist, or your doctor about any unusual tiredness, bruising, or infections.
- **Kidney problems:** Rarely, valganciclovir can cause kidney problems. Your doctor will watch closely for these problems and change the amount of medicine if needed.
- **Rash:** Contact the Transplant Clinic (see contact numbers at the end) or a healthcare professional if you get a rash.

Staying Healthy at Home

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Taking care of yourself

Even though you may have a working transplant at the end of one year, it may not last forever. Kidneys eventually fail. This may be after a short time (several years) or 15-20 years. Kidneys fail for many reasons. High blood pressure, not taking your medication regularly, smoking, and early rejection are some of the causes. It is important that we work together to protect your kidney.

Your anti-rejection medications increase your risk of these problems:

- You may be hungrier than usual (increased appetite).
- Diabetes. Blood sugar levels are higher than normal. This is more likely to happen to you if you ever had high blood sugars before your transplant. Insulin or pills may be needed.
- High cholesterol.
- High blood pressure. This is a very common problem after kidney transplant. If it is not treated, high blood pressure can damage your heart, blood vessels, and even your new transplant. Some people will need blood pressure pills. They all have side effects. The pills can work well for one person but may not be the best treatment for another. Your doctor will adjust and change these pills and the doses to find the right treatment for you. Always let your transplant doctor know if you have any problems which you feel are caused by your blood pressure pill. **Never stop or change blood pressure pills on your own.**
- Osteoporosis. The bones are weak and thin.
- Cancer.

A healthy lifestyle is important.

The following pages will give you some hints about how to prevent problems and how to identify them early if they happen.

Your family doctor

Your care is complex and requires the effort of many people. **Your family doctor is an important member of your health care team.**

The Clinic follows the transplant and other related medical problems. However, you must rely on your family doctor for routine care such as yearly flu shots, screening for cancer, and stopping smoking. We will keep your family doctor up to date by sending him/her a letter after each Clinic visit. It is important to see your family doctor regularly.

In the event of an emergency, call your family doctor or go to your local emergency department.

Yearly check-up

Cancer is more common after a transplant. People who have had cancer before are at greater risk and should be followed closely.

Every year you should:

- Visit your family doctor.
- Women: have a Pap smear, breast examination, and mammogram.
- Men: get checked for cancer of the testis and enlarged prostate gland.
- Have your flu shot.

Other checks

- Have your pneumovax injection every 7 years.
- Check your entire skin monthly for changes in freckles, moles, or spots. Tell your doctor if you see any changes.
- Your family doctor should investigate if you pass blood in your bowel movement.

Smoking

You should not smoke. Smoking will damage your lungs, heart, and blood vessels. The smoke from smokers is as harmful as smoking. You should avoid smoky workplaces, restaurants and other public places.

Exercise

Exercise is a very important part of a healthy lifestyle. Exercise helps you to keep or improve your overall strength and endurance. For the first 6 weeks, you should not lift any more than 10 pounds or 4.5 kilograms. Exercise also helps reduce the risk of osteoporosis and heart and blood vessel problems.

Driving

You will not be allowed to drive for 6 weeks after your surgery. It is law in all Canadian provinces to wear your seat belt while in a motor vehicle. Having a transplant is no exception to this law.

Healthy eating

It is important to eat healthy food. You should eat regular meals. Choose a variety of foods from the four food groups each day. Healthy eating can help control weight, cholesterol, high blood pressure, and high blood sugar.

After transplant, your new kidney should do all the functions of a normal kidney. This allows you to eat a less restrictive diet. You no longer need to follow a renal diet. Eat as little salt as possible. You do not need to limit dairy foods or high fibre foods, and you should eat protein in moderation. Some people may need to limit foods high in potassium but this is usually temporary.

Cholesterol has useful roles in our body but too much cholesterol can clog the arteries. Your medications can increase your cholesterol levels. If your cholesterol was elevated before surgery, it may go even higher after surgery. An elevated cholesterol level would increase your chances of having a stroke or heart attack.

It is important to eat calcium rich foods since a side effect of prednisone is an increased risk of osteoporosis. If you cannot eat enough calcium rich foods, your dietitian may suggest a pill to increase your calcium intake. This must be discussed with your doctor before you start taking them.

Your dietitian will give you information about eating salt, fat and sugar in moderation, which may help reduce your chances of developing problems. If you have already developed one or more of these, your dietitian can work with you to make changes in your diet.

The goals of the diet are:

Reach and keep a healthy weight

- Eat 3 regular meals each day. Skipping meals can lead to overeating at other meals.
- Cut back on portion sizes.
- Add less fat to your food.
- Eat **slowly** and stop when you feel full. It is okay if you do not clean your plate.
- Choose fresh fruits and vegetables as snacks.
- Shop for groceries on a full stomach. This may help you make healthier choices.

Eat less salt

- Use only a small amount of salt in cooking.
- Do not add salt at the table.
- Try using herbs, spices, and lemon juice instead of salt.
- Do not eat salty snacks.
- Do not eat pickled, cured, and smoked foods.
- Read labels. Avoid foods with salt, sodium, MSG (monosodium glutamate) near the beginning of the list of ingredients.

Eat less fat

- Use less margarine, oils and other fats.
- Choose fat low in saturates such as oil and soft margarine. Replace meat with fish 2-3 times a week. These changes reduce the saturated fat you are eating.
- Choose a variety of fish, poultry, and lean meats. Limit portion sizes. One serving = 3 oz/90g (roughly the size of a deck of cards). Two servings a day is plenty.
- Watch for hidden fat found in many bakery or grocery store items such as muffins, biscuits, cookies, crackers and frozen dinners.
- Choose lower fat dairy foods.
- Read labels carefully for fat content.

Eat more fibre

Eat whole grain breads and cereals (whole wheat, bran), as well as fresh fruit and vegetables daily. This fibre can help you feel full longer, which may help you keep a healthy weight.

Include foods like oat bran bread and cereal as well as dried peas, beans, and lentils in your diet. This fibre may help control your cholesterol.

Use **Canada's Food Guide to Healthy Eating** to help you make smart food choices. Your dietitian will give you a copy.

An additional resource is www.kidney.ca. See the link to “kidney community kitchen”.

Dental care

It is very important to keep your gums and teeth healthy. Your medications increase your risk of mouth infections.

Keep your teeth and gums healthy by:

- Brushing your teeth twice a day.
- Using a brush with soft bristles.
- Using a toothpaste with fluoride.
- Rinsing with fluoride or mouthwash.
- Flossing once a day.
- Visiting your dentist every 6 months.
- Telling your dentist about your transplant. Depending on your past medical history, antibiotics may be needed before you have any dental work. If required, your dentist can call the Transplant Clinic to ensure the appropriate antibiotic is prescribed.

Hair growth

Some medications may cause hair growth. You may wish to have some of this hair removed. Waxing and electrolysis are done in skin care centres and beauty salons.

Electrolysis removes the hair roots. This is a gradual process that leads to permanent hair removal. Waxing is a method to remove hair short term. You can get special creams from the drug store for temporary hair removal. Discuss hair removal with the nurse at the Clinic.

Eye care

Some of the pills taken to prevent rejection can cause cataracts. You should have your eyes checked each year by an eye specialist.

Sexuality

You will probably have a lot more energy after your transplant. You may resume your sexual activity whenever you feel well enough. This is usually about 6 weeks after surgery.

Some medications may decrease your sex drive. If this happens, discuss it with your doctor.

Some medications used to control high blood pressure may prevent a man from having an erection. It may be possible to change your medication.

Safe sex

Because your immune system is “turned down”, you are at a greater risk of getting an infection. It is important to protect yourself. Everyone should be concerned about sexually transmitted diseases, such as AIDS, herpes and hepatitis. These diseases are passed when body secretions are exchanged during sexual activity. Using a latex condom with contraceptive foam will decrease your risk of catching a sexually transmitted disease.

Birth control

A man should be able to father a child. Women may be infertile while on dialysis although this is not always so. Fertility increases with a functioning transplant. Women should protect against pregnancy while on dialysis and early after a transplant. You should use a double barrier method to prevent pregnancy. This involves using contraceptive foam and either condoms or a diaphragm. A woman must see a gynecologist to be fitted for a diaphragm. If you are thinking of using other methods of birth control, discuss them first with your transplant doctor. Doctors recommend that childbearing be postponed for at least 2 years after transplant. Speak with your doctor or the Clinic nurse if you are planning a pregnancy. Some of your medications may not be safe for someone who is pregnant and should be changed if a pregnancy is planned.

MedicAlert®

MedicAlert® identification could save your life in an emergency. If you have MedicAlert® identification, it needs to be updated and replaced. Make sure that you always wear your bracelet or necklace. Ask your nurse to help you fill out a MedicAlert® form. It can take up to 8 weeks for delivery.

Sunscreen and preventing skin cancer

We all need to protect our bodies from the sun's harmful rays. Your medications make your skin more sensitive to damage from the sun.

Protect yourself in the sun:

- Use a sunscreen with a SPF of 50 or greater.
- Wear a hat, a long sleeved cotton shirt and cotton pants.
- Avoid the sun between 10 a.m. and 2 p.m. This is when the sun's rays are most damaging.
- Wear UV-filtering sunglasses to protect your eyes.

Your environment

Food poisoning

Two million Canadians get food poisoning every year. Most of them recover quickly. You will have a weak immune system after your transplant. This makes food poisoning a threat to your life.

- Keep cold food cold and hot food hot.
- Avoid contact between raw and cooked food.
- Cook meat, poultry, fish, and eggs until well done.
- Do not eat raw meat, seafood, or fish dishes like steak tartar or sushi.
- Wash all fresh fruit and vegetables before cooking or eating them.
- Only buy pasteurized milk, cheese, and honey.

- Do not eat food after the “best before” date.
- Test your well water for bacteria regularly.
- Use bottled water when you are away from home.
- When in doubt, throw it out.

Personal hygiene

- Wash your hands with soap and hot water:
 - › Before and after you touch food
 - › After you use the washroom
 - › After touching an animal
 - › Many times during the day
- Brush and floss teeth at least twice a day.
- Have a bath or shower every day.
- Keep your nails trimmed and clean.

Housekeeping

- Clean your counter tops and cutting boards:
 - › Wash with hot soapy water
 - › Rinse
 - › Clean with a bleach solution. Add 2 ml (1/2 teaspoon) of bleach to 500 mls (2 cups) of water
 - › Rinse
- Do not let dust build up in your house.
- Do not use wooden cutting boards.
- Always clean your microwave oven after use.

Pets

After your transplant you have a weak immune system. Your pet could make you sick.

- Keep your pet clean and groomed.
- Have your pet on a flea control program.
- Do not touch your pet's body fluids (vomit, bowel movements, urine, and saliva). This includes kitty litter.
- Fluids should be cleaned up with a disinfectant. If possible, have someone else do this.
- Do not let a pet lick you.
- Take your pet for a check-up every year.
- Keep your pet's nails cut short.

Some animals are more likely to carry diseases. This makes them harmful to you.

Stay away from:

- Stray or wild animals
- Animals with diarrhea
- Sick animals
- Exotic animals, including monkeys and turtles

West Nile Virus

West Nile Virus is a mosquito-borne virus that can cause swelling in the brain and the lining of the brain or the spinal cord in humans and animals.

The exact risk for severe disease by this virus in immunosuppressed persons, such as organ transplant recipients, is not known. It may be higher than in the general population.

West Nile Virus is almost always spread to humans, birds, and other animals through the bite of an infected mosquito.

In areas where West Nile has been detected, only a small proportion of the mosquitos are likely to be infected. Most people bitten by an infected mosquito do not get sick. Less than 1% of the people who are infected will become seriously ill. For those who are seriously ill, one in 10 may die.

Symptoms

They generally appear about 3-14 days after exposure.

Mild symptoms: slight fever, headache, body ache, swollen glands, sometimes a skin rash.

Severe symptoms: high fever, intense headache, stiff neck, and confusion.

Prevent West Nile Virus by getting rid of breeding areas around your home.

Control mosquitoes from breeding

- Turn over or remove containers in your yard where rainwater collects (such as potted plant trays, buckets, or toys).
- Change the water in bird baths twice a week.
- Remove old unused items like tires from your yard.
- Empty wading pools, pet bowls, and livestock watering tanks regularly.
- Clean out eaves troughs and get rid of standing water on flat roofs.
- Do not let water collect in garbage cans.

Protect yourself and your family

- Wear long-sleeved, loose and light coloured shirts, pants, socks, and a hat when mosquitoes are active.
- If possible, stay indoors at dusk and dawn when mosquitoes are biting.
- Make sure that your door and window screens fit tightly and have no holes. Do not leave non-screened doors and windows open.
- Use insect repellent with the smallest percentage of DEET that protects for the length of time you are exposed to mosquitoes, but no more than 50% for adults and 10% for children under 12.
- Only adults should apply repellent on children.
- Spray repellent on your hand and then apply to your face.
- Only apply repellent to exposed skin and clothing. Do not use repellent under clothing.
- Do not apply repellent over cuts, wounds, sunburn, or irritated skin.

For more information

Dead crows, ravens, or jays should be reported to the Nova Scotia Department of Natural Resources in your area. The Department of Natural Resources will assess whether the bird can be used for testing. They will tell you how to safely dispose of the bird if it cannot be tested.

Returning to work

Discuss returning to work with your transplant doctor. He/she will suggest the best time for you to go back to work based on the physical demands of your job, your age, and job stress. Your body needs time to fully recover. Usually, you can return to work 3 months after you leave the hospital. At that time, you are less likely to have a rejection episode. You will also need to make fewer Clinic visits.

Answering machine or voicemail service

Once you return home and become more active, it may be helpful to have an answering machine or a voicemail service. This will greatly help the Clinic staff get in contact with you about any medication changes or share other information with you.

Travelling

You can travel safely after your transplant. It has to be planned well. Always discuss your travel plans with the Transplant Clinic nurse or doctor.

- Do not leave Canada for 6 months after your transplant. After this time, travelling should become easier as you will need to make fewer Clinic visits and need less frequent medication adjustments.
- Always buy cancellation insurance.
- Always buy health insurance if you are going outside the country.
- Ask your Clinic for a travel letter.
- Always carry your medications with you. Do not put your medications in your checked baggage.
- Take at least an extra 2-day supply of medication with you in case you are delayed.
- Ask your travel agent if there are any special medical concerns about the country you plan to visit.
- Relax and enjoy your vacation.

Sources of support

During the first few months, a common feeling is the desire to get back into the routine you had before you became ill. However, this has to be done slowly. Your body needs time to get back in shape.

If you were sick for a while before your transplant, there may have been many changes in your lifestyle.

Your partner or other family member or friends may have had to take on jobs or tasks that you were unable to do. It may take a period of adjustment for everyone to sort out new jobs and responsibilities.

If there are complications after transplant, you may feel you have just changed one set of problems for another. You may develop feelings of “why me?” or believe nothing in your life is going right. This is especially true if you see other transplant patients who seem to be doing well. The Transplant Team will try to help you deal with these issues and help you find support.

Social work services

The social worker at your hospital can also help you locate other resources in your area.

Peer support

The Kidney Foundation offers a Peer Support Program, Kidney Connect. If you want to talk to someone who has also had a transplant, call 1-866-390-PEER (7337) or visit www.kidney.ca.

Transplant Clinic telephone numbers

Cape Breton Regional Hospital
Sydney, NS
902-567-8067

Chaleur Regional Hospital
Bathurst, NB
506-544-3598

Dr. George Dumont Hospital
Moncton, NB
506-862-3707
506-862-4133

Health Care Corporation of Saint John's
Waterford Site
St. John's, NL
709-777-3663
709-777-3985

Queen Elizabeth II Health Sciences
Centre - Victoria General site
Halifax, NS
902-473-4190

Queen Elizabeth Hospital
Charlottetown, PEI
902-894-0019

Saint John Regional Hospital
Saint John, NB
506-648-6850

Western Memorial
Cornerbrook, NL
709-637-5396

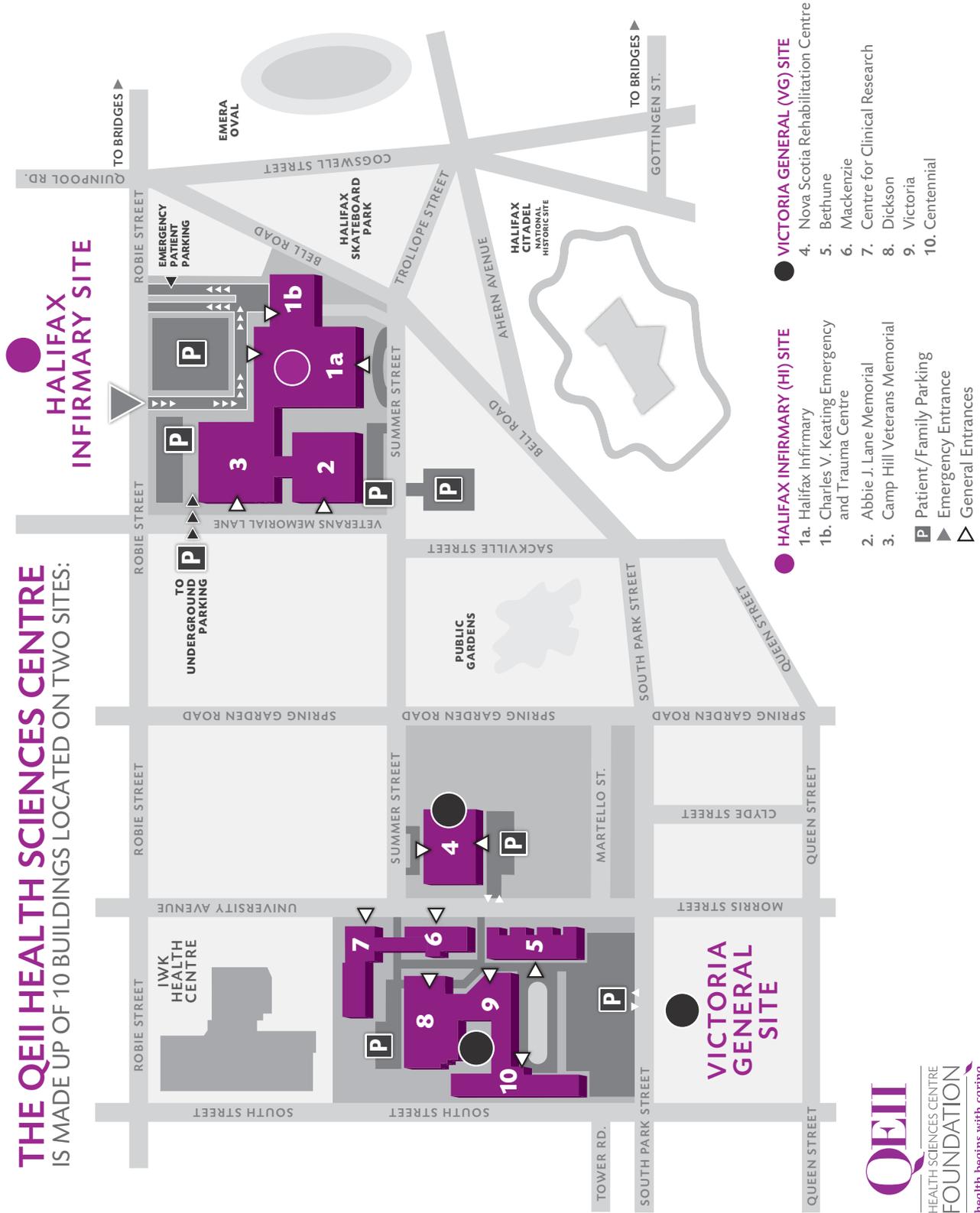
Websites:

Multi Organ Transplant Program (MOTP)
www.motphalifax.net

The Kidney Foundation of Canada
www.kidney.ca

Queen Elizabeth II Health Sciences Centre map

THE QEII HEALTH SCIENCES CENTRE
IS MADE UP OF 10 BUILDINGS LOCATED ON TWO SITES:



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