Patient & Family Guide

2022

Your Kidney Transplant

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Your Kidney Transplant

This guide will help you learn about what will happen before, during, and after your kidney transplant.

The transplant process can be long and challenging. You, your family, and your support person(s) are an important part of this process.

Remember: A kidney transplant 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 are here to help you.

Important phone numbers

Your primary health care provider and other members of your health care team are here to answer your questions.

Primary health care provider: ______________________________

Hospital: ______________________________

Pharmacy: ______________________________

Emergency contact: ______________________________

Queen Elizabeth II (QEII) Health Sciences Centre, Victoria General Site, Halifax

- Transplant Coordinator: 902-473-2609
- Transplant Clinic: 902-473-4190
- Transplant Social Worker: 902-473-5180
- QEII switchboard: 902-473-2222
  - **(If it is after hours, ask for the kidney transplant doctor on call.)**
- QEII Outpatient Pharmacy: 902-473-7986
- Transplant Unit Manager/Transplant Clinic Manager: 902-473-7008
- Patient Representative: 902-473-2133

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Your Kidney Transplant

Having a kidney transplant is a treatment for kidney failure. Kidney failure is also known as Chronic Kidney Disease (CKD). A healthy kidney from one person (the donor) is placed (transplanted) into another person (the recipient). Treatment is usually very successful.

Remember: A kidney transplant is a treatment, not a cure. You must take medication for the rest of your life.

Some people find waiting for a transplant very stressful. Your health care team is here to help you and your family before, during, and after your transplant.

Together with your Transplant Team, you will decide whether a kidney transplant is right for you.

How to use this guide

- **Review this guide before and after your surgery.** There is a lot of information in this guide — you will not be able to remember it all. This is OK.
- **Bring this guide with you when you are admitted for your transplant.**
- **Your health care team will go over the information in this guide with you.** If you have any questions or concerns, please contact your Transplant Team.

Words to know

Antibody: A protein made by the body when a foreign substance (antigen) invades the body. These proteins help fight the foreign substance.

Antigen: A foreign substance not normally present in the body. When it does get in, your body responds by making antibodies to destroy it. Kidneys are more successfully transplanted between 2 people if they do not have any antibodies against their donor antigen.

Human Leukocyte Antigens (HLA): Proteins often found on white blood cells. HLA helps your immune system find healthy body tissue and foreign substances that may cause infection. Each person has unique HLA, so possible organ donors and recipients must be tested to see if their HLA match.

Catheter: A thin, hollow tube used to carry fluids to or from your body.

Creatinine: A waste product found in blood and urine (pee). High levels of creatinine mean that your kidneys are not working well.

Cross match for transplant (tissue typing): A blood test to find out if your body will accept a kidney. Your blood is mixed with the donor's blood. If your blood destroys the donor's blood cells, the cross match is positive and you would reject this kidney. If your blood does not destroy the donor's blood cells, the cross match is negative and the chances of rejection are much lower.

Deceased donor: A person who has died in the intensive care unit (ICU) and whose family has donated their organs for transplantation.

Delayed graft function/acute tubular necrosis (ATN): This is when the kidney does not work right away. It may take several days or a few weeks before the kidney starts to work. You may need dialysis until the kidney starts to work.

Expanded criteria donors (ECD): Older donors or donors with medical problems (like high blood pressure or diabetes).

Graft: The transplanted kidney.

Immune system: A network of cells and tissues (spleen, lymph glands) that fight foreign substances like viruses, bacteria, or someone else's organ.

Immunosuppressive medication: Medication used to lower your body's immune system. Also called anti-rejection medication.

Live donor: A living person who donates a kidney for transplantation. A donor may be related by blood (a relative) or not related by blood, but emotionally connected (like a friend or spouse).

Lymphocele: After surgery, fluid may collect near the kidney. It can become large enough to block the ureter (tube that connects the kidney to the bladder) and prevent urine from flowing to the bladder. The fluid may need to be drained.

NAT testing: A test done on the donor's blood to check if they are positive or negative for infectious diseases. This test makes sure the donor has no infectious diseases before transplant, to ensure the transplantation is safe for the recipient.

Obstruction: When the ureter becomes blocked or kinked and urine is not able to flow from the kidney to the bladder.

Rejection: The body's immune system identifies the transplanted organ as foreign and tries to destroy it (see 'Rejection and infection' on page 33).

Renal scan: This test measures blood flow to the kidney, how well the kidney is working, and drainage of urine to the bladder. A small amount of radioactive substance is injected with a needle into a vein in your arm. A scanner (large metal device) placed over your kidney tracks the movement of the substance.

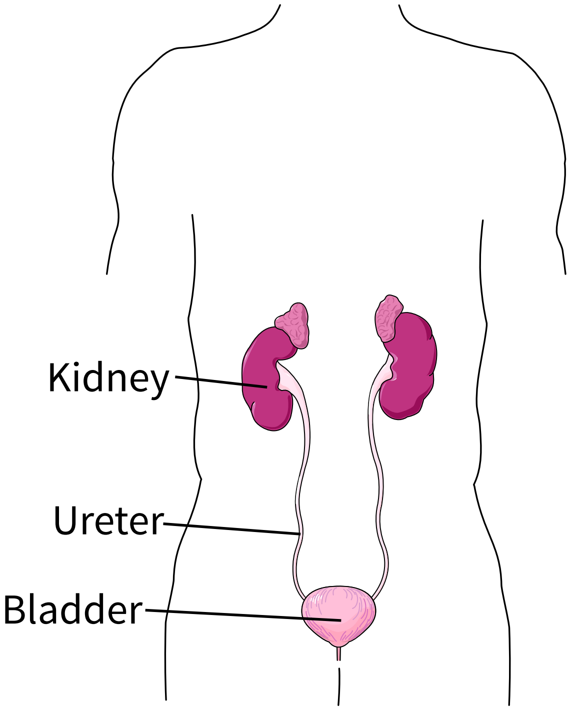
Renal biopsy: A needle is used to freeze your new kidney. Then a long thin needle is used to remove a small piece of tissue. This test lets your health care team check how the kidney is working or find out why it is not working.

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.

Kidney disease

Why do I need a kidney transplant?

- Many diseases can cause the kidneys to fail (stop working as they should).
- Some of these diseases are:
  - Diabetes
  - Glomerulonephritis
  - High blood pressure
  - Polycystic kidney disease
  - Infection
  - An obstruction (blockage) in the urinary tract



If you do not know why your kidneys failed, ask your primary health care provider.

For more information:

The Kidney Foundation of Canada

- www.kidney.ca

Risks and benefits of receiving a kidney transplant

When you are deciding if you want to have a kidney transplant, you should think about the benefits and risks of surgery and dialysis. You are only ready to decide after you have talked about all of the options with your primary health care provider and family/support person(s).

What are the benefits of a transplant?

Do not need dialysis

If you have a working transplant, you will not need dialysis. After transplant, 1 out of 10 kidney transplants do not work right away. This is because of the shock of moving the kidney from one person to another. This is called acute tubular necrosis (ATN). You may need dialysis while the kidney recovers.

Better quality of life

Having a working kidney transplant will give you more energy and a better appetite.

Live longer

Some people with functioning transplants may live longer than if they had stayed on dialysis. **This is not true for everyone.** About 4% of people who receive a transplant will die within the first year. This may be due to pre-existing medical problems (problems you had before the transplant), but may also be due to immunosuppression medication.

What are the risks of a transplant?

Surgery

The surgery itself is a risk. This risk is different for each person, based on their health. Your transplant team will talk with you about these risks based on your situation.

Rejection

- About 1 in 3 recipients 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.
- Even someone who is quite healthy may have a severe (very bad) rejection episode.
- Sometimes kidney transplants do not work right away.

Loss of kidney

- A kidney can be lost from chronic (ongoing) rejection.
- The disease that caused the original kidney problem may come back.
- Kidneys are often lost if medications are not taken properly.
- It can be emotionally hard to return to dialysis if your kidney fails.

You will need medications to prevent rejection after your transplant.

- To make sure your kidney lasts as long as possible, you must not miss any clinic visits and always take your immunosuppression medications. Some common side effects of these medications are:
  - High risk of heart disease, diabetes, high blood pressure, and high cholesterol levels
  - Prednisone may cause diabetes, high blood pressure, and high cholesterol levels. One (1) in 10 people receiving a transplant will develop diabetes. This happens more often in older people. If this happens, you may need insulin injections.
  - Higher risk of infection
  - Higher risk of skin cancer. You can lower this risk by staying out of the sun, using sunscreen, and wearing protective clothing.
  - Higher risk of lung and bone cancers
  - Cataracts, hair growth, liver inflammation (swelling), and other problems
  - Changes in mood

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

What are the benefits of dialysis?

Staying on dialysis may be the safest choice if you have serious heart, lung, or liver disease or infections that cannot be cured. The anti-rejection medications needed after a transplant can make cancer or infections worse.

What are the risks of dialysis?

Very high risk of heart disease

This may be caused by years of having high blood pressure, high cholesterol levels, and other problems that happen with chronic kidney failure.

Some people on dialysis have low blood counts.

You may need medication (Aranesp®), iron, or a blood transfusion.

- Blood transfusions are safer now than in the past, but there is still a very small risk of getting a virus.
- Blood transfusions can also increase your risk of developing antibodies.

Complications from hemodialysis and peritoneal dialysis are different.

  - › With hemodialysis, there is a high risk of infection in the bloodstream.
  - › With peritoneal dialysis, there is a risk of infection in the abdomen (stomach area).

These problems are rare for someone with a functioning transplant.

You must think carefully about the risks and benefits before deciding if you want a kidney transplant. Talk with your doctor, and family/support person(s) to decide what treatment is right for you.

Your health care team

- **You** and your **family/support person(s)** are the most important members of your health care team.
- There are also many other members of the team who will be involved in your care.
- Your **nephrologist** (kidney doctor) and **transplant surgeon** will work together to direct your care before and after your transplant. Before your surgery, you will meet with your nephrologist. After your surgery, you may meet with your nephrologist or transplant surgeon at the Transplant Clinic.
- Your **transplant coordinator** will be your point of contact:
  - When you are referred for kidney transplant, they will provide education and organize your testing before you are listed for kidney transplant.
  - When you are listed for kidney transplant, they will keep monitoring your health, arrange for updated testing, and keep your file up to date until your transplant.
- Your **primary health care provider** (family doctor or nurse practitioner) gives routine care (like your flu shot, cancer screening, and support to stop smoking). The Transplant Clinic follows your transplant and related medical problems. We will keep your primary health care provider up to date by sending them a letter after each of your Clinic visits. **It is important to see your primary health care provider regularly.**
- Other **specialists** (like infectious disease, cardiologist [heart doctor], dermatologist [skin doctor], and others) may be asked to help with your assessment and treatment if there are problems.
- **Nurses on the inpatient unit** will help you get ready 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.
- A **transplant fellow** is a specialist in training who helps the surgeons and nephrologists in your care after transplant.

- **Nurses in the Transplant Clinic** will help care for you after you leave the hospital.
    - If you are from mainland Nova Scotia, the Transplant Clinic nurses will continue to follow you for the life of your kidney.
    - If you are from Cape Breton, New Brunswick (NB), or Newfoundland and Labrador (NL), you will be followed by a transplant clinic close to you for the life of your kidney.
    - For patients from PEI and NB, **liaison nurses** may assist in coordinating your care, such as transportation.
- **Research nurses** follow patients who have chosen to take part in a research study. They are available 24 hours a day to answer your questions about the study.
- A **social worker** can help you and your family adjust to the changes in your lifestyle. They will counsel and support you and your family, as needed. They can also help you connect with other resources in the community. You can talk to a social worker at any time. If you would like to talk to a social worker, please tell your transplant team.
- Your **dietitian** will help you make an eating plan before and after your transplant. After surgery, the dietitian will follow up with you in the Transplant Clinic.
- **Spiritual care providers** are available to help you with your spiritual needs. You and your family can talk to someone at any time during your hospital stay. There is always someone on call. Tell your nurse if you would like to talk with a Spiritual Care provider.
- You may need to work with a **physiotherapist** to improve your strength and flexibility.
- The **patient representative** works with all departments on your behalf. They can help you with any concerns or questions you may have that are not answered by other staff members.

Getting on the kidney transplant wait list

When your nephrologist refers you for a kidney transplant, you will have education and tests to see if you are a candidate for a kidney transplant. These tests may include checking to make sure your heart and lungs are safe for surgery, and ruling out cancer and infections. How long this process takes will depend on your age and medical history. Your transplant coordinator will help you through this process.

How do I get added to the transplant wait list?

- **If you have cancer, some types of kidney disease, heart disease, or other medical conditions, a transplant may be too high risk for you.**
- To be placed on the kidney transplant wait list, you will need a letter from your nephrologist.
- **You will need a number of tests before you can be placed on the wait list.**
    - A chest X-ray
    - Electrocardiogram (ECG/EKG)
    - Urine test to check for infection
    - Tuberculin (TB) skin test
    - Abdominal ultrasound and CT scan
    - Dental check-up

Blood tests you may need:

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.** If your blood group does not match with your live donor, you will be entered into the Kidney Paired Donation program instead.

Viruses

We check for hepatitis, cytomegalovirus (CMV), Epstein-Barr virus (mono), and HIV to help us plan the best care for you. You will have blood tests every 6 months to 1 year to check if you are negative or non-immune.

Tissue typing

Human leukocyte antigens (HLA) are bits of genetic material that we inherit (are passed down) from our parents. We get half from our mother and the other half from our father. This test lets us compare your antigens with a donor's antigens.

Cytotoxic antibodies

- We measure the antibodies in your blood. You may have antibodies if you had a blood transfusion, a previous transplant, or have ever been pregnant. Antibodies could cause you to reject a kidney from certain donors.
- A person with high antibodies is harder to match. If you have high antibodies, you may have to wait longer for a kidney than someone who does not have any antibodies. There is a national registry for patients with high antibody levels.

Highly Sensitized Patient Program (HSP)

- The Highly Sensitized Patient Program (HSP) was developed by Canadian Blood Services. It includes organ transplant programs across Canada.
- Highly sensitized patients have antibodies to 95% or more of the general population. HSP increases kidney transplant opportunities for patients needing a very specific donor match.
- When a deceased donor anywhere in Canada has 2 eligible kidneys, 1 kidney gets offered to the HSP program. The HSP will try to find a match with a recipient across Canada.

Other tests you may need:

- Pap test or prostate exam
- Mammogram if you are over age 50 or have a family history of breast cancer
- Stool (poop) occult blood test if you are over age 50
  - People living in Nova Scotia should do their own test. It is automatically sent by mail as part of colorectal cancer screening guidelines.
- Glucose tolerance test (if you are not diabetic)

Tests you may need if you have cardiovascular (heart) disease and/or diabetes:

Heart disease can cause major problems at the time of a transplant. **If you have irreversible (cannot be repaired) heart disease, you cannot have a kidney transplant.**

- **Exercise stress test:** An exercise stress test is a special type of ECG/EKG that compares your heart's electrical activity at rest and when working hard. The test is painless. An ECG/EKG is done while you exercise in a controlled environment.
- **Dobutamine stress test:** This type of stress test is done if you are not able to exercise. It helps your primary health care provider measure how your heart reacts to exertion. You will be given a drug that causes your 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 your heart's size, shape, movement, and blood flow. Sound waves (ultrasound) are used to get a picture of the heart which is then viewed on a monitor. The pictures are saved for the doctor to study later. The doctor can check your 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. You may need a cardiac catheterization 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 that lead to your heart. If the vessels are narrowed, they can sometimes be opened up by surgery (like angioplasty or cardiac bypass surgery).

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

After the tests and education are finished, your chart will be reviewed by the transplant committee. The Transplant Team will talk with you about your test results. Together, you will decide the best treatment for you.

After these tests are done, your information will be reviewed by our transplant team. If you are approved for transplant surgery, you will be added to the transplant wait list.

Types of kidney transplants

Deceased (not living) donor

- This kidney is from someone who has died in the intensive care unit (ICU) and whose family has donated their kidney. The donor's death is usually from an injury or stroke. Donation is only considered after all life-saving methods have been tried.
- On average, a kidney from a deceased donor lasts about 10 years. This is hard to predict.

Live donor

- The donor is usually a family member, spouse, or close friend who wishes to donate their kidney.
- On average, a kidney from a live donor lasts about 10 to 15 years. This is hard to predict.

How does a live donation work?

- A possible live donor must be in very good health and offer to donate 1 of their kidneys. As with any major surgery, there is a risk in donating a kidney.
- **The donation should be voluntary — there should not be any feelings of pressure or guilt.**
- If someone is interested in donating a kidney, they should call the live donor coordinator to start the process (see page 68).
- They will need several blood tests to check if their blood is compatible (matches) with yours. A cross match (tissue typing) will be done to see if your body will likely accept the new kidney. If these tests show that the possible donor may be compatible, the live donor coordinator will contact them.
- They will need a complete medical check-up and many other tests to make sure they are in very good health.
- The surgeon and nephrologist will carefully review the results of these tests. They will work with you to decide what is best for you.
- If they decide it is safe to go ahead with the kidney transplantation, we will try to arrange your surgery at a time that is best for both you and the donor.

Kidney Paired Donation program

There is a national registry to help match a donor who is compatible with you with another donor anywhere in the country. Please see the pamphlet provided or visit:

  - www.blood.ca/en/organs-tissues/living-organ-donation/kidney-paired-donation

What to do while you wait for a kidney transplant

You are now on the kidney transplant wait list.

- Talk with your family/support person(s) about having a kidney transplant. They can help you decide whether or not it is right for you.
- Once you are added to the wait list, you can expect to wait for 2 to 3 years (on average). If you are already on dialysis, your wait time starts to accumulate (add up) from your dialysis start date.
- You may have many different emotions during this time. For many, this time can be hard.
  - You may feel excited and hopeful that you will get your new kidney quickly.
  - At times, you may be filled with doubts that you will ever get a new kidney.
  - At times, you may feel guilty about taking someone else’s kidney, especially if it depends on someone else dying.

  These feelings are normal.

How does the wait list work?

- The database matches donors with people on the wait list. After you are added to the transplant wait list, you are listed as ‘active’ in the database.
- The database helps to choose the right person for a transplant, but the nephrologist and surgeon make the final decision. Deciding who will receive a kidney is based on many things, including:
  - A negative cross match between you and the donor
  - How well your tissue typing matches with the donor’s
  - How long you have been on the wait list
- **Your place on the wait list is based on your first dialysis treatment.** If you are not on dialysis, you can only store up to 90 days (3 months) of wait time until you start dialysis.

What if I have a live donor?

If you have been approved for transplant by the Transplant Team and your live donor has started their tests, you will be listed as ‘live’ (for live donor) in the database. You will also be marked ‘not active’, since you already have a donor. Only patients who still need a donor are marked ‘active’ in the database.

Being placed on hold

You may be placed on hold if:

- You have an infection and need antibiotics. For example, if you have peritonitis (swelling of the stomach lining tissue), you will be put on hold until the infection is gone.
- You are waiting for other surgery.
- You have had a heart attack in the last 6 months.

Being placed on hold is temporary. If you are only on hold for a short time, you will still accumulate (add) time on the wait list. When you are better, your status will be changed in the database, and you will be matched against donors again.

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

How much does it cost to have a transplant?

While you are waiting for a donor match, it is important to get ready for the costs related to having a transplant (like medications, travel, a place to stay, and more).

Worries like these can cause stress and take away from the joy of the transplant experience.

Getting ready now means less stress for you and your loved ones later. Many people say, “I never thought it would happen, so I never prepared.”

Do not be caught off guard when you receive “the call” from the transplant coordinator.

Some of the costs you can expect before and after your transplant include: Medications

- You are responsible for all medication costs after discharge from the 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 provincial drug plan, some of the medications needed after discharge may be covered.
- If you have a private insurance plan, check to see if your medications are covered. If so, you may have to pay part of the cost and your part of the co-payment. It is possible that the medications are covered only for certain health problems.
- Your primary health care provider may need to complete a special authorization or “exception status” form before you will know if your plan will cover the medications.

Nova Scotia

- All Nova Scotia Pharmacare Programs cover the same medications. The amount you will have to pay depends on the type of program you have.
- To register for Nova Scotia Pharmacare:
  - › Phone (toll-free): 1-877-330-0323
  - › www.nspharmacare.ca

New Brunswick and PEI

- New Brunswick and PEI have provincial Pharmacare programs. Liaison nurses or a social worker can give you information about these programs and help you apply.
  - › **New Brunswick:** https://library.nshealth.ca/NB-PDP
  - › **PEI:** https://library.nshealth.ca/PEI-Pharmacare

Newfoundland

- If you have Newfoundland Prescription drug coverage, bring your medications with you.
- Newfoundland patients will be paid back for part of their medical travel expenses through the Medical Transportation Assistance Program.
  - › Phone (toll-free): 1-877-475-2412
  - › www.gov.nl.ca/exec/las/medical-transportation-assistance-program-mtap/

Accommodations

- If you do not live in Halifax, you may need a place to stay after your surgery.
- If you are from outside of Nova Scotia or live more than 50 km (one way) from the Victoria General Hospital, you may be able to stay at Offsite Patient Accommodations. Your transplant coordinator will talk with you about this.
    - › If you meet the criteria to stay in Offsite Patient Accommodations, a subsidy will be offered to help cover the cost of meals.
    - › If you do not meet the criteria, your transplant coordinator will suggest places to stay that offer discounted rates for patients and their families.
- If you are required to stay in Halifax for follow-up after your transplant, all costs will be covered. The post-transplant nurses will talk with you about this, if needed.

Newfoundland

Newfoundland does not offer preapproval of costs for health care outside of the hospital. You must keep a record of all medical, accommodation, and food expenses while you are in Nova Scotia for reimbursement when you return to Newfoundland.

Travel

You are responsible for all travel costs to and from the hospital before and after your surgery.

Loss of income

- You and your family may experience a loss of income when you have your surgery. Your recovery will also take time. Look into options such as sick leave and Employment Insurance to help cover the costs.
- Some patients receive financial support from fundraising.
- The transplant social worker can help you with supports you may need during your transplant and recovery, if needed.
- **We strongly encourage you to set money aside in advance. Please prepare for your transplant even if you think it will never happen.**

If you would like to talk with a social worker:

- › Tell your transplant coordinator.

OR

- › Contact your social worker.

Your responsibilities

While on the transplant wait list, there are some things you must do:

Every month:

- Blood test for antibodies: **If we do not have a fresh tube of blood, you may miss your chance for a transplant.**

Every 6 months:

- Blood test for cytomegalovirus (CMV), hepatitis B, hepatitis C , and Epstein-Barr Virus (EBV)

Every year:

- Blood test for HIV
- If you have a prostate, blood test for prostate health (PSA levels) if you are over age 50
- You may require a mammogram if you are over age 50 or have a family history of breast cancer
- Cardiac (heart) check-up (ECG/EKG and chest X-ray)

Other tests

- If you have internal female organs, you may require a Pap test.

Your transplant coordinator or nurse will tell you when you need these tests.

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

If you are on hemodialysis, the dialysis clinic will do your blood tests. If you are not on dialysis or are on home dialysis, you will be given requisition forms for blood tests. **If you lose your requisition form, please contact your transplant coordinator.**

Keep your health care 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, like an infection or pneumonia (lung infection).
- plan to move, take a trip, or change your phone number. **The transplant coordinator must know how to reach you within a few hours when a kidney becomes available. Keep your coordinator updated!**

- See clinic phone numbers on page 67.

Stay as healthy as possible.

Getting on the wait list is only the first step. To stay on the list, you must try to stay as well as possible. While waiting for a donor match, remember to follow the advice of your health care team. You can get a match at any time, so it is important to be ready!

Important:

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

What to expect when you get called for a kidney

When a kidney becomes available

When a kidney becomes available, the transplant coordinator will call you. They only have a few hours to find you and **will not give up on the first try**. If you cannot be reached at the first phone number, they will try the other numbers you have given.

It is very important to keep your transplant coordinator updated about where you are and any changes in your address or phone number.

The transplant coordinator cannot give you specific details about the donor, but they will tell you the following:

- **If the deceased donor is a DCD:** This means donation after cardiac (heart) death. This is a donor who has irreversible (cannot be fixed) brain injury and may be near death, but does not meet the formal criteria of brain death. There is a 50% chance that DCD donations **<u>may not</u>** go through, as the donor must pass away within a certain time after care is withdrawn in order for their organs to be healthy enough for transplant.
- **If the deceased donor is an NDD:** This means neurological determination of death. This is a donor who has permanently lost all function as a result of a severe brain injury or irreversible trauma.

If the donor is Exceptional Distribution or an Increased Risk Donor

What is an Increased Risk Donor (IRD) organ?

- This is an organ from a donor who identifies certain lifestyle behaviours that are at a higher risk of transmitting infectious diseases to transplant recipients. Although these donors may test negative for infections, they may still be at risk of spreading Human Immunodeficiency Virus (HIV), Hepatitis C Virus (HCV), and Hepatitis B Virus (HBV) to transplant patients.
- Some risks are higher than others. Health Canada has listed the criteria which identify a donor as being at a higher risk to you. These criteria are associated with lifestyle behaviours which have been shown to have a higher risk of passing on infectious diseases, including HIV, Hepatitis C, and Hepatitis B.
- If you are offered an organ from a deceased donor, the health care team will tell you if it is an increased risk organ.

What are some of the things that make a donor an Increased Risk Donor?

There are several things that can lead to a donor being called IRD. Some of the common criteria include:

  - › A person with current or recent IV drug use
  - › A person who has recently been in a youth correctional facility, jail, or prison
  - › A person who has had recent, high-risk sexual activity
  - › A person who has been exposed to someone with high-risk behaviours

Why would I think about accepting an organ from an Increased Risk Donor?

- Deciding to accept an organ from an IRD may increase your chance of getting a transplant. Keep in mind:
  - › There are never enough organs available that can be used for transplant.
  - › The number of Atlantic Canadians waiting for life-saving organ transplants is increasing.
  - › The waiting time for an organ transplant can be up to several years, depending on the organ. It is possible that you will not get another offer if you become too sick to stay on the wait list or if you die while you are waiting.
  - › The infection can be cured.

How will I know if I develop an infection?

- If you decide to accept the organ, you will be monitored after your transplant to make sure that you did not get an infection.
- In the unlikely case that you do get an infection, treatments are available. The infectious disease doctors will treat you, if needed.

Who decides if I should accept an organ from an Increased Risk Donor?

- It is up to **you** to decide whether or not to accept any organ. The right choice for you will depend on your health. Your health care team will talk about this with you.
- The best choice for you may change if your health changes. If you have questions, talk with a member of your health care team while you are waiting for your transplant.

If I do not agree to accept an organ from an Increased Risk Donor, will it hurt my chances of getting another organ?

No. It is up to you to decide whether or not to accept the organ. If you decide NOT to accept the organ, you will NOT lose your place on the waiting list.

If there is a Hepatitis C Virus Viremic Donor

It is important to understand the risks and benefits associated with a Hepatitis C Virus Viremic Donor.

What is Hepatitis C Virus (HCV)?

- HCV is a virus that infects about 1 in 100 Canadians. Most people have no symptoms, but about 1 in 4 go on to develop cirrhosis (scar tissue replaces healthy liver tissue, which stops the liver from working normally) or liver cancer over 20 to 30 years.
- In the past, there was no treatment for HCV. Some people eventually died from complications, or they received a liver transplant. Now HCV can be cured with medication.
- We test all donors for HCV. Until recently, donated organs from infected patients were either not used or were transplanted into patients with HCV infection.

How well do kidneys from HCV positive (viremic) donors function?

- Organs from HCV positive donors are often of excellent quality. The organs are screened to check for damage. We do not use damaged organs.
- An organ is defined as viremic if it is positive for the NAT test (see page 3).
- If an HCV infected organ is used, you must take medication to get rid of the virus.

How is HCV treated?

- HCV is treated with medications called Direct Acting Antivirals (DAAs). These are pills that act on the virus to get rid of it from your body. These medications work to get rid of the virus in 99 out of 100 people.
- If the DAAs do not work, there are other medications available. These medications work 998 times out of 1000.
- You will need to take one (1) pill a day for 4 to 12 weeks. This will depend on the organ that was used.
- This treatment is well tolerated. Side effects may include nausea, diarrhea fatigue, or rash. This can happen in up to 1 out of 20 people.

How much does the treatment cost?

- The treatment is expensive. If you are considering accepting an HCV infected organ, a transplant pharmacist or a social worker will review the possible costs with you.
- If you need help paying for the treatment, a pharmacist and/or a social worker will work with you and your insurance provider to come up with a solution.

Why would I think about accepting an organ from an HCV infected donor?

Deciding to accept an organ from an HCV infected donor may increase your chance of getting a transplant. Keep in mind:

  - There are never enough organs available that can be used for transplant.
  - The number of Atlantic Canadians waiting for life-saving organ transplants are increasing.
  - The waiting time for an organ transplant can be up to several years, depending on the organ. It is possible that you will not get another offer if you become too sick to stay on the wait list or if you die while you are waiting.
  - The infection can be cured.

Who decides if I should accept an organ from an HCV infected donor?

- It is up to **you** to decide whether or not to accept any organ. The right choice for you will depend on your health. Your health care team will talk about this with you.
- The best choice for you may change if your health changes. If you have questions, talk with a member of your health care team while you are waiting for your transplant.

If I do not agree to accept an organ from an HCV infected donor, will it hurt my chances of getting another organ?

No. It is up to you to decide whether or not to accept the organ. If you decide NOT to accept the organ, you will NOT lose your place on the waiting list.

Your coordinator must ask you some important questions before the transplant can be planned. They will ask:

- Are you in good health?
- Do you have an infection?
  - **If you are not well, be honest with yourself and the team. It can be very dangerous to receive a transplant when you have an infection.**
- How will you get to the hospital?
- When do you expect to arrive at the hospital?
- When was your last dialysis treatment?
- Have you had a blood transfusion lately?
  - If you have had a recent transfusion, tell us as soon as possible. The transfusion may have caused you to develop new antibodies. If you have a transplant, these antibodies may attack your transplanted kidney. We will keep track of your antibody levels. If you developed new antibodies, that is OK. It may just take more time to find the right kidney for you.

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We will give you time to collect your thoughts and make travel plans.

You may be worried about being able to respond properly when you get the call. You may worry that you will freeze up or be too excited or anxious to do what needs to be done.

Although many people feel this way, it has never happened. You are likely to feel excited and relieved that a donor has been found. You may feel sad for the donor's family and anxious about the surgery.

Your main task is to get to the hospital safely.

Important

Be sure to bring these items with you to the Transplant Unit:

- Provincial health care card
- All of your medications (including insulin, if needed)
- Blood glucose monitor and strips, if needed
- CPAP machine, if needed
- Fluid for one dialysis exchange
- This guide

Your family

- You may bring a support person to the Transplant Unit. After the surgery, your family can visit you, but **they cannot sleep in your room or in the family room**. They will need to find a place to stay overnight while you are admitted to the hospital.

Remember: Your family is responsible for the cost of accommodations.
The following places are close to the Victoria General (VG) Site and/or have reasonable rates.

- Point Pleasant Lodge, 1121 South Park Street: 902-421-1599
  - There is a shuttle service to the VG Site.
- The Westin Nova Scotian, 1181 Hollis Street: 902-421-1000
  - There is a shuttle service to the VG Site.
- Lord Nelson Hotel & Suites, 1515 South Park Street: 902-423-6331 or (toll-free): 1-800-565-2020
- Atlantica Hotel, 1980 Robie Street: 902-423-1161 or (toll-free): 1-888-810-7288
- Halifax Haven Guest Home, 5897 Inglis Street: 902-421-1650
- Garden South Park Inn, 1263 South Park Street: 902-492-8577 or (toll-free): 1-877-414-8577

How do I get to the Transplant Unit?

The map at the end of this guide shows the VG site, off South Park Street, and the main doors to the hospital.

- **If you arrive between 7 a.m. and 5 p.m.**
  - Use the main entrance off South Park Street. Go to Admitting on the 10th floor of the Victoria Building. From there, you will go to Unit 6B.
- **If you arrive between 5 p.m. and 7 a.m.**
  - Go to the main entrance of the Dickson Building. This building is attached to the main hospital and is off University Avenue. Staff will direct you to the Transplant Unit on the 6th floor of the hospital.

Your hospital stay

You will be cared for on:

Unit 6B, Centennial Building
Queen Elizabeth II (QEII) Health Sciences Centre, Victoria General (VG) site
1276 South Park Street
Halifax, NS B3H 2Y9

For more information, please see the map at the end of this guide or visit:

› www.nshealth.ca/locations?title=&field_address_locality=halifax

There are many things to do before your transplant. You may feel rushed. Please ask questions at any time.

Just before your surgery

A nurse and a doctor will let you know what to expect.

You will have:

- Blood work and urine tests
- An ECG/EKG
- A chest X-ray
- Swabs of your groin and nose for MRSA, if needed
- Intravenous (IV) medications or an IV infusion, as needed

Research

A research nurse may invite you to take part in a research study. If you wish to take part, the nurse will explain the study in detail, answer your questions, and ask for your consent to take part. **It is up to you whether you choose to take part in the study. Your care will not be affected in any way.**

Surgery

- When you go to the Operating Room (OR), nurses will meet you.
- An anesthetist (doctor who puts people to sleep for surgery) will assess you and give you medication to fall asleep.

- Once you are asleep, a catheter (long, hollow tube) will be inserted (put in) in your bladder and an IV line will be inserted in your neck.
- The surgeon will make an incision (cut) in your lower abdomen and insert your new kidney. The transplanted kidney will be connected to your bladder. Your kidneys will not be removed.
- The surgery will take 2 to 4 hours.

After your surgery

- You will stay in a recovery room for a couple of hours as you recover from the anesthetic (medication to put you to sleep for surgery).
- When you return to 6B, you will be cared for in the 4-bed IMCU (Intermediate Care Unit) for at least 24 hours (1 day).
- There may be both men and women on this unit.
- You will get oxygen.
- You will get help with deep breathing and coughing exercises. These are done every hour to expand your lungs after having an anesthetic. You will need to get up and moving soon after surgery. This is very important.
- The doctor may put a special IV line in your neck to give you fluids and take blood samples. You may also have a regular IV in your arm. You will have this line in while you are admitted on Unit 6B. The nurses will take it out before you are discharged home.
- The nurse will remove the dressing on your abdomen the day after your surgery. If there is drainage from the incision, they may apply a new dressing. It will be changed as needed.
- The incision may be closed with staples or glue. The nurse will check the incision every day and monitor for drainage. If you have staples, they will be taken out by the Transplant Clinic nurse 10 to 14 days after surgery.
- You will have a catheter to drain your urine for at least 4 days. The amount of urine you are making will tell us how well your transplanted kidney is working. Your urine may have a reddish colour at first. This will go away within a few days.
- You may have a drainage tube to drain any fluid that collects around the kidney for the first few days. It will be taken out the day after your catheter, or when there is less fluid draining.
- Your blood pressure, temperature, oxygen levels, and pulse will be checked often.

- You will not be able to drink anything until your nurse hears bowel sounds. Bowel sounds usually return within 12 hours after surgery.
- You may vomit (throw up) if you drink before your bowels are active (you are able to poop).
- Until your nurse hears bowel sounds, only use sterile (purified) water when you take your medications and rinse your mouth. Nursing staff will give you sterile water — **do not drink tap water**.

Recovery

- Each person recovers differently from surgery. The average hospital stay is between 5 to 10 days, but some people may need to stay longer.
- You may have complications during your hospital stay or after you go home.
- Blood will be taken every morning to check your kidney function and medication levels. **Do not take any medications before your blood is taken.**
- We will measure the amount of anti-rejection medication in your blood. Your dose may be changed, as needed. This is normal.
- Urine samples will be checked 2 times a week.
- Members of the transplant team will visit you 2 times a day. Make a list of any questions you would like to ask during their visit.
- About 24 hours after your surgery, you will be able to sit up in a chair. Within a day, you will be able to walk with help. Being active will help to prevent pneumonia and blood clots in your legs.
- **It is very important to learn about your medications so you can care for your new kidney.** Within 2 days of your surgery, you will start to learn about your medications. You will learn why you need them, when to take them, and possible side effects. We will help you learn to take your medications on your own during your hospital stay.
- It is important to check with your nurse every day, as your doses may change often. Write down your actual dose on your record sheet (see page 40). Use this record sheet at home.
- After surgery, you may need to eat different foods. After you are discharged, you will meet with a dietitian at the Transplant Clinic to talk about this.
- A social worker is available for you and your family/support person to talk about any concerns you may have.

- If you have a fistula in your arm, it will not be removed. Call your primary health care provider if it gets swollen or painful.
- If your kidney was from a living donor, your peritoneal dialysis catheter may be taken out. If you receive a kidney from a deceased donor, the catheter may be left in for up to 3 months.
- Your medications may cause you to feel emotional. As your medications are adjusted, the emotional ups and downs will get better.

What are the possible complications after surgery?

Cytomegalovirus (CMV)

CMV 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 inactive. The virus can become active if your ability to fight infection is lowered. Your anti-rejection medication can prevent you from fighting CMV.

Call your primary health care provider if you have:

- › Fatigue (tiredness)
- › Fever (temperature above 38° C/100.4° F)
- › Aching joints
- › Headache
- › Cough and/or phlegm (thick mucus)

Herpes

The herpes viruses may cause:

- › Cold sores
- › Chicken pox
- › Shingles or genital herpes

Precautions:

- Keep sores clean and dry.
- Wash your hands with soap and water after touching any sores.
- Do not kiss anyone who has a cold sore.

If you have never had chicken pox, call your primary health care provider right away if you are exposed to chicken pox or shingles.

Rejection and infection

- Your immune system helps your body fight against disease and infection. It also protects your body against anything foreign. After your transplant, your body sees your new kidney as foreign and will try to reject it.
- Immunosuppressant (anti-rejection) medications protect your new kidney by lowering 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 need to take anti-rejection medications for the rest of your life.
- One (1) in every 3 patients will have a rejection episode. Rejection usually happens within the first 3 months after surgery, but can happen at any time. **This does not mean you will lose your new kidney.**
- Most rejection can be controlled by changing or adjusting your medications. **The best way to prevent rejection is to always take your medications.**

Call the transplant team if you have any of these signs of rejection:

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

- The anti-rejection medications also lower your body's ability to fight infection. The risk of infection is higher in the first few months after surgery. This is because you are more likely to be taking larger doses of anti-rejection medications at this time.
- Some common infections you may have are incision, bladder, or lung (pneumonia).

Call your primary health care provider if you have:

- › A sore that does not heal
- › Burning or a bad smell when you urinate (pee)
- › Fever (temperature above 38° C/100.4° F) and chills
- › Cough and/or phlegm

Planning for discharge

- **A transplanted kidney brings new responsibilities. You are now the lifetime caretaker of your new kidney.**
- **You must take your medications as told.** If you do not take your medications, it may harm you or your new kidney. This may result in you losing your kidney or having poor kidney function.
- Discharge plans must be made well before you leave the hospital.
- Before you go home, your nurse will talk with you about returning to the Transplant Clinic.
- If you have any concerns about your discharge plans, talk with a member of your Transplant Team as soon as possible. We are happy to help you.
- Follow-up visits are very important to help you stay healthy.
- Many people are anxious about leaving the hospital. They worry that something will happen to their new kidney. They feel safe with the "experts" at the hospital, and worry that people outside the hospital will not be able to help them. These feelings usually do not last long and often go away as soon as you leave the hospital.

Writing a letter to your donor’s family

- You may wish to send a card or a letter to your kidney donor’s family to say thank you. This is a personal decision. **It is up to you whether or not you choose to write to your donor’s family.**
- For organ donations and transplants that take place in Nova Scotia after January 18, 2021, **you and your donor’s family may be eligible to contact each other directly**. You and your donor’s family must both be willing to have contact and also meet certain criteria.
- For more information on the Direct Contact process, contact the Family Support Liaison:

Legacy of Life Organ and Tissue Donation Program

Room 4091, Abbie J. Lane Building
5909 Veterans’ Memorial Lane
Halifax, NS B3H 2E2

  - Phone: 902-718-9124
  - Email: DonorFamilySupport@nshealth.ca

For more information on writing to your donor’s family, please see the pamphlet *Writing to Your Donor’s Family*:

  - https://www.nshealth.ca/patient-education-resources/1212

Transplant Clinic

- After your transplant, your follow-up visits will take place at your home Transplant Clinic.
- If you do not live in Halifax, we will send your file to a specialist in your area for follow-up.

Follow-up visit instructions:

- Bring your provincial health care card with you to all appointments.
- Bring all of your medications or a list of your medications with you to all appointments.
- If you need to cancel an appointment, please call the Clinic.
- During your visit, staff will review your medications and talk about any problems you are having. Your medications may need to be changed. A dietitian, pharmacist, and research nurse are available to talk with you about any of your concerns.
- Before you leave the Clinic, make sure to arrange your next appointment. Write the appointment down as a reminder.

Recovery

During the first 3 months, you will need to visit the Clinic often. At first you will need to visit 3 times a week. Over time you will need to visit 2 times a week, then once a week, once every 2 weeks, and once every month. Your health care team will decide how often you need to visit. **You will continue to be followed in the Clinic for the life of your new kidney.**

Medications

- You will need to take several different types of medications after your transplant. As well as immunosuppressants, you may be prescribed medications to prevent infection and stomach ulcers, and to control blood pressure, blood sugar, and cholesterol.
- You may also have to continue some medications you were taking before your transplant surgery (like thyroid medications, antidepressants, anti-seizure medications, etc.).
- During your hospital stay, you will start to take your medications on your own. The nurse will help you with this by making a medication record for you to follow. This will help you get ready to take your medications at home. **Be sure to tell your nurse if you have problems with your vision, hearing, or memory.**
- **Your nurse will help you learn:**
  - The name of each medication you are taking
  - Why you need to take each medication
  - When and how to take each medication
  - The side effects that may happen with each medication
  - How to get each medication
- We will give you a supply of your medications and a medication record. 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 well you are managing your medications.

Reminders

- **You will need to take anti-rejection medications for the rest of your life.**
- Take your medications as told.
- **Do not stop taking any medication without asking your primary health care provider.**
- Take your medications at the same time each day.
- If you forget a dose of your anti-rejection medication:
  - **Medications you take 2 times 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 regular time.
  - **Medications you take once a day:** Take your dose as soon as you remember it. If you do not remember until the next day, take your normal dose at the regular time. **Do not take a double dose.**
- If you are vomiting, you are probably bringing up your medications.
  - If you vomit within 30 minutes of taking a dose of anti-rejection medication, take that dose again after your stomach settles.
  - If you vomit more than 30 minutes after taking a dose, **do not repeat that dose** unless you see the pills in your vomit. Take your next dose at the regular time. **Do not take a double dose.**
  - If you still feel nauseous (sick to your stomach), call your primary health care provider.
- If you have diarrhea (loose, watery poop) that lasts more than a couple of days, call the Clinic and your primary health care provider.
- 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 primary health care provider, pharmacist, and dentist about the medications you are taking.
- Always carry a list of your medications with you.
- **Some over-the-counter medications may affect the level of your anti-rejection medications.** Do not take over-the-counter medications (like cold medications) without talking with your primary health care provider or pharmacist.
- **Do not** take any other medications, including vitamins or herbal supplements, without talking with your primary health care provider or pharmacist.

How to get your anti-rejection medications

If you live in NS, NL, or PEI:

- Your anti-rejection medications are provided through a government-funded program. They are not available in your local pharmacy.
- 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 pharmacy.
- Before you are discharged, make sure that you know how to get your medications.

Storing your medications

- Keep all medications out of the reach of children and pets.
- **Do not** store them in damp areas, like the bathroom.
- **Do not** store them in direct sunlight, like on a windowsill.
- **Do not** store pills or tablets in the fridge.
- **Do not** remove any medication that is in a foil package until you are ready to take it.
- **Do not** keep old medications or medications that you no longer need. Take these to your local pharmacy. They will get rid of them safely.
- **Do not** share your medications with anyone.

Your medications

- After your transplant, your medications will include some of the following:
  - Acyclovir or valganciclovir
  - Mycophenolate mofetil
  - Mycophenolate sodium
  - Prednisone
  - Sirolimus
  - Sulfamethoxazole/trimethoprim
  - Tacrolimus
- Information on these medications can be found on the following pages.

Medication record

Name of medication	Dose	How often	Reason for taking this medication	Times								

Important:

- **Contact your primary health care provider (family doctor or nurse practitioner) if you have any side effects from your medications.**
- **Do not stop any medication on your own. This is dangerous.**

Acyclovir

Generic name: Acyclovir

Brand name: Zovirax®

What is acyclovir?

- Acyclovir is a medication used to treat or prevent infections caused by viruses.
- It is used to treat or prevent viral infections like chicken pox, shingles, and cold sores.

How do I use acyclovir?

- **Do not stop taking acyclovir on your own.** Talk to your primary health care provider first.
- Take this medication at the same time each day.
- Acyclovir can be taken with or without food.
- Acyclovir can cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or transplant nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- If you have started taking a new medication and are worried that it may have an effect on acyclovir, or you forgot to take your medication and are not sure what to do, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- Store acyclovir at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Call your primary health care provider if you do not feel well while taking acyclovir. Possible side effects include:

- **Upset stomach:** Taking this medication with food may help to prevent upset stomach.
- **Blood problems:** Acyclovir can lower red blood cells, white blood cells, and platelets (part of the blood which helps it to clot). This can cause fatigue, higher risk of infection, bruising, and/or bleeding problems. The transplant team will watch closely for these problems and will change the amount of your medication, if needed. Please talk to your primary health care provider, pharmacist, or Transplant Clinic nurse about any unusual fatigue, infections, bruising, or bleeding.
- **Kidney problems:** Rarely, acyclovir can cause kidney problems. The transplant team will watch closely for these problems and will change the amount of medication you take, if needed.
- **Rash:** Call your primary health care provider or the Transplant Clinic if you get a rash.

Mycophenolate mofetil

Generic name: Mycophenolate mofetil (MMF)

Brand name: CellCept®

What is MMF?

- MMF is an immunosuppressant/anti-rejection medication that weakens your immune system.
- It is used to prevent your body from rejecting your new kidney.

How do I use MMF?

- **Do not stop taking MMF on your own.** Talk to your primary health care provider first.
- Take this medication at the same time each day.
- MMF can be taken with or without food, but it is best absorbed on an empty stomach. Always take this medication the same way each day.
  - For example, if you take it with food, always take it with food.
  - If you do not take it with food, never take it with food.
- MMF can cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or Transplant Clinic nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- The transplant team will watch your blood counts closely. They will change the amount of your medication, if needed.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- Leave MMF in its packaging until you are ready to take it.
- If you have started taking a new medication and are worried that it may have an effect on MMF, or you forgot to take your medication and are not sure what to do, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- Store MMF at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Contact your primary health care provider if you do not feel well while taking MMF. Possible side effects include:

- **Higher risk of infection:** Tell your primary health care provider about any signs or symptoms of an infection (fever, sore throat, chills, fast heartbeat, etc.) right away.
- **Higher risk of getting cancer:** Tell your primary health care provider about any lumps, or changes in skin colour or moles.
- **Upset stomach, loss of appetite, nausea, vomiting, and diarrhea:** These symptoms often happen early in treatment and should go away over time. **Talk to your primary health care provider 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 have any fainting, see your primary health care provider right away.
- **Blood problems:** MMF can lower red blood cells, white blood cells, and platelets (part of the blood which helps it to clot). This can cause fatigue, higher risk of infection, bruising, and/or bleeding problems. The transplant team will watch closely for these problems and will change the amount of your medication, if needed. Please talk to your primary health care provider, pharmacist, or Transplant Clinic nurse about any unusual fatigue, infections, bruising, or bleeding.
- **If you are able to become pregnant:** Do not get pregnant while taking MMF, as it can harm the baby. Ask your primary health care provider or pharmacist for help choosing the right birth control method for you. If you are planning to get pregnant, talk with the transplant team months before you are ready to try, as some of your medications may need to be changed.

Mycophenolate sodium

Generic name: Mycophenolate sodium

Brand name: Myfortic®

What is mycophenolate sodium?

- Mycophenolate sodium is an immunosuppressant/anti-rejection medication that weakens your immune system.
- It is used to prevent your body from rejecting your new kidney.

How do I use mycophenolate sodium?

- **Do not stop taking mycophenolate sodium on your own.** Talk to your primary health care provider first.
- Take this medication at the same time each day.
- Mycophenolate sodium can be taken with or without food, but it is best absorbed on an empty stomach. Always take this medication the same way each day.
  - For example, if you take it with food, always take it with food.
  - If you do not take it with food, never take it with food.
- Mycophenolate sodium can cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or Transplant Clinic nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- The transplant team will watch your blood counts closely. They will change the amount of your medication, if needed.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- If you have started taking a new medication and are worried that it may have an effect on mycophenolate sodium, or you forgot to take your medication and are not sure what to do, talk to your pharmacist or Transplant Clinic nurse.
- Store mycophenolate sodium at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Call your primary health care provider if you do not feel well while taking mycophenolate sodium. Possible side effects include:

- **Higher risk of infection:** Tell your primary health care provider about any first signs or symptoms of infection, like fever (temperature above 38° C/100.4° F), sore throat, chills, fast heartbeat, etc., right away.
- **Higher risk of getting cancer:** Tell your primary health care provider about any lumps, or changes in skin colour or moles.
- **Upset stomach, loss of appetite, nausea, vomiting, and diarrhea:** These symptoms often happen early in treatment and should go away over time. Talk to your primary health care provider 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 have any fainting, see your primary health care provider right away.
- **Blood problems:** Mycophenolate sodium can lower red blood cells, white blood cells, and platelets (part of the blood which helps it to clot). This can cause fatigue, higher risk of infection, bruising, and/or bleeding problems. The transplant team will watch closely for these problems and will change the amount of your medication, if needed. Please talk to your primary health care provider, pharmacist, or Transplant Clinic nurse about any unusual fatigue, infections, bruising, or bleeding.
- **If you are able to become pregnant:** Do not get pregnant while taking mycophenolate sodium, as it can harm the baby. Ask your primary health care provider or pharmacist for help choosing the right birth control method for you. If you are planning to get pregnant, talk with the transplant team months before you are ready to try, as some of your medications may need to be changed.

Prednisone

Generic name: Prednisone

Brand name: none

What is prednisone?

- Prednisone is an immunosuppressant/anti-rejection medication that weakens your immune system.
- It is used to prevent your body from rejecting your new kidney.

How do I use prednisone?

- **Do not stop taking prednisone on your own.** Talk to your primary health care provider first.
- Prednisone should be taken with food to prevent upset stomach.
- Prednisone may cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or transplant nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- If you have started taking a new medication and are worried that it may have an effect on prednisone, or you forgot to take your medication and are not sure what to do, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- Store prednisone at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Call your primary health care provider if you do not feel well while taking prednisone. Possible side effects include:

- **Mood changes:** Prednisone can change your mood. You may become depressed, or very happy or energetic. Prednisone can also make psychiatric (mental health) disorders worse. **If you have a psychiatric disorder and think it is getting out of control, or you think you may be having mood problems, call your primary health care provider right away.**
- **Higher risk of infection:** Tell your primary health care provider about any signs or symptoms of infection, like fever (temperature above 38° C/100.4° F), sore throat, chills, fast heartbeat, etc., right away.
- **High blood pressure or cholesterol:** Prednisone can make your blood pressure and cholesterol levels higher. Eating well and exercising can help.
- **Upset stomach:** Taking this medication with food may help to prevent upset stomach. Talk to your primary health care provider or pharmacist before taking any over-the-counter medications to treat this symptom.
- **Fluid retention:** Prednisone can make your body retain (hold onto) fluid. This can cause edema (swelling). If you think you are retaining fluid, talk to your Transplant Clinic nurse.
- **Weakened bones:** Prednisone can weaken bones over time. This can cause osteoporosis. Making sure you are eating enough foods with calcium can help.
- **High blood sugar:** Prednisone can make your blood sugar higher. This can cause diabetes. Eating well and exercising can help.

Sulfamethoxazole/trimethoprim

Generic name: Sulfamethoxazole/trimethoprim, co-trimoxazole

Brand name: Septra®, Bactrim®, Sulfatrim®

What is sulfamethoxazole/trimethoprim?

- Sulfamethoxazole/trimethoprim is an antibiotic medication that treats or prevents infections caused by bacteria.
- It is used to treat or prevent bacterial infections, including one caused by pneumocystis jiroveci pneumonia (PCP).

How do I use sulfamethoxazole/trimethoprim?

- **If you are allergic to "sulfa drugs" or sulfonamides**, tell the transplant team before you start taking sulfamethoxazole/trimethoprim.
- **If you are glucose-6-phosphate dehydrogenase (G6PD) deficient** (do not have enough), call the Transplant Clinic before you start taking sulfamethoxazole/trimethoprim.
- **Do not stop taking sulfamethoxazole/trimethoprim on your own.** Talk to your primary health care provider first.
- Sulfamethoxazole/trimethoprim can be taken with or without food, but taking it with food may prevent upset stomach.
- Sulfamethoxazole/trimethoprim can cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or Transplant Clinic nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- If you have started taking a new medication and are worried that it may have an effect on sulfamethoxazole/trimethoprim, or you forgot to take your medication and are not sure what to do, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- Store sulfamethoxazole/trimethoprim at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Call your primary health care provider if you do not feel well while taking sulfamethoxazole/trimethoprim. Possible side effects include:

- **Upset stomach:** Taking this medication with food may help to prevent upset stomach. Talk to your primary health care provider or pharmacist before taking any over-the-counter medications to treat this symptom.
- **Blood problems:** Sulfamethoxazole/trimethoprim can lower red blood cells, white blood cells, and platelets (part of the blood which helps it to clot). This can cause fatigue, higher risk of infection, bruising, and/or bleeding problems. The transplant team will watch closely for these problems and will change the amount of your medication, if needed. Please talk to your primary health care provider, pharmacist, or Transplant Clinic nurse about any unusual fatigue, infections, bruising, or bleeding.
- **Kidney problems:** Rarely, sulfamethoxazole/trimethoprim can cause kidney problems. Your transplant team will watch closely for these problems and will change the amount of your medication, 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 trouble getting rid of potassium. Your transplant team will watch closely for these problems and will change the amount of your medication, if needed.
- **Rash:** Call your primary health care provider or the Transplant Clinic if you get a rash.

Tacrolimus

Generic names: Tracrolimus, FK506

Brand names: Advagraf®, Prograf®

What is tracrolimus?

- Tacrolimus is an immunosuppressant/anti-rejection medication that weakens your immune system in your body.
- It is used to prevent your body from rejecting your new kidney.

How do I use tacrolimus?

- **Do not stop taking tacrolimus on your own.** Talk to your primary health care provider first.
- Take tacrolimus at the same time each day.
- Tacrolimus can be taken with or without food, but it is best absorbed on an empty stomach. Always take tacrolimus the same way each day.
  - For example, if you take it with food, always take it with food.
  - If you do not take it with food, never take it with food.
- The transplant team will watch your blood counts closely. They will change the amount of your medication, if needed.
- **Do not take tacrolimus before a blood test.** Bring it with you so you can take it after your blood is taken.
- Tacrolimus can cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or Transplant Clinic nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- If you have started taking a new medication and are worried that it may have an effect on tacrolimus, or you forgot to take your medication and are not sure what to do, talk to your primary health care provider, pharmacist, or Transplant Clinic nurse.
- Store tacrolimus at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Call your primary health care provider if you do not feel well while taking tacrolimus. Possible side effects include:

- **Higher risk of infection:** Tell your primary health care provider about any signs or symptoms of infection (fever, sore throat, chills, fast heartbeat, etc.) right away.
- **Higher risk of getting cancer:** Tell your primary health care provider about any lumps, or changes in skin colour or moles.
- **Upset stomach, loss of appetite, nausea, vomiting, and diarrhea:** These symptoms often happen early on in treatment and should go away over time. **Talk to your primary health care provider 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 have any fainting, see your primary health care provider right away.
- **High blood pressure, blood sugar, or cholesterol:** Tacrolimus can make your blood pressure, blood sugar, and cholesterol levels higher. The transplant team will watch closely for these problems and will change the amount of your medication, if needed.
- **Kidney problems:** Tacrolimus can be toxic (poisonous) to the kidneys. Your transplant team will watch closely for these problems and will change your amount of medication, if needed.
- **Slight hand trembling:** This symptom often happens early in treatment and goes away over time as your dose is lowered.
- **If you are able to become pregnant:** Do not get pregnant while taking tacrolimus, as it can harm the baby. Ask your primary health care provider or pharmacist for help choosing the right birth control method for you. If you are planning to get pregnant, talk with the transplant team months before you are ready to try, as some of your medications may need to be changed.

Valganciclovir

Generic name: Valganciclovir

Brand name: Valcyte®

What is valganciclovir?

- Valganciclovir is an antiviral medication that treats or prevents infections caused by viruses.
- It is used to treat or prevent viral infections, including one caused by cytomegalovirus (CMV).

How do I use valganciclovir?

- **Take valganciclovir as told by your primary health care provider.**
- **Do not stop taking valganciclovir on your own.** Talk to your primary health care provider first.
- Valganciclovir should be taken with food.
- Valganciclovir can cause problems if you take it with other medications. Talk to your primary health care provider, pharmacist, or Transplant Clinic nurse before taking any other medication. This includes prescription and non-prescription medications, natural products, and/or supplements.
- If you are not sure how much medication to take, or think you may be having side effects, talk to your Transplant Clinic nurse or pharmacist.
- If you have started taking a new medication and are worried that it may have an effect on valganciclovir, or you forgot to take your medication and are not sure what to do, talk to your Transplant Clinic nurse or pharmacist.
- Store valganciclovir at room temperature away from heat, light, and moisture.

What are the possible side effects? (Note: This is not a complete list of all possible side effects.)

Side effects can happen with all medications. Call your primary health care provider if you do not feel well while taking valganciclovir. Possible side effects include:

- **Upset stomach:** Taking this medication with food may help prevent upset stomach.
- **Blood problems:** Valganciclovir can lower red blood cells, white blood cells, and platelets (part of the blood which helps it to clot). This can cause fatigue, higher risk of infection, bruising, and/or bleeding problems. The transplant team will watch closely for these problems and will change the amount of your medication, if needed. Please talk to your primary health care provider, pharmacist, or Transplant Clinic nurse about any unusual fatigue, infections, bruising, or bleeding.
- **Kidney problems:** Rarely, valganciclovir can cause kidney problems. Your transplant team will watch closely for these problems and will change the amount of your medication, if needed.
- **Rash:** Call your primary health care provider or the Transplant Clinic if you get a rash.

Staying healthy at home

Taking care of yourself

Even if you have a working transplant at the end of one year, it may not last forever. Over time, kidneys fail. This may be after a short time (several years), or after 15 to 20 years. Kidneys fail for many reasons, including high blood pressure, not taking your medications regularly, smoking, and early rejection. **It is important to work with your transplant team to protect your new kidney.**

Your anti-rejection medications increase your risk of:

- Increased appetite (more hungry)
- Diabetes (high blood sugar)
  - This is more likely to happen if you had high blood sugar before your transplant.
  - You may need medication.
- High cholesterol
- High blood pressure
  - This is very common after a kidney transplant. If it is not treated, high blood pressure can damage your heart, blood vessels, and your new kidney.
  - You may need medication. Each blood pressure medication has side effects. A medication may work well for one person, but not for another. Your primary health care provider will work with you to find the right treatment. **Always tell your transplant doctor if you have any problems that you think are being caused by your blood pressure medication.**
  - **Do not stop or change your blood pressure medication on your own.**
- Osteoporosis (weak, thin bones)
- Cancer

If it is an emergency, call 911 or go to the nearest Emergency Department right away.

Yearly check-up

Cancer is more common after a transplant. You have an even higher risk if you had cancer before your transplant. In this case, your primary health care provider will need to watch closely for any signs or symptoms of cancer.

Every year:

- Visit your primary health care provider.
- Get a flu shot.
- **Females:** Have a Pap smear, breast exam, and mammogram (according to guidelines).
- **Males:** Get checked for cancer of the testes and an enlarged prostate gland.

Every month:

- Check all of your skin for changes in freckles, moles, or spots. Tell your primary health care provider if you see any changes.

Every 5 years:

- Have a pneumovax injection.

If you see blood in your poop, talk to your primary health care provider.

How can I have a healthy lifestyle?

Smoking

Do not smoke. Smoking damages your lungs, heart, and blood vessels. Help your family and friends to stop smoking. Smoke from other smokers does as much harm as smoking yourself.

Exercise

- Exercise is very important. It helps you to keep or improve your overall strength and endurance.
- Exercise also helps to lower your risk of osteoporosis, and heart and blood vessel problems.
- **For the first 6 weeks after surgery, do not lift more than 10 pounds (4½ kg).**

Driving

- **Do not drive for 6 weeks after your surgery.**
- **Do not drive while taking pain medication.**
- Always wear a seatbelt while in a vehicle (car, truck, van, etc.) **This is the law in all Canadian provinces and territories.** Having a transplant is not an exception to this law.

Healthy eating

- It is important to eat healthy, well-balanced meals. Choose a variety of foods from the 4 food groups each day. Healthy eating can help to control your weight, cholesterol, blood pressure, and blood sugar. For more information, visit:
  - https://food-guide.canada.ca/en/
- After surgery, your transplanted kidney should work like a normal kidney:
  - You will no longer need to follow a “kidney diet” or “renal diet”.
  - You will no longer need to limit dairy products or high-fibre foods.
  - You should keep eating protein in moderation.
  - You should keep eating foods that are low in sodium (salt).
- **Ask your primary health care provider if you should limit foods that are high in potassium for a short time.**
- Your medications can increase your cholesterol. If your cholesterol was high before surgery, it may be even higher after surgery. High cholesterol raises your chance of having a stroke or heart attack.
- It is important to eat foods with a lot of calcium, since prednisone increases your risk of osteoporosis. If you cannot eat enough calcium-rich foods, your dietitian may suggest a supplement (pill) to increase your calcium. **Do not start taking a calcium supplement on your own.** Talk to your primary health care provider first.
- Your dietitian will give you information about eating salt, fat, and sugar in moderation. This may help to lower your chances of developing health problems (like high blood pressure, high cholesterol, or diabetes). If you have already developed one or more of these health problems, your dietitian can work with you to make changes in your eating habits.

Goals

Reach and keep a healthy weight.

- Eat 3 meals each day. Skipping a meal can lead to overeating at your other meals.
- Cut back on portion sizes.
- Add less fat (like butter, cream, cooking oil, etc.) to your food.
- Eat slowly and stop when you feel full. It is OK if you do not eat everything on your plate.
- Choose fresh fruits and vegetables as snacks.
- Shop for groceries on a full stomach. This can help you make healthier choices.

Eat less salt.

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

Eat less fat.

- Use less margarine, oils, and other fats.
- Choose fats low in saturates (like oil and soft margarine) and replace meat with fish 2 to 3 times a week. These changes lower the saturated fat you are eating.
- Choose a variety of fish, poultry (chicken, turkey, etc.), and lean meats. Keep portion sizes small.
  - 1 serving = 3 oz or 90 g (about the size of a deck of cards)
  - Have only 2 servings a day.
- Watch for hidden fats found in many bakery and grocery store items (like muffins, biscuits, cookies, crackers, frozen dinners).
- Choose lower fat dairy foods.
- Read nutrition labels carefully for fat content.

Eat more fibre.

- Eat whole grain breads and cereals, and fresh fruits and vegetables each day. Fibre can help you feel full longer and help to control your cholesterol.
- Choose breads and cereals with oats and bran.
- Choose dried peas, beans, and lentils more often.

Dental care

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

To keep your teeth and gums healthy:

- Brush your teeth 2 times a day.
- Use a brush with soft bristles.
- Use toothpaste with fluoride.
- Rinse your mouth with fluoride or mouthwash.
- Floss once a day.
- Visit your dentist every 6 months.
- **Tell your dentist about your transplant.** You may need to take antibiotic medication before you have any dental work. Your dentist can call the Transplant Clinic, if needed.

Hair growth

Some medications may cause hair growth. You may wish to have some of this hair removed (such as with waxing, electrolysis, or creams). If you have questions about this, talk to a Transplant Clinic nurse.

Eye care

Some anti-rejection medications can cause cataracts. **See your eye doctor once a year.**

Sex

- You may have sex whenever you feel well enough. This is usually about 6 weeks after surgery.
- Some medications may lower your sex drive or cause erectile dysfunction (not able to get an erection). If this happens, talk to your primary health care provider. It may be possible to change your medication.
- Because your immune system is weakened, you are at a higher risk of getting an infection. It is important to protect yourself. Everyone should be concerned about sexually transmitted diseases (STIs), like AIDS, herpes, and hepatitis. These diseases are passed in body fluids exchanged during sex. **It is important to wear a condom correctly every time you have sex to lower your risk of an STI.**

Birth control

- After having a kidney transplant, you may be more fertile (able to get pregnant more easily). But, the risk of complications during pregnancy (for both mother and baby) are higher in people who have had a transplant.
- **You should wait for at least 2 years after your transplant surgery before getting pregnant.**
- While you are on dialysis and for 2 years after your transplant surgery, you should use 2 types of birth control. Ask your primary health care provider about back-up or double barrier birth control.
- If you are planning on getting pregnant, some of your medications may need to be changed. Talk to your Transplant Clinic nurse if you are planning on getting pregnant.

MedicAlert®

- **You should get MedicAlert® identification (ID) after your surgery, as it could save your life in an emergency.**
- If you already had MedicAlert® ID before your surgery, it will need to be updated and replaced.
- Ask your Transplant Clinic nurse to help you fill out a MedicAlert® form. It can take up to 8 weeks (2 months) for delivery.
- **Make sure that you always wear your ID.**

Preventing skin cancer

We all need to protect our bodies from the sun. **Your medications make your skin more sensitive to sun damage.**

Protect yourself in the sun:

- Use a sunscreen with an SPF of 50 or higher.
- 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 dangerous.
- Wear UV-filtering sunglasses to protect your eyes.

Your environment

Food poisoning

2 million Canadians get food poisoning every year. Most of them recover quickly. After your transplant, your immune system will be weak. This makes food poisoning a threat to your life.

- Keep cold food cold and hot food hot.
- Do not let raw and cooked foods touch.
- 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 fruits 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.**
- Remember: 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 your teeth at least 2 times a day.
- Have a bath or shower every day.
- Keep your nails trimmed and clean.

Housekeeping

- Clean your counters and cutting boards regularly:
  - Wash with hot, soapy water.
  - Rinse with clean water.
  - Clean with a bleach solution: Add 2 ml (1/2 tsp) of bleach to 500 ml (2 cups) of water.
  - Rinse with clean water.
- Do not let dust build up in your house.
- **Do not use wooden cutting boards.** They are harder to clean and can hold onto bacteria.
- Clean your microwave after each use.

Pets and other animals

After your transplant surgery, your immune system will be weak. Your pet could make you sick.

- Keep your pet clean and groomed.
- Keep your pet on a flea control program.
- **Do not** touch any animal's body fluids (like vomit, pee, poop, or saliva), including your pet's. This includes kitty litter. Clean up body fluids with a disinfectant. If possible, have someone else do this.
- **Do not let your pet or any animal 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

Protecting yourself from viruses

‘The flu’ (Influenza)

The flu is a respiratory viral illness that usually comes on suddenly. It may affect the nose, throat, and lungs. The flu is different from a cold. The flu can cause mild to severe illness. For most people, it takes several days up to 2 weeks to recover.

West Nile virus

- West Nile virus is a virus carried by mosquitoes. It is almost always spread to humans, birds, and other animals through the bite of an infected mosquito. It can cause swelling in the brain, brain lining, or spinal cord lining in humans and animals.
- We do not know the risk of severe disease caused by West Nile virus in immunosuppressed people (like organ transplant recipients). It may be higher than in people who are not immunosuppressed.
- In areas where West Nile virus has been found, only a small number of mosquitoes are likely to be infected. Most people bitten by an infected mosquito do not get sick. Less than 1% of people who are infected get seriously ill. For those who are seriously ill, 1 in 10 may die.

Symptoms

- Symptoms usually appear about 3 to 14 days after you are bitten.
  - **Mild symptoms:** slight fever, headache, body aches, swollen glands, rash
  - **Severe symptoms:** high fever, very bad headache, stiff neck, confusion
- Prevent West Nile virus by getting rid of breeding areas around your home. To stop mosquitoes from breeding:
  - Turn over or remove containers in your yard where rainwater collects (like potted plant trays, buckets, or toys).
  - Change the water in bird baths 2 times a week.
  - Remove unused items (like tires) from your yard.
  - Empty wading pools, pet bowls, and livestock watering tanks regularly.
  - Clean out eavestroughs and get rid of standing water on flat roofs.
  - **Do not let water collect.**
- Protect yourself and your family
  - Wear long-sleeved, loose, light-coloured shirts and pants, socks, and a hat when mosquitoes are active.
  - If possible, stay indoors at dusk and dawn when mosquitoes are most active.
  - Make sure that your door and window screens fit tightly and have no holes.
  - Do not leave doors and windows open without screens.
  - Use insect repellent with the smallest amount of DEET (no more than 50% for adults and 10% for children under age 12) that protects for the length of time you will be exposed.
  - Only adults should apply insect repellent on children.
  - Spray repellent on your hand and then apply it to your face.
  - Only apply repellent to exposed skin and clothing. **Do not use repellent under clothing.**
  - Do not apply repellent on cuts, wounds, sunburns, or irritated skin.

If you see any dead birds, contact the Nova Scotia Department of Natural Resources. They will decide if the bird can be tested. They will tell you how to safely get rid of the bird if it cannot be tested.

Going back to work

- Talk with your transplant doctor about when you can go back to work. They will suggest the best time for you to go back based on the physical demands of your job, your age, and job stress. Your body needs time to fully recover.
- Usually, you can go back 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

Once you return home and become more active, it may help to have an answering machine or voicemail. This will help Clinic staff contact you about any medication changes or other information.

Travelling

You can travel safely after your transplant. It must be planned well. Always talk with the Transplant Clinic nurse or doctor about your travel plans.

- **Do not leave Canada for 6 months after your transplant.** After this time, it should be easier to travel. You will need fewer Clinic visits and medication changes.
- Always buy cancellation insurance.
- Always buy health insurance if you are leaving 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 medications with you in case you are delayed.
- Ask your travel agent if there are any medical concerns in the country you plan to visit.
- Relax and enjoy your vacation.

Support

- During the first few months after your surgery, it is normal to want to get back in the routine you had before you got sick. But, you must do this slowly. Your body needs time to recover.
- If you were sick for a while before your transplant, there may have been many changes in your lifestyle.
- Your family or friends may have had to do jobs or tasks that you were not able to do. It may take time for everyone to adjust to their new jobs and responsibilities.
- If you have complications after your transplant, you may feel like you have just changed one set of problems for another. You may have feelings of “why me?” or believe that 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 help you deal with these issues and find support.
- The social worker at your hospital can also help you find resources in your area. Tell your nurse if you would like to talk with the social worker.

Peer support

The Kidney Foundation of Canada offers a Peer Support Program called Kidney Connect. If you want to talk to someone who has also had a kidney transplant:

  - https://kidney.ca
  - Phone (toll-free): 1-866-390-PEER (7337)

Resources

Multi-Organ Transplant Program of Atlantic Canada (MOTP)

- www.motpatlantic.ca/

The Kidney Foundation of Canada

- https://kidney.ca

Transplant Clinic phone numbers	
Cape Breton Regional Hospital Sydney, NS › 902-567-8067	**Queen Elizabeth II (QEII) Health Sciences Centre, Victoria General site** Halifax, NS › 902-473-4190
Chaleur Regional Hospital Bathurst, NB › 506-544-3598	**Queen Elizabeth Hospital** Charlottetown, PEI › 902-894-0019
Dr. Georges-L.-Dumont University Hospital Moncton, NB › 506-862-3707 › 506-862-4133	**Saint John Regional Hospital** Saint John, NB › 506-648-6850
Eastern Health - Kidney Care Centre Mount Pearl, NL › 709-777-3601	**Western Memorial Regional Hospital** Cornerbrook, NL › 709-637-5396

Living Kidney Donation Program Coordinators

Newfoundland

- Corner Brook Transplant Coordinator
  - › Phone: 709-784-6190
- St. John’s Living Donor Coordinator
  - › Phone: 709-777-3570

Nova Scotia and PEI

Live Donor Transplant Coordinator

Multi-Organ Transplant Program

- › Phone: 902-473-5501

OR

- › Phone: 902-473-2695

Cape Breton, Nova Scotia

- › Phone: 902-567-8067

New Brunswick

- Transplant Coordinator
  - › Phone: 506-869-2441

OR

  - › Phone: 506-648-6850
- Pre and Post Transplant
  - › Phone: 506-544-3567

What are your questions? Please ask.
We are here to help you.

In Nova Scotia you can call 811 to talk with a registered nurse about your health care questions 24/7.

QEII Health Sciences Centre Map
Victoria General Site

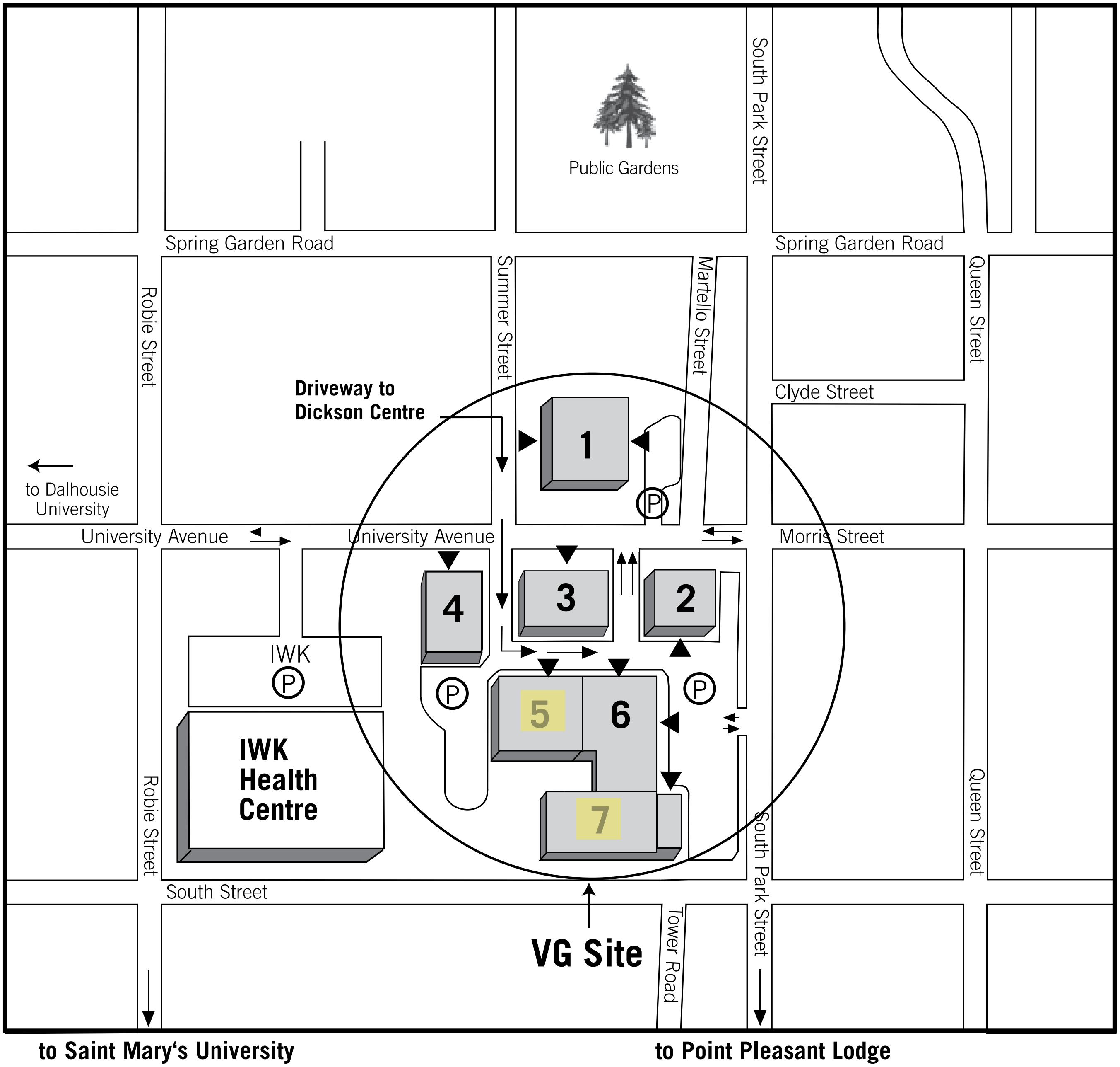
VG Site

1. Nova Scotia Rehabilitation Centre
2. Bethune Building
3. MacKenzie Building Laboratories
4. Centre for Clinical Research
5. Dickson Building
6. Victoria Building
7. Centennial Building

Ⓟ Patient Parking

▶ Entrance Doors

Please do not wear scented product when you come to Nova Scotia Health.



What are your questions?
Please ask. We are here to help you.

Questions for my health care team

Notes:

Find this pamphlet and all our patient resources here:
https://library.nshealth.ca/Patients-Guides

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: https://811.novascotia.ca

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The information in this pamphlet is to be updated every 3 years or as needed.