

Kidney Transplant Guide



Dedication

This manual is dedicated to the families of deceased donors and all our living donors who make kidney transplants at our centre possible.

A kidney transplant comes with the hope for an improved quality of life and the possibility of living a longer and more normal life. Accepting a transplant organ also comes with the responsibility for following, to the best of your ability, your care plan, assessment schedule and the medication regime you are prescribed.

We, the members of the transplant team, take the responsibility of caring for you and your transplant very seriously. We will endeavour to provide you with the best possible transplant care based on current research and our clinical expertise.



Patient & Family Education
Improving health through education

This handbook has been reviewed by the
Patient and Family Education Program

Please visit the UHN Patient Education website for more health information: www.uhnpatienteducation.ca

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Welcome to the Multi-Organ Transplant (MOT) Program and the Kidney Transplant Team

Introduction

The Multi-Organ Transplant (MOT) program at the Toronto General Hospital (TGH) is Canada's largest transplant centre. The kidney transplant program has done more than 1,500 transplants over the last few years and averages 160 transplants a year.

The kidney transplant program offers both living and deceased donor transplants for people with end-stage kidney disease. Transplant is considered the best treatment option for most patients with end-stage kidney disease.

Inside this guide you will find information about these topics:

- Learning about the kidneys
- The role of different members of your health care team
- Why you need a kidney transplant
- What to expect before, during and after a kidney transplant
- Learning about what to watch for after a transplant
- When to call the transplant team

Please bring this guide with you when you are admitted for your transplant.

Important: The University Health Network tries to keep patient resources up-to-date, but some information may change. Please contact any agencies or organizations that may be listed inside this guide to make sure the information is correct or to find out more about their services.

Our Philosophy of Care

- We believe that our work is possible because of the generosity of organ donors. Our work must honour these remarkable gifts from donors and their families.
- We believe that respect, dignity, integrity, and empathy drive care and support relationships. We expect courtesy and consideration in every interaction.
- We believe that the goal of the Kidney Transplant Program is to work as partners with individuals, families, and the community to promote optimal health and quality of life for patients through all phases of transplantation.
- We believe that transplantation is a very specialized area in health care. To succeed, we need the knowledge, skill, expertise, and ability of our multidisciplinary team.
- We believe that all members of the health care team are an important and valuable part of the plan of care. Each member of the team is a dedicated professional who continually maintains a current knowledge base and is consistently striving to advance the science and art of transplantation.
- We believe that all people are unique, with their own needs, goals, and abilities.
- We believe that people achieve optimal health when they are working with the health care team.
- We believe that information and education provide patients with knowledge to exercise their rights and responsibilities to make informed decisions about their health care.
- We believe that the best possible care is based on patient needs, resources, and ethical principles.

How we can work together

- ✓ Work as partners to make sure you have the best possible treatment, rehabilitation, discharge planning, and follow-up care.
- ✓ Provide accurate information and share any concerns with the health care team.
- ✓ Let the team know if you do not understand so the health care team can better explain instructions or provide more information.


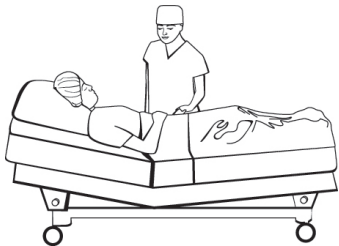


My transplant team







Throughout your transplant journey, we will teach you how to take care of your new organ and your health. Our team will support you through this process.

Who we are:

- Transplant Nephrologists and Surgeons
- Post-Transplant Coordinators
- Social Workers
- Dietitians
- Spiritual Care
- Transplant Assessment Coordinators
- Administrative Assistants
- Psychiatrists
- Physiotherapists
- Pharmacists
- Registered Nurses
- Other health care professionals, and most importantly... **YOU**

Some of the health care professionals that you will meet are:

<p>Transplant Nephrologists (Doctors who diagnose and treat kidney disease)</p> 	<ul style="list-style-type: none">• Sees you before you go on the transplant list or before your living donor transplant.• Reviews your assessment and answers any questions you may have.• When you are admitted for transplant, a nephrologist is part of your care team.• You see them for follow-up appointments after you go home from the hospital.
<p>Kidney Transplant Surgeon (Doctor who does the transplant)</p> 	<ul style="list-style-type: none">• Takes part in your assessment before your transplant.• Manages your recovery after your transplant and your surgical care.
<p>Transplant Assessment Coordinator (Registered Nurse)</p> 	<ul style="list-style-type: none">• Gives transplant education before the surgery.• Coordinates the transplant evaluation process.• Is someone you can contact if you have any questions about your upcoming transplant.
<p>Post-Transplant Coordinator (Registered Nurse or Nurse Practitioner)</p> 	<ul style="list-style-type: none">• Works with your Transplant Nephrologist to check on how you are doing after the surgery.• Arranges your clinic visits and any tests you need after transplant.• Can answer questions about your transplant health concerns.

<p>Administrative Assistant</p> 	<ul style="list-style-type: none"> • Works closely with the Transplant Coordinators during the assessment and after your transplant. • Can pass along concerns to the transplant team but cannot give medical advice.
<p>Social Worker</p> 	<ul style="list-style-type: none"> • Meets with you and your family or friends during the assessment process. • Helps you to prepare for transplant, for example: provides you with information about drug coverage, disability benefits, community resources, and ways to cope. • Provides counselling for you and your family before and after transplant.
<p>Psychiatrist</p> 	<ul style="list-style-type: none"> • Helps you and your family cope with chronic illness and its effects during the transplant process. • May meet you during your transplant evaluation. • Supports you before, during and after your transplant to help you transition to your new life.
<p>Registered Dietitian</p> 	<ul style="list-style-type: none"> • Gives you information about nutrition and counselling and monitors your nutrition after your transplant. • Works with you to develop a meal plan based on your weight, blood work results and medications. • Recommends a balanced diet that meets your personal needs.
<p>Physiotherapist</p> 	<ul style="list-style-type: none"> • May work with you after your transplant to help you with your strength and flexibility.
<p>Spiritual Care</p> 	<ul style="list-style-type: none"> • As part of the team, Spiritual Care professionals provide help that is sensitive to cultural and religious diversity.

Pharmacist



- Works closely with your doctors and the transplant team to make sure you receive the best possible medication therapy.
- Teaches you about your transplant medications during the Self-Medication Class. You and your support person will go to this class before you leave the hospital.
- Reviews all of your medications with you before you leave the hospital and answers any questions you may have.
- Provides you with a medication schedule to help you keep track of your medications and take them correctly at home.
- If you choose to have your prescriptions filled at the Transplant Outpatient Pharmacy, a Transplant Pharmacist can help you continue to manage your medications after your transplant.

Health Care Providers outside of the Transplant Team

Your **family doctor** will still be your main health care provider. It is important for you to go to regular check-ups and to your appointments with the transplant team. The transplant team will work with your family doctor to provide care before and after your transplant.

Transplant patients with diabetes also need to see a diabetes specialist (endocrinologist) regularly.

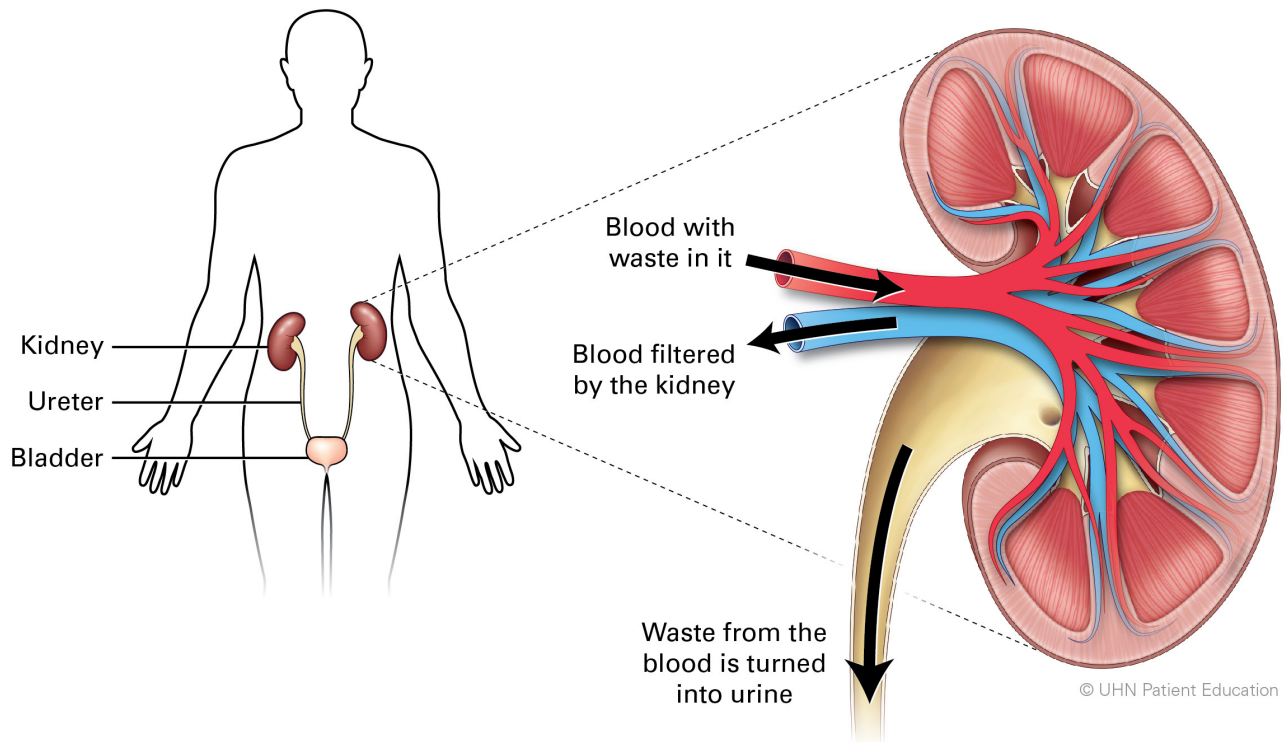


Transplant patients may see other specialists, such as cardiologists, hematologists, and other doctors, as needed.

Chapter 1: Why You Need a Kidney Transplant

Your doctor has suggested that you may need a kidney transplant. To understand why, it is important to know how the kidneys work.

Your kidneys are found at the back of your body with one on each side, just a few inches above your waist. The kidneys are about the size of your fist and reddish brown in colour.



What do your kidneys do?

- The kidneys are made up of about one million smaller parts called **nephrons**. Nephrons filter waste products, water, and other substances from the blood. The unwanted substances come out of the body as urine (pee). Urine is made by your kidneys and passes down into your bladder.
- The kidneys also make sure that there is a balance of **electrolytes**. Electrolytes are minerals such as calcium, phosphorus, sodium, and potassium found in your blood. When they are in balance, they help your bones to form properly, your heart to beat, and your muscles to contract.
- Kidneys help keep an acid-base balance in the blood. This very important for the body's proteins to work properly.
- The kidneys also produce hormones that you need to form red blood cells, regulate blood pressure, and make sure calcium is absorbed properly.

When both kidneys become diseased, they cannot do these important things well. But one healthy kidney can do them all. This is why transplanting only one kidney is enough for the needs of the body.

Why do I need a transplant?

There are 2 main types of kidney disease:

- Acute kidney injury (AKI)
- Chronic kidney disease (CKD)

AKI is reversible depending on your health, age, and the seriousness of the disease causing AKI.

CKD means the slow loss of kidney function over time.

CKD can lead to end-stage renal disease (ESRD). This means the kidneys are no longer working and a patient needs dialysis or a kidney transplant.

While dialysis is able to filter blood, it cannot be done all the time. Also, dialysis cannot provide many of the other things that a healthy kidney provides (such as hormones). This is why a kidney transplant is the best treatment option for ESRD.

Chapter 2: The Transplant Assessment Process

The transplant assessment process involves all the tests needed to decide whether a transplant is right for you. It tells us about your general health and whether you can probably go through the transplant surgery without complications (problems). Your tests may show that you have other health issues which make it unsafe for you to receive a transplant.

By carefully checking your health, the transplant team can prepare your own individualized care plan before surgery.

These tests help the transplant team deal with any medical problems that could affect your outcome after the transplant. You may need to visit the transplant clinic a few times so we can deal with all the issues.



It is very important that you go to all your scheduled visits to make sure your assessment is complete.

Transplant tests you can expect to have

Some tests are ordered for all patients and some are ordered for only certain patients, depending on their medical history, age and other factors. In general, the tests below are part of the assessment:

1. Blood tests

Blood typing

All patients need to have their blood type checked at TGH.

Human Leukocyte Antigen (HLA) typing

Your HLA is a set of proteins found on the surface of the cells in your body. We compare this information with the HLA typing of the donor kidney. This test shows us if a particular kidney is right for you and which anti-rejection drugs should be used after your transplant.

Panel Reactive Antibodies (PRA)

All patients are tested for PRA. PRA measures the antibodies that you may have developed against other peoples' HLA proteins. If you do have antibodies in your blood against other people, we say that you are sensitized. A particular kidney might not be right for you if we find that you have antibodies against that kidney's HLA proteins.

While you are on the waiting list, your blood sample is sent every 3 months to the HLA laboratory to check for matching with a potential donor.

It is important that you have a PRA sample drawn every 3 months if you are on the kidney transplant waiting list. Your dialysis unit usually does this.

If the HLA laboratory does not have a recent PRA sample for you, you may not be matched for a kidney even if one becomes available for you.

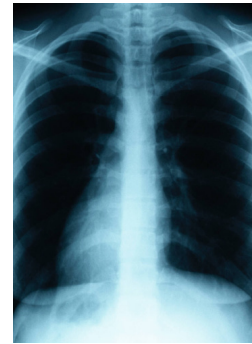
Viruses

All donors and recipients are tested for HIV, Hepatitis B, and Hepatitis C so the transplant team can make decisions about anti-rejection medications, antibiotics or tests to be done after the transplant. If your potential donor carries these viruses, the donor may be turned down.

We also screen for other viruses such as cytomegalovirus, Epstein-Barr virus, varicella virus, human T-lymphotrophic virus, and West Nile virus.

2. Imaging

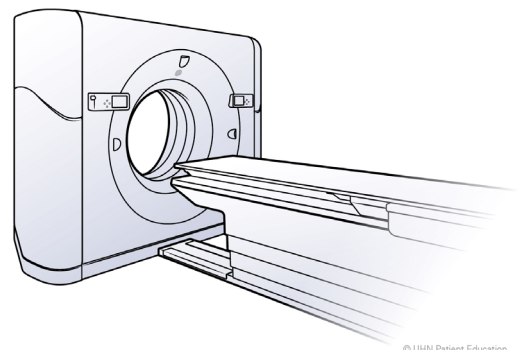
A **chest x-ray** checks for any problems with your lungs.



An **abdominal ultrasound** looks at the organs in your abdomen such as your liver, pancreas, spleen, and kidneys.

Iliac dopplers measure blood flow in your pelvis and legs to make sure the blood vessels can attach to the new kidney. **Carotid dopplers** measure blood flow to your brain through the neck vessels. This test is only done in specific patients as needed.

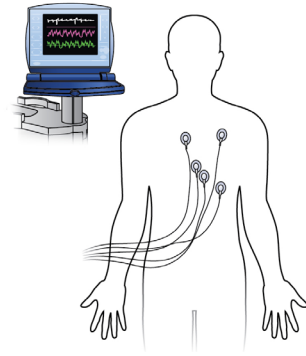
A **CT scan** is sometimes done to further check the flow and condition of the blood vessels in your legs.



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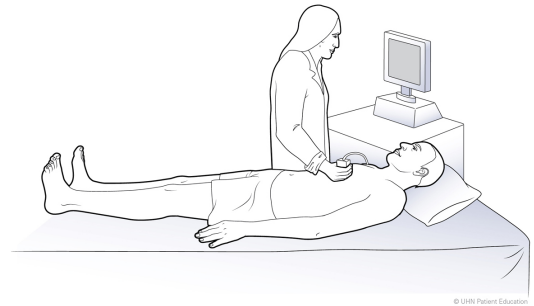
3. Electrocardiogram (ECG)

An ECG checks the rhythm and rate of your heart.



4. Echocardiogram

An echocardiogram tells us how well the heart is pumping blood. It also gives information on your heart valves and the size of your heart.



5. Myocardial Perfusion Study or Dobutamine Stress Echocardiogram

This is usually called a **stress test**. A technologist injects a mild radioactive substance into your vein and then takes images of your heart. The test shows how the blood is flowing in and around your heart muscle and how strong the muscles are.

A similar test that may be done called the dobutamine stress echocardiogram. A technologist injects a medication called dobutamine to increase the heart's rate and contraction. Then images of the heart are taken by ultrasound.

6. Tests that check the urinary system

If there is a concern with your urinary tract or how your bladder is working, we will refer you to a urologist (specialist in the urinary tract).

7. Diabetes screening

All non-diabetic kidney transplant candidates must have an **oral glucose tolerance test (OGTT)** to check for diabetes. Any results that are not normal will be looked at by your dialysis team. This information may also be used to help determine the type of immunosuppression you will receive after your kidney transplant.

8. Cancer screening

There are a few tests done before transplant listing to screen for common types of cancer. We follow the current Canadian guidelines for cancer screening. Depending on your age cancer screening may include a PAP test, mammogram, and colon cancer screen. Your family doctor usually decides.

Regular screening is important and should be arranged by your family doctor or nurse practitioner.

9. Consultations

You may need to speak with other members of the team as part of your assessment, including a psychiatrist, social worker, transplant surgeon, anesthetist, or other specialists. In some cases, a specialist at TGH may give a second opinion at the time of transplant.

10. Tuberculin (TB) skin test

A TB skin test is done to see if you have ever been exposed to tuberculosis (TB). The test is done by putting a small amount of TB protein under the top layer of skin on your inner forearm. If you have ever been exposed to the TB bacteria, your skin will react by developing a firm red bump at the site within 2 days.



You will not be approved for a transplant until all the tests are completed and all recommendations have been followed. More testing and treatment may be needed. Your transplant team will let you know.

Each kidney transplant candidate is reviewed by the entire transplant team before a final decision is made about being placed on the transplant list.

After the assessment process

Once the tests and consults are done, the transplant team will review all of the results.

There are a few possible outcomes:

It is too early to give you a transplant

Your kidney disease has not progressed enough to need a kidney transplant. Your nephrologist and the transplant nephrologist will check you regularly.

Sometimes the assessment finds other medical or surgical problems that need more testing before we can make a final decision. The transplant team will arrange for more testing and appointments with medical specialists.

Transplant is too high risk

The assessment may show that you are not likely to benefit from a transplant due to certain medical and/or psychosocial issues. In this case, the transplant team feels that the best thing for you would be to remain on dialysis.

You are accepted for living donor kidney transplant

If there are no problems, and you have a willing and eligible living donor available, you can go ahead with a live donor transplant. You may need to meet with the surgeon to talk about any concerns. Your donor must be cleared by the donor team before the transplant can be booked.

You can be added to the waiting list for a deceased donor kidney transplant

If you have done all the assessments and are suitable for a transplant but you do not have a live donor, you will be added to the kidney transplant waiting list.

This is a list of all TGH patients waiting to receive a kidney transplant from a deceased donor. You are placed on the list according to the date that you first began dialysis. Your transplant team will speak to you about how long the wait will be.

Making the decision about getting a kidney transplant

Every person is assessed individually to make sure that a transplant is the right decision for that person. The best situation for a kidney transplant is:

1. Your transplant assessment shows that you are healthy enough for a transplant and can probably go through the surgery.
2. You want to have a transplant and you understand and accept the responsibilities before and after the transplant.
3. You have a family member or support person to help you through the process.
4. You have proof that you can pay for your medication (through work or the provincial Trillium program).

We will help you understand the benefits and risks of a transplant. This will give you the information you need to make an informed decision. If a transplant is recommended, the final decision to have it is up to you. We will support your choice whether you would like to have the transplant or not.

Having a transplant will change your life a lot. Before you make this choice, you need to be prepared to make many life-long changes. These include:

- Being a part of your health care team
- Learning about your treatments
- Taking your medications
- Exercising regularly
- Getting blood tests and other tests done as scheduled
- Going to your clinic appointments

Our goal is to make your transplant as safe and as successful as possible. We will do everything we can to make your transplant work for you. We will work with you in making decisions and help you to understand your treatments.

After my assessment: having my transplant

A kidney transplant is not a cure for kidney failure. It is only one treatment option.

Transplanted kidneys do not last forever. The half-life of deceased donor kidneys is about 10 to 12 years. **Half-life** is that time point at which 50% of patients have lost their kidney transplant while living donor kidneys last longer. Some patients need a second or even third transplant.

There are advantages and disadvantages to kidney transplants. For most people, the positives far outweigh the negatives.

Here is a list of the advantages and disadvantages:

Advantages	Disadvantages
<ul style="list-style-type: none">• No more dialysis• More energy• Fewer restrictions on what you can eat or drink• Feeling better and healthier• On average, living longer than people on dialysis	<ul style="list-style-type: none">• Taking medication to prevent rejection for the rest of your life• Slightly higher chance of infection, cancers and diabetes• Side effects from medications

Types of transplant

Consent is part of all donations and transplants.

Consent means that the donor or legal representative **agrees** to donate their organs. A transplant can only happen if the recipient consents to the procedure.

There are 2 possible types of transplant:

1. Living donor transplants
2. Deceased donor transplants

1. Living donor transplants

About half of all kidney transplants at Toronto General Hospital come from living donors. Living donors are people who choose to donate one of their kidneys to a loved one or someone in need of a kidney.

Living donors can donate only at UHN and across Canada if:

- They are old enough (so that an informed decision about donation can be made).
- They are donating **under their own free will and altruistically**. This means that no one is forcing them to donate a kidney and they are not being paid to donate.

Living donation has both advantages and disadvantages for the recipient:

Advantages	Disadvantages
<ul style="list-style-type: none">• High success rate for recipients of living kidney donations• A transplant date that can be booked ahead of time• Less time on dialysis before your transplant or possibly no dialysis at all• Donor feels good about helping another person	<ul style="list-style-type: none">• Asking a family member or friend to donate• Risk of the surgery for the donor• Long-term risks to the donor after surgery such as high blood pressure and slightly reduced kidney function

Living donors go through many tests similar to the recipient to find out if they are healthy enough to donate and can donate specifically to their intended recipient. These tests will assess:

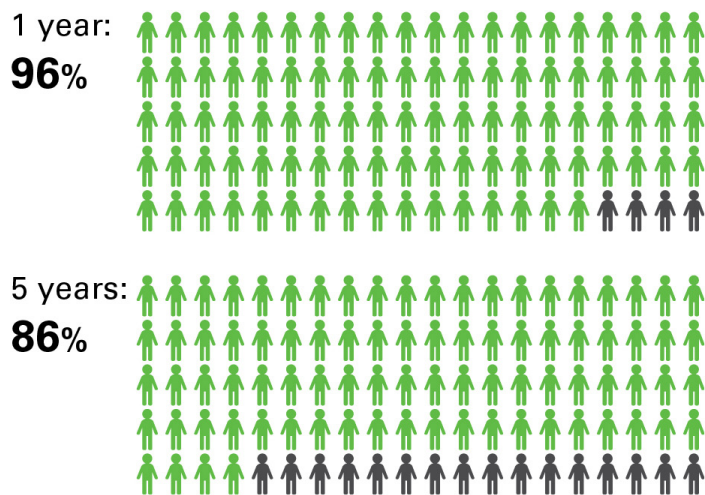
- The overall health of the donor
- How the kidneys are working
- Structure (anatomy) of the kidneys
- Blood pressure
- Blood type
- HLA (tissue) typing
- Testing for viruses such as HIV, hepatitis B and C

If any issues arise, more tests are done. In some cases, the donor may not be able to donate their organ. Often, conditions such as high blood pressure, heart disease, obesity, and diabetes make the transplant unsafe for the donor.

Your donor will be assessed by a separate specialist and any information about the donor will only be passed on to you if the donor has agreed to it. When a donor is considered eligible, a transplant date is booked.

What is the success rate?

The success rate for living donor kidney transplants at the Toronto General Hospital is 96% at 1 year and 86% at 5 years for people having their first transplant.



What are the risks to the donor?

Risk means the chance that something will go wrong after the surgery. There are risks to the donor when donating a kidney. All surgery, including kidney donation, has risks. Fortunately, the risk of death is very small (about 3 in 10,000 surgeries).

One of the hardest parts about living donation is how you will feel about someone donating one of their kidneys to you. You may feel worried or even guilty, but this is normal. Psychosocial professionals on the transplant team can talk with you and your donor about these feelings. Please talk openly with your transplant team about your concerns.

How does a donor contact the hospital to get an assessment?

All live donors should call the assessment office (see page 129) and/or submit a health questionnaire. The office will contact the donor directly by phone or mail to discuss the next steps.

Patients with donors outside of the Toronto area can be assessed for donation.

Out-of-province donors need to do basic blood and urine testing which can be done through a family doctor. These tests are reviewed by the donor nephrologist. If the tests are acceptable, the transplant assessment office will contact the donor to complete an assessment at a transplant centre closer to the donor's home.

Out-of-country donors need to complete blood and urine tests in their home country. The results tell us if they should be evaluated further. The transplant office will mail a letter to the donor with to take to his/her Canadian Embassy when applying for a visitor's visa. A complete assessment is done when the donor arrives in Canada. Donors from outside of Canada need to be prepared to stay for about 4 months to complete the assessment, book the surgery, and recover from surgery. The Program for Reimbursing Expenses of Living Organ Donors (PRELOD) is available for out-of-country donors. Please contact the donor assessment office for more information. See page 129 for contact information.

Even though this guide covers the donor process, donor assessment information is private. The assessment coordinator will only share donor information when absolutely necessary and the donor must agree to share this information first.

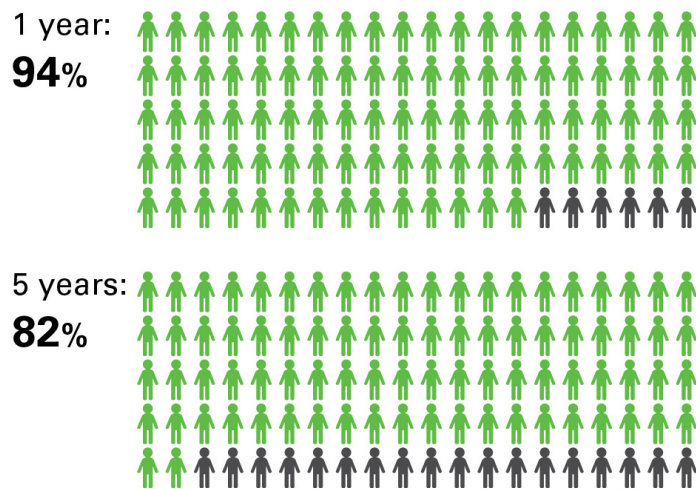
2. Deceased donor transplants

Kidney transplants from deceased donors are from people who have agreed (either directly by signing their organ donor card or through their families) to donate their kidneys after death.

Deceased donors are one of two types: either brain dead donors or donors after cardiac death. In the first case, the donor is declared brain dead by a doctor using strict and widely accepted criteria. A person who is brain dead will not survive, no matter what medical care they receive. In the second case, the donor is not brain dead but has such severe disease that it is impossible for him or her to recover.

What is the success rate?

The success rate for deceased donor kidney transplantats at the Toronto General Hospital is 94% at 1 year and 82% at 5 years for people having their first transplant.



Since these donors die of sudden and unexpected causes, it is impossible to predict when a kidney will become available. This is why it's hard to predict exactly how long a person will wait for a transplant. In general, the waiting time for a transplant ranges from 4 to 10 years from the date of starting dialysis.

These are the common advantages and disadvantages of deceased donor transplants:

Advantages	Disadvantages
<ul style="list-style-type: none">• Important source of kidneys for those without a living donor• Donor has their wish fulfilled	<ul style="list-style-type: none">• Waiting time for transplant is unknown, but can be years• Kidney may not work right away• Longer time spent on dialysis may affect a person's health and make them too sick for transplant• Longer time on dialysis before transplant is linked to poorer results after transplant

For deceased donors, recipients are chosen based on:

1. Where they are on the waiting list
2. How well they are matched to the donor (based on tests which are the same for all potential donors).

Note that your listing date is your dialysis start date regardless of when you become active on the waiting list. The listing date for patients who had kidney transplant(s) in the past is the most recent return date to dialysis.

Special transplant programs

There are special programs at the Toronto General Hospital that may help you to receive a living or deceased donor kidney transplant. These are explained below.

Living donor programs

Sometimes a donor is fit to donate but the donor and the recipient don't have matching blood groups. Another problem is if the **crossmatch test** is positive. This means that the recipient has antibodies in their blood to the donor's kidney.

In both of these cases, a kidney transplant can lead to a very serious rejection right after transplant.

There are 4 ways that a kidney transplant can still happen in either case. These are:

1. Living Donor Paired Exchange program
2. Desensitization program
3. ABO incompatible donor program
4. List Paired Exchange program

1. Kidney Paired Donation (KPD)

Two donors switch recipients so that they can still donate and their original recipient receives a suitable transplant organ. The KPD is a national program that includes all of the transplant programs across Canada and is run by the Canadian Blood Services. Some donors may have to travel to other cities for their transplant surgery. The waiting time may vary depending how long it takes for matches to be found.

2. Desensitization Program

This program has recipients take medications and do other treatments before the transplant to reduce the level of antibodies in your blood to your donor's kidney. You can possibly receive the donated organ although the risk of rejection is higher. Your doctor will discuss this with you.

3. ABO Incompatible Donor Program

If you and the donor have incompatible blood types, the medications and treatments used for desensitization can also allow you to receive a kidney from your donor.

4. List Paired Exchange Program

Often, the exchange program is done after other options have already been tried.

The donor will donate an organ anonymously to the kidney transplant waiting list at the Toronto General Hospital in exchange for their intended recipient receiving the next available deceased donor kidney.

Expanded Criteria Donor Program

A deceased donor qualifies as an Expanded Criteria Donor (ECD) if:

- The donor is age 60 or older
- The donor is age 50 to 59 years and has certain risk factors
- The donor has at least 2 of the following:
 - A history of high blood pressure
 - Stroke as the cause of death
 - Reduced kidney function

Kidney transplants from an ECD have a higher chance of not working in the long term. For some recipients ECD kidneys can help them live longer compared to staying on dialysis. It may shorten the time needed to wait for a kidney (sometimes to 1 or 2 years).

This program has increased the number of deceased donor kidneys available for those on the waiting list. Donors in this category are only approved for transplant after the transplant doctors and surgeons decide there is a strong chance of a successful transplant.

When an ECD kidney is available, the transplant team will decide whether to offer the two kidneys to two separate people or both kidneys to one person.

Some people would do better with an ECD kidney transplant than others would. Your transplant nephrologist will tell you more about this program if he or she feels that you qualify and would benefit from this type of transplant.

Chapter 3: The Cost of Having a Transplant

Costs of transplant medications

The day you go home from the hospital after your transplant, you must be ready to pay for your medications. The cost can range from \$2,000 to \$4,000 each month. Even the best private insurance programs may not completely pay for all these medications.

You must arrange to pay for your transplants costs before transplant

This includes having a private drug plan and/or a government program to help you.

If you do not these, you need to pay the **full cost** of the medications by:

- VISA or MasterCard
- Cash or debit

The Transplant Unit will **not** give you medications to take home. The Toronto General Hospital **does not** have a drug assistance plan for transplant patients.



What about private insurance?

If you have private insurance coverage from an insurance carrier (such as Sun Life or Manulife), we will ask you for this information. Here are some questions you need to ask your insurance carrier:

- How much of the medication costs is covered by my private insurance?
- Will you pay for my medications automatically (online) or do I have to pay up-front and you reimburse me later?

If you have to pay for your transplant medications up-front, you must have a plan. Transplant medications are very expensive and can cost several thousand dollars a month. Your insurance carrier may agree to have the pharmacy bill the insurance company for your medications, but this **MUST** be arranged by you and set up in writing ahead of time.

- Are there any yearly or lifetime maximums for drug coverage?
- If I pay for your medications up-front, how long will I have to wait for reimbursement?
- Should I submit a medication list for your pre-approval?

Not all insurance companies will want to review the whole list, but you can ask about the main immunosuppression medications that are also the most expensive ones. Ask your Social Worker or Transplant Coordinator for this list. Or, download a copy from the Patient Toolbox area of the Transplant Pharmacy website at www.transplantpharmacy.ca.

Whatever your private insurance drug coverage may be, you must also have Ontario Drug Benefit (ODB) coverage – from the Trillium Drug Program, Senior Benefits, or Ontario Works (OW) / Ontario Disability Support Program (ODSP).

What is the Trillium Drug Program (TDP)?

The **Trillium Drug Program** (TDP) is an Ontario government program that helps Ontario residents pay for the high costs of prescription medications. It is one way to access Ontario Drug Benefit coverage (ODB). Patients with or without a private drug plan can apply.

Registering with the TDP is free. Applying for it may take minutes, but it takes at least several weeks for the TDP to process your application. **Apply early!**

If you're not sure about any part of your application, you may call the Trillium Drug Program (see page 42). If you still need help, call your Social Worker or Medication Reimbursement Specialist.

Being registered with the TDP does not affect your private drug coverage and patients with private coverage can still use this program. You can apply to the Trillium Drug Program to help pay for drugs that are not covered or only partly covered by your private drug plan. The Trillium Drug Program checks your combined household income with Canada Revenue Agency for the previous taxation year, so it is best to have your income tax up-to-date. If your taxes are not up-to-date, there may be other documents TDP will accept as proof of income. Ask your Social Worker about this.

You will need to pay a **deductible** every year. The deductible is an amount of money you have to pay to the pharmacist before your insurance plan will start to pay for your medications. In other words, your insurance plan “kicks in” only **after** you’ve paid the amount of your deductible out of your own pocket.

The deductible is based on your household’s net (or after tax) income and the number of people in the household. This deductible is based on the number of people in your household and is about 4% of their combined income.

The Trillium Drug Program is a household plan. List everyone who lives in your home on the application so all those people will have coverage for eligible medications.

Important: Households that have inactive accounts for more than 18 months or 1 benefit year plus the first 2 quarters of the next benefit year will be terminated.

The government will send you a Letter of Termination, so you need to contact the TDP right away to reopen your account. Even if your account is closed, you can still re-apply. You must keep your registration active with the TDP and make sure your coverage is active at the time of your transplant and after. Renew every year before **August 1st**, whether you have had a transplant surgery or not. Send any out-of-pocket receipts to the Trillium Drug Program (and keep copies for yourself) to show activity on your account.

The Trillium Drug Program will send out a letter every spring, either asking you for updated information or confirming automatic renewal of your application. If you do not receive such a letter by mid-June, please contact the TDP.

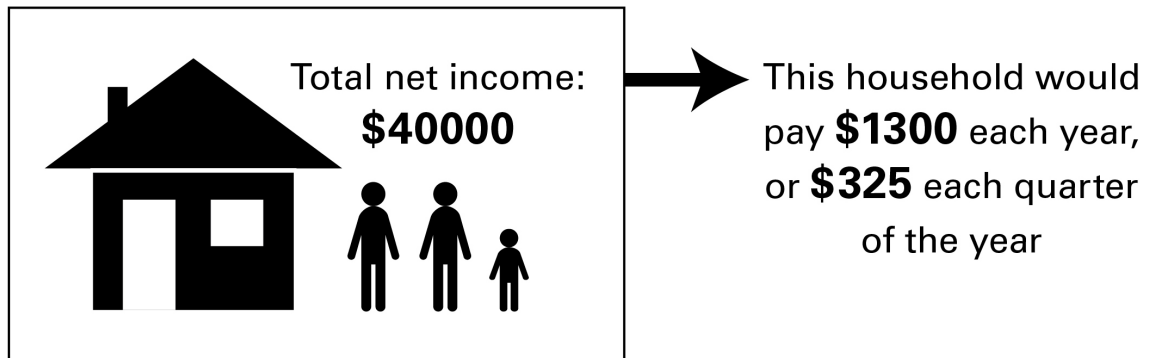
How does the TDP work?

The TDP sets out the deductible for the whole ‘Trillium’ year. To make it easier to pay this deductible, Trillium divides the amount into 4 payments or quarters:

- August 1 to October 31
- November 1 to January 31
- February 1 to April 30
- May 1 to July 31

Once you have paid your quarterly deductible, the TDP will pay for the rest of the medications for that quarter, except for a \$2 **co-payment** fee for each prescription.

For example, a household with 2 adults and 1 child with a total net income of \$40 000 will have a yearly deductible of about \$1,300. In each quarter, the family will have to pay \$325 in prescription drug costs before the TDP will pay the rest (except for the \$2 co-payment per prescription).



You can join the TDP part of the way through a program year and this will mean you will have to pay only the portion of the deductible for the part of the year you will be covered. Sometimes you can backdate your enrolment.

The program only covers prescription drugs on the Ontario Drug Benefits (ODB) list of covered drugs, which may not include all of the drugs your doctor prescribes.

Prescriptions filled outside of Ontario or written by a doctor outside of Ontario are not covered.

Some medications are covered by the ODB only in certain cases. These are called **limited use medications**. If you are on Limited Use medications, the paper prescription you take to your pharmacy should have a 3-digit Limited Use number (LU###). If you are sending receipts to the TDP, make sure you get and send a copy of that paper prescription to make sure the TDP knows that the medication is covered for you. If you just send the receipts and the LU number is not shown on them, the TDP will not consider that medication eligible.

Who can apply?

You can apply if:

1. You live in Ontario and have a valid Ontario Health Card
2. You are under age 65.

What if I am 65 or over?

As an Ontario resident, your Senior's Ontario Drug Benefit (ODB) will be in effect on the first day of the month after you turn 65. You do not have to apply for it. Let your pharmacist know you are 65 and show your Ontario Health Card.



Seniors have to pay a \$100 deductible at the beginning of the ODB year (starting August 1) and then a \$6.11 co-payment per prescription. If you are filling your prescriptions at a UHN hospital pharmacy (such as the Transplant Outpatient Pharmacy), this co-payment will be lower.

Low-income seniors may qualify for a reduced co-payment. You should apply for this if you are a single person and have a net income below \$16,018 or as a couple, you have a net income of below \$24,175. Ask your pharmacist how to apply.

If you are on the Trillium Drug Program but will be turning 65 in the coming 'Trillium' year, make sure you re-apply because you will need it until your Senior's ODB takes effect.

How do I apply?

Applications are available:

1. At most pharmacies
 2. Through your Social Worker
 3. Online at:
http://www.health.gov.on.ca/en/public/programs/drugs/opdp_forms.aspx.
(You cannot submit the application online. It must be printed, and sent with hand written signatures).
- Fill out the application. You need proof of income for each household member age 18 and over is required.
 - Send receipts for prescriptions you have already paid for—they may count towards your yearly deductible. (In this case, remember to backdate your enrolment to the date of the first prescription filled since August 1st).
 - If you have no previous out-of-pocket drug costs, or very small costs, then you can use the current date as your enrolment date. Your deductible will be less because it is prorated after August 1st. This means that you will only pay a portion of the yearly deductible equal to the portion of the year you will have coverage.
 - You will receive a letter within 3 to 5 weeks confirming that you are accepted into the program. The letter will state how much your household's yearly deductible will be.
 - Sometimes people receive a letter asking for more information. Your coverage will not be in place until the TDP has this additional information and sends you the letter stating your file is complete.
 - Once you are registered with the program, you will need to use your Ontario Health Card when filling your prescriptions at the drug store.

What if I have more questions?

Contact the Trillium Drug Program directly or visit their website at:
www.health.gov.on.ca/en/public/programs/drugs/programs/odb/opdp_trillium.aspx

Address: PO Box 337 Station D
Etobicoke, ON
M9A 4X3



Hours: 8:30 am to 5:00 pm

Phone: 416-642-3038 (Toronto)

Toll Free: 1-800-575-5836

Text telephone (TTY): 1-800-387-5559

Fax: 416-642-3034

Email: trillium@ontariodrugbenefit.ca

Others ways to get Ontario Drug Benefit (ODB) coverage

Senior's ODB: see “What if I am 65 or over?” *above*.

Ontario Works (OW) and Ontario Disability Support Program (ODSP):

If you receive OW or ODSP, you'll receive a monthly drug card for ODB in the mail. Usually, it is kept on file with your local pharmacist. Be sure to bring an up-to-date copy to the hospital when get your transplant. You will need it to pay for your prescriptions the day you leave the hospital at the Transplant Outpatient Pharmacy.



Remember:

- All Ontario Drug Benefit programs and all prescriptions include an out-of-pocket expense.
- Patients must be prepared to pay for their medications when they leave the hospital.

All patients must be registered with the Trillium Drug Program or have access to an ODB program before being placed on the transplant waiting list or proceeding with a living donor transplant.

Financial information

Being sick for a long time and having a transplant affects your finances. It is important for you to know this and plan ahead. Your income may change and you may have new expenses. Each person's situation is different.

This section has information about how you may get financial support.

You may be eligible for financial help from:

- Insurance – through your workplace or Employment Insurance (EI) Sickness Benefits
- Canada Pension Plan Disability (CPP-D)
- Ontario Works (OW)
- Ontario Disability Support Program (ODSP)
- Employment and retraining funding

Insurance

Workplace Benefits

Some people have **short-term disability (“sick pay” or STD) or long term disability (LTD)** benefits from their employer. Your employer will be able to tell you more about this.

Employment Insurance (EI) Sickness Benefits

If your work does not have sick pay or disability benefits, you might qualify for Employment Insurance (EI) Sickness Benefits. You must have worked and paid into EI for a certain number of hours.

EI Sickness Benefits give you up to 15 weeks of income after a 2-week waiting period.

Your local EI office (phone Service Canada **1-800-206-7218**) can give you information about qualifying. Your employer will give you a Record of Employment as part of the application process and a doctor will need to complete a medical certificate.

Canada Pension Plan (Disability) (CPP-D)

If you are under 65 years old with a serious illness or disability for a long time, you are not able to work, and you meet the eligibility criteria for paying into CPP, you can apply for CPP Disability benefits. CPP considers your application based on the medical information that they receive from your doctor. Drug benefits are not included.

Fill out an application as soon as possible. It can take many months to process.

Ontario Works (OW) (formerly “Welfare”), also called Social Assistance

You can apply for Ontario Works (OW) if you have a low income, few assets, and are at least temporarily not able to work. Your total household income and assets determine if you are eligible. (Your home is not usually included as an asset in determining eligibility). Ontario Drug Benefits are provided.

Ontario Disability Support Program (ODSP)

If your doctor says your illness will prevent you from working for a year or more, you may qualify for the Ontario Disability Support Program (ODSP). This program is for patients who are medically approved and have a low household income and few assets. Your home is not usually included as an asset in determining eligibility. Ontario Drug Benefits are provided.

Important: When getting both CPP-D and ODSP

If you are approved for CPP-D, you may still be eligible for a supplementary amount if your CPP-D amount is lower than the ODSP maximum payment. Let ODSP know that CPP-D has already approved you and this will speed up your ODSP application.

If you are on ODSP and then approved for CPP-D, you must let ODSP know how much you will be getting from CPP-D. Your ODSP amount will be reduced by that amount, but this avoids an ODSP overpayment which you will have to pay back.

Employment and retraining funding

Some patients returning to work after transplant need to change their job. You may qualify for Ontario or Canadian government programs for vocational assessment and retraining.

There may be a waiting list and we suggest speaking with the programs before transplant, if possible. If you are accepted into the program, you may qualify for financial assistance to cover retraining costs and a living allowance.

For those on ODSP: contact your caseworker.

For those on CPP Disability: contact Service Canada.

Private companies also offer vocational assessments, counselling, and retraining for a fee. Some community agencies offer career counselling free of charge or for a small fee.

Other financial questions to think about

Here is a list of some costs that you will have to pay before and after your transplant. Also find some tax tips to help you recover or get back some of this money.

Parking

Parking near the hospital is expensive. The closer to TGH you park, the more expensive it is. There are some parking lots a short walk from the hospital. Check the costs of nearby lots if you will be coming to TGH often. Consider taking public transit, the TTC or Go Transit, whenever possible.

Wheel Trans

If you are physically disabled, you can apply for Wheel Trans. It is available to people who are not mobile enough to use the regular Toronto transit system.

To get a Wheel Trans registration number, you must have an interview with the TTC. They may be able to give you transportation to the interview appointment if you are in a wheelchair or use a cane or walker to move around.

- Phone 416-393-4111 to set up an appointment.
- Visit their website at <https://mywheel-trans.ttc.ca/>



Accommodation

If you live outside Toronto and need to drive to Toronto General Hospital often, you may need to stay in Toronto or closer to Toronto for a few weeks after transplant for your follow-up care. Talk with your Social Worker if you have questions. We can give you a list of hotels and other accommodations close to the hospital.

This list is also available on the UHN website at:
www.uhn.ca/PatientsFamilies/Patient_Services/Pages/places_to_stay.aspx

Travel

For patients living in northern Ontario, the **Northern Health Travel Grant** helps to pay for some of the travel costs to medical appointments. You must pay first and then apply for a partial reimbursement. Your local doctor needs to fill out their section of the travel grant form. Then, bring this form to your TGH specialist to fill out their section.

If you are receiving OW or ODSP, they may help you with travel costs. You must apply ahead of time at your local office for help. OW and ODSP must approve first before they will reimburse you.

Other costs

There are other costs during your transplant. You may need to buy special supplies that are not covered by drug plans. For example, if you develop diabetes, you will need equipment and supplies that may not be covered by drug plans.

Tax tips

Call the Canada Revenue Agency (CRA) for information about which income tax deductions relate to your illness and your transplant.

Or, visit their website for information about Medical Expenses and Disability Tax Credits: www.cra-arc.gc.ca/menu-eng.html



Remember: you must have receipts for all your expenses. You cannot claim anything for which you have received other re-imburements.

Medical Expenses that you **may** be able to claim include:

- Long distance telephone calls to the hospital
- Any diagnostic tests you paid for (such as blood tests and scans)
- Payments to hospitals
- Medications that you paid for yourself, including the amount of your Trillium Drug Program deductible
- Premiums for private health insurance plans
- Ambulance co-payment fees
- Parking
- Out of Canada medical expenses – for the part that OHIP did not cover

You may be able to claim expenses for yourself, your spouse, and perhaps your dependents. You can claim expenses for any consecutive 12-month period ending in the year for which you are filing your income tax return.

- If you travel more than 40 km one-way for treatment, you may be able to claim transportation costs: train, bus, or taxi costs.
- If you used your own car, you can claim a reasonable amount (check with the Canada Revenue Agency). You will need to prove the number of trips you made. Keep a travel log with the mileage that you travelled. Have your health care provider sign and date it each time you come to the hospital.
- If you travel more than 80 km one-way, you can claim reasonable expenses for meals and accommodation as well.

Disability tax credit

This credit applies mostly to people on dialysis and not usually to people after a successful transplant.

People on dialysis should apply for this tax credit. One of the eligibility criteria is undergoing “life sustaining therapy to support a vital function.”

You can ask your doctor to fill out a Disability Tax Credit certificate. Include this in your tax return. You may qualify for a credit up to \$7,697.00 (2014 amount)

Website: www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html

The Kidney Foundation of Canada has a section on their web site called Tax Tips. They have included an extra form called the Addendum to the Disability Tax Credit that may help you qualify for the credit.

Please visit their website at <http://www.kidney.ca/taxtips>

If you have any questions about this credit, please ask your Social Worker in your dialysis centre.

Chapter 4: What is Advanced Care Planning?

Advanced Care Planning means thinking about who your Power of Attorney is or who your Substitute Decision Maker will be, as well as making **Advanced Directives** or **Living Wills**.



Decisions about your health care should reflect your wishes and values. There may be a time in the future that you are unable to make decisions about your medical care. This situation may be temporary or permanent. It could happen suddenly or slowly. If you become unable to make decisions for yourself, there are 2 important things for you to consider and make known:

1. What are your specific wishes about your health care?
2. Who would you want to make decisions for you? See more information about “Powers of Attorney” on page 52. If you are unable to make decisions about your health care, the law allows other people to make decisions on your behalf.

It is important that the person making decisions for you follow your wishes, not what they feel would be right for them. Sometimes family members assume that they should be your Substitute Decision Maker but you may want someone else in that role. It is a good idea to discuss your choice with them. You may wish to discuss this in more detail with your Social Worker.

A Living Will or Advanced Directive is a document that could be written into the “Instructions, Conditions and Restrictions” section of the Power of Attorney for Personal Care form.

A Living Will is not the same as a Last Will and Testament, which directs your wishes after your death. A Living Will or Advanced Directive directs your wishes while you are living but incapable to make healthcare decisions.

Please talk about your care wishes with your family and anyone else who might make decisions for you in the future. We are always happy to answer any questions that you have about Advanced Care Planning.

There are guides that you can use to help you with Advance Care Planning, please visit the website link below:

www.advancereplanning.ca/making-your-plan/how-do-i-do-advance-care-planning/advance-care-planning-workbooks-and-guides.aspx

Powers of Attorney

There are 2 kinds of Powers of Attorney (PoA) in Ontario:

- Power of Attorney for Personal Care
- Power of Attorney for Property

Please visit the Power of Attorney booklet online from the Ministry of Attorney General to access PoA forms:

<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>

Power of Attorney for Personal Care

A Power of Attorney (PoA) for Personal Care is a legal document that allows you to choose a person to make decisions about your care when you are not able to make them yourself.

To appoint a Power of Attorney, you need to fill out a legal document called Power of Attorney for Personal Care.

If you do not assign a PoA for Personal Care, the law states who can make decisions in the following order of priority (see below). This person is called your **Substitute Decision Maker**.

- spouse
- adult children (16 and over) and parents
- siblings
- extended family members

If there is no one to make decisions for you, the law states a public official can be appointed to make decisions for you when you cannot.

Give copies of your PoA document to the person(s) you have appointed and to your hospital caregivers (Social Worker or Transplant Coordinator) to keep in your chart.

Power of Attorney for Property

Your Power of Attorney for Property is a legal document that allows you to appoint a person or persons (age 18 or over) to make decisions about your finances or assets. This person is called your Attorney. (Your “Attorney” used here is not your lawyer.)

Unlike the Power of Attorney for Personal Care, your Attorney is empowered to act on your behalf once the document is signed, unless you specify that your Attorney can only act on your behalf if you become incapable. Read page 10, “Date of Effectiveness” of the Power of Attorney booklet from the Ministry of Attorney General (see link on previous page) to understand your options and safeguards.

Also, unlike the Power of Attorney for Personal Care, if you do not complete this document, there is no list of substitutes that automatically have the authority to manage your affairs. It may mean that your bills, rent, etc. may not get paid or your plans to buy or sell a property or car cannot be completed until you are well enough again to do that yourself.

If you don’t manage your finances for a long period of time, your family may have to go to court to get someone appointed. This person can to act on your behalf if you have not already chosen someone.

Because Powers of Attorney for Property are powerful documents, you may want to talk to a lawyer.

Chapter 5: Being on the Waiting List

Going on the list

When a final decision is made that you are eligible for a transplant and your transplant assessment is complete, you will be placed on the Trillium Gift of Life Network (TGLN) waiting list.

The waiting list is made up of people throughout Ontario who are waiting for a donor kidney. TGLN is the organization that takes care of the organ sharing system in Ontario. They are responsible for the allocation, retrieval and transportation of organs. They support donor families and organize the organ donation process with transplant centres. Visit the TGLN website for more information: <http://www.giftoflife.on.ca/en/>

The TGLN wait list is on a central computer and is based on a set of provincial guidelines. There are strict criteria that place you on the list for transplant. How long you will wait for a transplant depends on:

- Your blood group
- Your length of time on dialysis
- Organ availability
- Antibodies or PRA against the donor (see page 18)

The deceased donor process

If getting a kidney transplant from a living donor is not an option, your name will be placed on the waiting list for a deceased donor kidney.

Organ donation in Canada is based on the kindness and generosity of the donor's family who agrees to donate a loved one's organs and tissues at a time of tragedy, stress, and grief. The continued success of transplantation relies on organ donation.

Here are the steps involved:

- Once a possible organ donor is found, TGLN determines if they have signed a donor card and if not, the legal decision maker is asked to consent to donate the organs.
- The organ donor is tested to make sure their organs are suitable for transplant. Tests include blood tests, virus tests, x-rays, and scans.
- After testing, organs are given to the most suitable patient on the waiting list.
- After the transplant program accepts the organ, the donor is taken to the operating room. A specialized team of surgeons work carefully to remove the organs for donation.

The waiting time for a deceased donor kidney varies from a few months to many years. This can be a very stressful and discouraging time for you.

Remember to live your life to the fullest that you are able to while you wait. Don't wait by the phone. Instead, do as much as you can, making sure all the time that we are able to reach you if we need to. Do all you can to stay healthy while you wait. Exercise if you can, even if all you can manage is short walks. Eat a good diet, and follow the diet plan your dietitian has given you. If you are overweight, try to lose weight. Obesity increases your surgical risks.

It is normal to feel afraid during this time. There are many resources available to help you deal with this stress. A good place to start is with the members of your transplant team.

Contact us at any time if you have a possible living donor.

Listed clinic

While you are on the waiting list, you may be asked to have your transplant testing updated and come to the Transplant Listed Clinic to see your Transplant Coordinator and Transplant Nephrologist. It is very important that these tests are completed and you keep your scheduled appointments because they are valuable opportunities for the transplant team to monitor your health and ensure you are suitable for transplant.

Keeping in touch with us

When a kidney becomes available, time is critical. We need to get in touch with you right away. We need to have **all** your phone numbers including home, cell and work.

We must know how to contact you at **all** times. Please provide us with:

- Pager number (if applicable)
- Home number and address
- Work number (if applicable)
- Cell phone number
- Contact information for a nearby friend or relative

Always keep your contact information up-to-date.

Going on hold

Once you are on the wait list, situations may come up that will not allow you to have a kidney transplant. This may be for medical or personal reasons, such as temporary absences from Ontario.

In such cases, you must call your Transplant Coordinator to tell them that you will be temporarily away so they can put your name on hold on the waitlist.

You must tell your coordinator right away if:

- Any of your contact numbers change
- You will be more than 2 to 3 hours away from Toronto and unable to return in time for transplant
- You are admitted to another hospital
- You are sick or have an active infection
- You no longer have drug coverage

Going on hold does not affect your place on the waiting list. On hold means you are inactive on the TGLN wait list. Please note that you are still gaining time on the wait list but you are not eligible to receive a kidney.

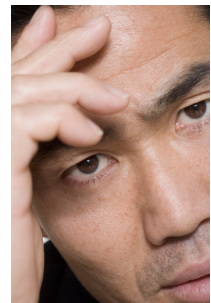
When you return from travel or vacation, please tell your Transplant Coordinator so that your name is no longer on hold. Your dialysis unit can ask to put you on hold on the waiting list and also ask to remove your name from the on-hold list.

Refusing to come in when called in for a transplant will mean that you are placed on hold. You must call your Transplant Coordinator to talk about your situation.

The stress of waiting

You can feel a lot of stress while waiting for a kidney transplant.

There is no right way to feel or react to stress. Everyone has their own experience during the transplant process and copes in different ways. Some of the common signs of stress are:



Physical Reactions:

- Fatigue
- Change in appetite
- Muscle tension, tremors
- Headaches
- “Butterflies” or nausea (upset stomach)
- Problems Sleeping
- Nightmares
- Startled reactions
- Dizziness

Emotional Reactions:

- Overly sensitive
- Feelings of helplessness
- Fear or anxiety
- Feeling numb and disconnected
- Self-doubt
- Mood swings
- Anger
- Frustration

Changes in Thinking:

- Problems concentrating
- Problems making decisions
- Trouble with problem solving
- Forgetfulness
- Slower thinking
- Loneliness and withdrawing from others

These reactions to stressful events are normal. If you feel overwhelmed or find that you are having problems with day-to-day coping, please contact the Transplant Team for help.

Ways to help manage stress

- Structure your time. Keep busy and try to keep your life on as normal a routine as possible.
- Talk to people – sharing your feelings is helpful in reducing stress.
- Write your feelings down in a journal or diary.
- Reach out to others or spend time with people you trust.
- Ask for help. People around you often want to help but don't know what to do. Let them know what would be helpful to you.
- Give yourself permission to feel sad and frustrated. Everyone can have an 'off' day.
- Do not use alcohol or recreational drugs to cope with stress. It may feel helpful at the time but it can cause more problems.
- Exercise as much as possible.
- Keep healthy and stay active.

Stress reduction programs

It is easier to cope with stress by having some practical tools to use.

The Multi-Organ Transplant Program offers individual support for managing stress and the Mindfulness-Based Stress Reduction (MBSR) program. This may help you deal with stress better. It can help you manage your anxiety and emotional responses better.

How do I enrol?

Call 416-340-4452 for more information about the 8-week Mindfulness Program. The course is free. There is a fee for the CDs that come with the program.

Coping with depression and anxiety

Because of the physical and emotional challenges of transplant, many patients feel depressed and/or deal with anxiety and panic. These conditions are **very common** and can be treated. It will not affect your status on the transplant list.

Symptoms of depression and anxiety are similar to those of stress:

Watch for these symptoms of depression:

- Irritability
- Frustration
- Fatigue
- Sadness
- Isolating yourself from others
- Changes in appetite
- Change in sleep patterns
- Loss of hope

Anxiety may feel like:

- Persistent tension
- A feeling of dread
- Excessive worry
- Restlessness
- Feeling on edge

Many patients benefit from a referral to Transplant Psychiatry to learn about different ways to handle their symptoms, receive counselling and support, and for medications.

Like any medical condition, sometimes medications are needed to help patients function at their best. The Transplant Psychiatry Team will review all your medications to make sure they are safe and effective before and after the transplant.

After transplant, depression and anxiety are also common. These problems may happen while you are still in hospital or for several months to years after transplant. Depression and anxiety can be treated with medication. The Transplant Psychiatric Team can help. Please let your Transplant Coordinator or doctor know if you need help.

Spirituality

The Spiritual Care department at UHN feels that health care involves the whole person – mind, body, and spirit. During times of illness, trauma, and loss, people often need more than physical care to help them cope. Many find that caring for their spiritual needs helps during life transitions.

Spiritual Care helps both the patient and their family or support person:

- Explore spiritual meaning in times of sickness
- Look at what the medical experience means in one's life, family, and community
- Cope with death or dying

The transplant program has a Spiritual Care Professional who is part of the Multi-Organ Transplant Team. Please feel free to contact this service at any time. You can see a Spiritual Care Professional through your Transplant Coordinator or in the In-patient unit.

Chapter 6: Getting the Call for Transplant

Time is critical when an organ becomes available. If the Recipient Transplant Coordinator on-call cannot reach you after 1 hour, he or she must choose another recipient.

Messages will be left where answering machines are available.

If you can't reach the person who called you, call the Transplant Inpatient unit at **416-340-5163**. Ask to speak to the Charge Nurse.

Call for a transplant may come at any time of the day or night. The Recipient Transplant Coordinator on-call will tell you their name and ask you:

- How are you feeling?
- Do you have any colds or fever?
- Do you have a sore throat or diarrhea?
- Did you have any recent surgery, blood transfusions, or infections?
- Are you taking any antibiotics?
- Are you on any blood thinners?
- When was your last dialysis session?

If there are no concerns about your current health, the Recipient Transplant Coordinator on-call will ask you to come to the hospital as soon as possible.

Do not eat or drink from this time on.



Remember: refusing to come in when called for transplant will mean that you are immediately placed on hold and must contact your Transplant Coordinator to talk about your situation.

If you live within the Greater Toronto Area, you are expected to be at the hospital within 2 hours of the call. If you are coming by car, please make sure that someone drives you.

We expect you to arrive at the hospital as soon as possible after you are called in for a kidney transplant. Depending on the time that you are called to the hospital, you will either go to the Admitting Department or the Emergency Department. The Recipient Coordinator on-call will tell you where to go.

Time	Location
Monday to Friday: 7:00 am to 11:00 pm	Admitting Department Toronto General Hospital 200 Elizabeth Street
Saturday, Sunday and holidays: 3:00 am to 11:00 pm	Ground Floor, Eaton Wing
After hours: 11:00 pm to 7:00 am or 8:00 am	Emergency Department

Once you arrive at the hospital, you will be admitted to the Multi-Organ Transplant Unit where the nurses will prepare you for surgery.

What if I am called in as a back-up?

In some cases, you may be called in as a back-up. This happens when there is a chance that the primary person will not receive the kidney. We will do a special blood test before surgery to see if you are a good match. The test usually takes about 5 to 6 hours. If tests shows that the primary person on the list is not a good match (this is called a 'positive' result), then you, as the back-up will be given the kidney.

When transplants are cancelled

A false alarm happens when you are called in for your transplant, and at the last minute, your surgery is cancelled.

This is one of the more upsetting things that can happen to you while you are on the transplant list. Please remember that false alarms can happen.

Your surgery can be cancelled for many reasons:

- Donor kidneys are found to be unsuitable
- Positive cross matches between you and your donor
- Your tests may show changes that mean the surgery cannot be done safely

Call your Transplant Coordinator to confirm your status on the waiting list after a cancellation.

You and your family may feel shock, disappointment, and sadness when this happens. All of these feelings are normal. You should call your Transplant Coordinator to talk about any concerns you have about a cancellation.

What to bring to the hospital

Bring these items with you to the hospital:

- Toronto General Hospital blue ID card
- Ontario Health Card (or provincial health card from another province)
- All of your medications in their original containers or packages and an accurate list of all of your medications (with names, doses, frequency)

After your surgery, and once you are transferred to the Multi-Organ Transplant Unit, your family or support person should bring:

1. This guide
2. Your drug card (if you have one)
3. A telephone calling card
4. A credit card to pay for a television or phone, medications and return trip home
5. Walking aids if you use any (such as a cane)
6. Small change to cover minor costs such as a newspaper or coffee
7. A small overnight bag
8. All the toiletries you need
9. Any sleeping aids such as mouth guards or a CPAP machine (for patients with sleep apnea)

Other ideas:

- Your own pillow if you have any special needs
- Portable headphones to use while watching TV or listening to music
- A change of comfortable, loose clothing
- Books, magazines, and portable devices to pass the time
- Free WIFI (“UHN Guest”) is available

Do not bring:

- Any valuables such as rings, watches, jewelry
- Large amounts of cash
- Any large electrical equipment that needs to be plugged in (you can bring an electrical razor or hair dryer)
- Cellular phone (you cannot use this in the hospital)

Valuable electronic equipment (such as laptop computers) might be stolen and should not be brought to the hospital. The hospital is not responsible for lost or stolen items.

Chapter 7: My Transplant Surgery

For a living donor kidney transplant, you are admitted 1 day before your surgery to finish your assessments.

For deceased donor kidney transplants, you will have the same assessments done right before the surgery to make sure it is safe to go ahead with the transplant.

You can expect to be in the hospital for about 7 to 10 days after your transplant surgery and stay in several different places. The chart below shows where you will be at different times during your care.

<u>Stage of your care</u>		<u>Where you will have your care</u>
Getting ready for transplant	→	MOT Unit - 7West
Right after your transplant	→	Post-Anesthetic Care Unit (PACU)
When you start to recover	→	MOT Acute Care Unit (ACU) – 10A
Completing your recovery	→	MOT Unit - 7West

Before and during my surgery

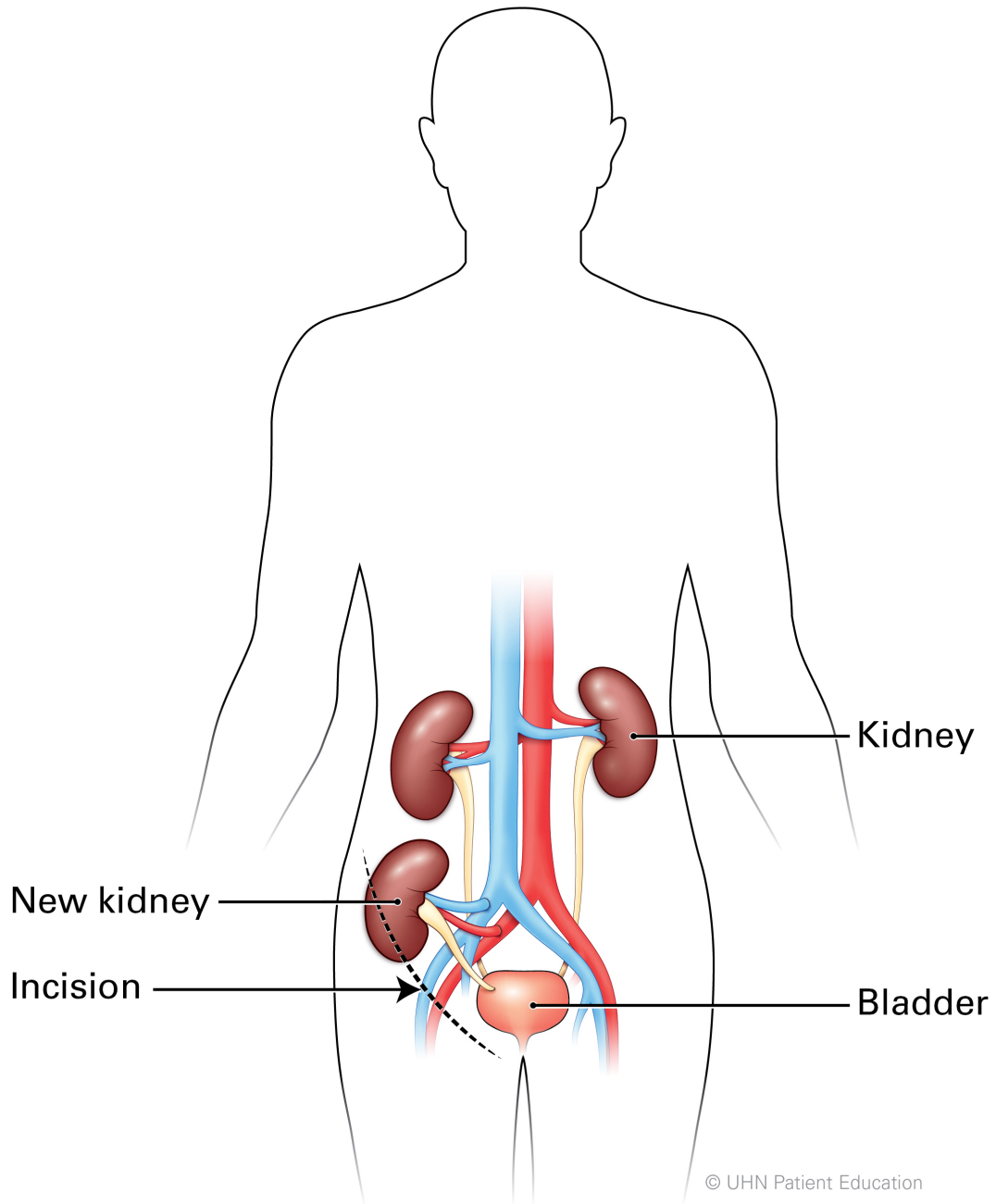
What happens before the surgery?

- You are admitted to the Multi-Organ Transplant Unit – Peter Munk Building (7 West).
- Nurses and doctors examine you.
- Some patients need dialysis before their transplant.
- Blood tests, an ECG, and a chest x-ray are done.
- An intravenous line (IV) is inserted into your arm and you will receive medications such as antibiotics and immunosuppressive drugs.
- Doctors will see you to talk with you about the surgery and answer any questions you may have.
- The time it takes to prepare you for the surgery lasts from about 3 to 6 hours. If you are having a living donor kidney transplant, you will be in the holding area for 1 to 1.5 hours.

What happens during the surgery?

- A transportation assistant takes you to the operating room.
- Your care is transferred to the operating nurse.
- The operative nurse comes to see you and later, takes you into the operating room.
- Once you are settled in the operating room, the anesthetist gives you your anesthesia to put you to sleep.
- The surgery takes about 3 to 4 hours.
- While you are asleep, your transplant team puts in several lines and tubes.
- The incision (cut) is in either your right or left lower abdomen (see the picture on the next page). It is about 10 to 15 inches long.
- In most cases, the surgeons attach the artery and vein of your new kidney to an artery and vein which go to your leg.
- The ureter (the tube carrying urine produced from the kidney) is attached to your bladder. The surgeon places a stent (small plastic hollow tube) in your ureter to lessen the chance of leaking or obstruction. This is removed about 6 weeks after transplant during a cystoscopy procedure.
- Staples are placed along your incision. A nurse in the transplant clinic removes the staples about 2 weeks after surgery. Having the staples removed causes a little discomfort because the staples only close the thin upper layer of skin. Small supporting tapes called steristrips are often placed on the incision for a few days after the staples are removed.

A picture of where the transplanted kidney may be placed.



After my surgery

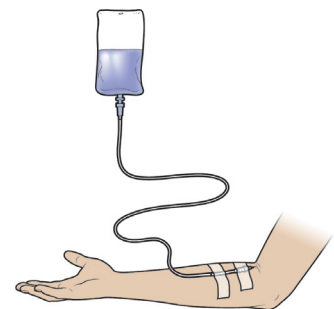
After your transplant, your new kidney may or may not work properly right away.

- You may need dialysis depending on how your new kidney is working. This doesn't mean your kidney transplant was unsuccessful.
- You will have several blood tests taken every day. This tells us how your transplant is working and gives us the information that we need to change your medications properly.
- You will have an ultrasound of your transplanted kidney.

What to expect while on the MOT Acute Care Unit (ACU):

Eating and drinking

You will start by receiving fluids through an IV. Usually 1 or 2 days after your surgery you will start to take food and drink by mouth. It is important to progress little by little because eating and drinking too soon after surgery can give you nausea (upset stomach) and vomiting.



Checking your heart and blood pressure

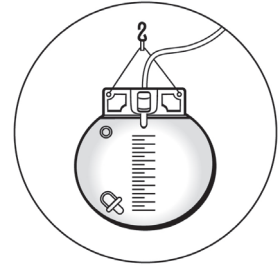
A heart monitor or ECG machine is used to watch your heart rate and rhythm. Leads with wires are attached to your chest to keep track of your heart. Nurses check on you using screens that are found on many places within the unit. Nurses check these monitors often. Alarms do not always mean there is a problem.

Caring for your incision site (cut)

The incision area will be sore after surgery. We will give you pain medications if you need them. There will be a large dressing over the incision that the nurse will change as needed. It will be uncomfortable to move at first, but it is important to get out of bed when your nurse asks you to protect your skin from pressure sores and to help keep your lungs clear.

Having a urinary catheter

The urinary catheter (also known as a Foley catheter) will drain your bladder of urine. The tube is connected to a collection bag which is emptied regularly. The catheter does not stop you from moving but it is important to let the bladder heal after the surgery. Nurses can also use it to keep track of how much fluid you are taking in and putting out; this tells us how your kidney is working.



Intravenous lines (IV)

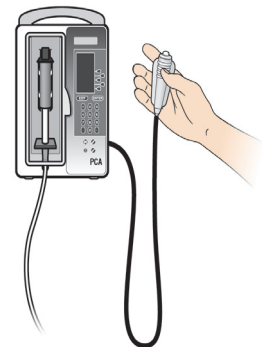
This is a small catheter inserted into a vein in your arm, hand or neck. It gives you fluids and medications. There are different types of IVs which may be used.



Coping with pain

Most patients have pain after surgery and are worried about it before the transplant. Pain medication will be used to help manage your pain. Some options are:

- IV patient-controlled analgesia
- IV pain medication given by the nurse
- Intramuscular injections
- Pills



Other ways to help with pain are also used, such as relaxation breathing.

Exercise

It is very important for you to become more independent after surgery by slowly doing more activity. Sitting up in the chair, self-care (such as washing and cleaning yourself), and walking in the hallway are excellent ways to improve your strength and get more energy. We also encourage your family or support person to help with this part of your recovery.

Deep breathing and coughing

Learn deep breathing and coughing exercises after your surgery to help lower your risk of lung problems such as pneumonia and infections after your surgery.



What to expect while on the MOT Unit – 7West:

Our transplant nurses will help you continue to recover, get stronger and learn how to manage with your new kidney transplant.

You may be in a private, semi-private or a room with 4 beds. Private rooms are first given to patients who need isolation, then to patients with private insurance coverage or those who pay the daily fee.

Sometimes we need to move patients from room to room. This can be upsetting and inconvenient for you. We move recipients only because we are trying to meet the needs of all our patients. We put safety first to make sure that all our patients get the best care possible.

Chapter 8:

Staying on the Multi-Organ Transplant Unit

Visiting hours are from 11:00 am to 9:00 pm each day.

- All visitors must sign in at the reception desk and wear a “visitor” sticker while on the unit. This is to make sure that only authorized visitors are on the unit.
- We recommend only 2 visitors in the recipient’s room at one time. We ask this because the recipient and family or support person need to focus on recovery at this time. If there are more people who would like to visit, this can be done in the visitor’s lounge or another part of the hospital.
- Overnight visitors are NOT allowed in patient rooms.
- Each patient should choose a spokesperson. Only that person should call for updates. Ask your designated spokesperson **not** to call from 7:00 to 9:30 in the morning or evening. This is a very busy time for the patients and nurses.
- Children under 12 should not visit because of the risk of infection to the child. An adult must be with children who are visiting at all times. If children are restless, visitors will be asked to visit with the recipient in another part of the hospital.
- Visitors for patients in isolation must follow the precautions in place to protect the patient, themselves, and others on the unit. This may mean wearing a gown, gloves and mask when entering the room.
- Visitors must wash their hands when they enter and leave the patient’s room and the Multi-Organ Transplant Unit. Hand sanitizer is also available throughout the hospital.

- Visitors with signs of fever or flu will not be allowed on the unit.
- Visitors are NOT allowed to use patient bathrooms. Public washrooms are located in the hallway outside of the inpatient area.
- Visitors may be asked to temporarily leave a recipient's room for staff to give care or talk about private matters with the recipient. Visitors in the next bed may also be asked to leave.
- Cut flowers, plants and latex balloons are NOT allowed on the transplant unit.
- Food may be brought in for patients while in hospital. Please check with your nurse to make sure that you are not on a restricted diet.

Chapter 9: After my Transplant

After your transplant we will focus on:

1. Checking on how your kidney is working
2. Watching for signs of rejection and infection
3. Changing your immunosuppressive medications if we need to
4. Recovery and rehabilitation
5. Teaching you about living with a transplant
6. Supporting you

Watching for rejection

Rejection happens when your body's immune system recognizes your new kidney as foreign (not part of your body). If rejection happens and we don't treat it, it can damage your transplant. We will do blood tests often, and possibly biopsies to check for rejection.

Making changes to your immunosuppressive therapy

After your transplant, you will start immunosuppressive medications. These medications stop your immune system from rejecting your new kidney. It is important that we have you on the right doses. It is normal to have many changes in your drugs until we find the right balance. We make changes based on: lab test results, symptoms, side effects to the medications and biopsy results.

Education and teaching

During your hospital stay, the transplant team will give you information about taking care of yourself now that you have a new kidney. We will help you to recover from your surgery and teach you how to return to your normal activities.

Rehabilitation

As you begin to feel better from your surgery, the nursing staff will help you to slowly increase your activity. Day by day, you will do more and more. This will help you as you go through the healing process.

Reassurance

As you recover, we will answer your questions. We will address your concerns. Please ask us if you have any questions and tell us if you are wondering about anything.

Chapter 10: Planning for Discharge

Your kidney team will see you each day and let you know when you will be able to go home. We call this **discharge**. We will let you and your family or support person know one day ahead of time so that you can make sure you are prepared before you go home.

Rehabilitation

The team may decide that spending a short time in rehabilitation may improve your strength and independence. If you and the team decide that this is the best option for your recovery, we will transfer you to St. John's Rehabilitation Hospital (or a similar hospital) and continue to work closely with our partners there to check on your condition and recovery.

Paying for medications

Every patient is expected to pay for their medications when they are discharged. Discharge can't be delayed because of issues with drug coverage. All patients, except seniors and those who receive a monthly drug card as part of their disability benefits, should be registered with the Trillium Drug Program before their surgery. If you have private insurance, you will need to have insurance information for our pharmacy.

Education

We believe that it is very important for you to have the information and knowledge needed to care for yourself at home after your surgery.

There are 2 important areas that we focus on:

1. The self-medication program
2. Self-care and monitoring education. Please read "Life After Transplant", chapter 14 of this guide, for more information.

You need to do this before being discharged from the hospital:

- Watch teaching videos about life after transplant (4 lessons)
- Join a self-medication class with a family member or support person
- Receive discharge teaching from a discharge coordinator

Be prepared

Before leaving the hospital, be completely prepared:

- Have the right clothes for the return trip home
- Arrange for transportation home
- Arrange transportation to your appointments

If you are worried about your discharge, please let your transplant team know as soon as possible.

Here is a checklist of what you need to do:

Before leaving the hospital, you should feel comfortable with:

- Knowing how to take all of your medications
- Wound care and dressing changes if necessary
- Your blood sugar monitor if necessary
- Measuring your own blood pressure
- Measuring the amount of liquid you drink and the amount of urine you make.



When you are discharged, please check that:

- You have a ride home and they know what time to come to the hospital
- You have received your medications
- You have your first follow-up appointment booked and a way to get there

Medic Alert

It is very important that you get a Medic Alert bracelet or necklace or update your old Medic Alert information after your transplant. This bracelet or necklace could save your life and protect your transplant if you become unable to speak for yourself. Your Medic Alert identification should show the type of transplant that you had (for example "kidney transplant"), and that you are **immunosuppressed**.

A form is included in a 'discharge package' that we give to you as you prepare to leave the hospital. Please ask for help, if needed, to complete the form. It will take 6 to 8 weeks to receive your Medic Alert bracelet or necklace.

Your Transplant Coordinator can assist you with completing the form. It is your responsibility to complete the form and mail it in. Once you receive your bracelet or necklace, you should always wear it.

Visit the Medic Alert website at: www.medicalert.ca for more information.



Medic Alert bracelet



Medic Alert necklace

Communication after discharge – The Easy Call System

Communication between you and your Transplant Coordinator is one of the most important parts of follow-up after transplant. To make this as easy as possible, the Multi-Organ Transplant Program has a patient voice message system called "Easy Call".

The system meets the special needs of transplant patients and their coordinators. It lets our transplant patients pick up and leave messages for their Transplant Coordinator quickly and easily.

You can use Easy Call any time you need to communicate with your Transplant Coordinator.

Easy Call features:

- Access 24 hours a day, 7 days a week
- Access from any touch tone phone
- Transplant Coordinators can contact patients urgently
- Messages will be answered through Easy Call as soon as possible depending on their urgency.
- Messages can be heard by other health care professionals
- Message cues are available in 6 languages
- Patients can repeat messages to make sure they understand
- Easy Call saves and archives all messages.
- Messages are picked up regularly on business days (Monday to Friday) between 8:00 am and 4:00 pm

Please have touch tone service on your phone so you can easily use the system (no rotary phones). Also, Easy Call will not work with phone lines that use ‘Bell call privacy’.

Each patient has a personal ID number to use his or her voice mailbox. This is called a PIN number. Each patient will also create a personal password.

Your PIN number:

- We will give you your own PIN number
- Please write it down in your transplant manual or in a safe place

My PIN number is: _____

My password is: _____

- Make sure that anyone who needs to hear your Easy Call messages, such as family members or support people, knows your PIN number and password.
- Give important phone numbers (cell, cottage, work, or other contact numbers) so your transplant team can reach you at all times
- If you change your address, phone number or health card please let your transplant team know as soon as possible
- Easy Call should only be used by you and your family. Family doctors or pharmacies can reach the Transplant Program using other numbers

How to use Easy Call

**To pick up or leave messages, please dial this phone number:
416-351-0793**

1. You will hear:
“Welcome to the Multi-Organ Transplant Program of the Toronto General Hospital. If you have a Personal Identification Number or PIN number, please press the pound sign (#) now.”
2. Press the # key on your telephone keypad.
3. You will hear:
“Using your touch tone keypad, please enter your PIN number.”
4. Enter your PIN, followed by the # key. The system will then say your name.
5. Enter your password after the # sign (if you haven’t changed your password yet, enter your PIN number again).

This password must be at least 8 numbers (for example: 12345678). Your password can be changed at any time. If you have tried to change your password and you get an ‘invalid password’ message, please hang up and end

- that session. Try again in a few minutes. To change your password, press '3'.
6. You are now in the **Easy Call** system.

The system will give you 2 choices:

“To listen to messages in your mailbox, please press 1.”

“To leave a message, please press 2.”

To pick up a message in Easy Call:

1. After using Easy Call with your PIN, press “1”.
2. You will hear:
“You have (number) new messages. To review new messages, please press 1.
To review old messages, please press 2.”
3. Choose and press either 1 or 2 to hear any new or old messages.
4. Sometimes the system will ask you to repeat a message that has been left by your coordinator. This makes sure that you have heard and understood the message correctly.

In this case, after hearing the message, you will hear:

“We need to make sure you have understood this message correctly.

Please repeat this message after the beep.”

5. In this case, repeat the message by pressing 1 to make sure you understood it. This lets your Transplant Team know you heard and understood the message correctly.

After listening to each message, you can listen to it again.

Messages cannot be deleted. They are saved for some time before being stored so that you can replay or review them if needed.

Once you are done listening to your messages, press 9 to hang up.

To leave a message in Easy Call:

1. After accessing Easy Call with your PIN, **press “2”**.
2. You will then hear: “To listen to messages in your mailbox, please **press 1**. To leave a message, please **press 2**.”
3. **Press “2”**.
4. You will then hear: “If you have a message about a clinic appointment, please press 1. To leave a message for your Transplant Coordinator, please **press 2**.”
5. Choose to press either 1 or 2 depending on what you need.
6. If you choose 2, you will hear: “Remember, messages left for your Transplant Coordinator will only be picked up from Monday to Friday, between 8:00 am and 4:00 pm. If this is a medical emergency, please go to your nearest Emergency Department, or hang up and dial 911. At the “beep”, record your message.”
7. Leave your message after the beep, and then hang up.

Tips for Easy Call:

- Pressing # may shorten cues
- Pressing 8 will return you to the previous menu
- If you forget your PIN number, you can still leave a message on Easy Call by listening further to the menu and choosing your coordinator’s name. Leave a message with your name and the transplant office will call you directly to let you know your PIN number
- If you forget your password, leave an Easy Call message and someone will call you with a temporary password – you have 24 hours to go in and create a new password or your temporary password will expire and you will need to call in again and get another temporary password
- As a new patient, you should check Easy Call every day – especially after clinic appointments
- After 3 to 6 months, depending on your health, you should be checking messages once a week
- Check before clinic visits in case you are asked to bring something or the clinic time or date has been changed
- You should also check messages a few times after clinic appointments or tests for any information

Chapter 11: My Medications

Your complete medication history

When you are admitted to the hospital, your Transplant Pharmacist will give you new prescriptions and review all of your medications with you to make sure that everything you need is ordered for you in the hospital. It is important for you to bring:

- **All** of your medications such as all prescription medications, any over-the-counter products, eye drops, puffers, creams
- A medication list, if you have one
- The name and phone number of your pharmacy

Your Transplant Pharmacist will give you a medication schedule to help you keep track of all the changes to your medications after your transplant and any new medications. They will review all the changes with you to help you understand how to take your medications properly at home. All of the medications you took at home before the transplant will be returned to you before you are discharged.

If you are re-admitted to the hospital for any reason after a transplant, it is still important that you bring in all of your medications. This will help your Transplant Pharmacist make sure that you keep taking the right medications while in hospital.

The Self Medication Program

The Self Medication Program helps you learn about your transplant medications so that you will be able to take them properly and safely when you go home.

After your transplant, you will take a Self Medication Class taught by one of the Transplant Pharmacists. Your support person(s) should also take it with you. These classes are usually held on the Transplant Unit every Monday, Wednesday and Friday afternoon. You must take a class before you can be discharged from the hospital after your transplant.

During the Self Medication Class, you will learn about:

- The different transplant medications you will be taking
- Why you need to take these medications
- How to take them properly
- The possible side effects of each medication

In these classes, the Transplant Pharmacist will also answer any medication questions you may have.

After you take the class, you will start taking some of your transplant medications on your own while in the hospital. We will give you a one-week supply of each medication to keep at your bedside. We will also ask you to fill out a form to record when you took each dose. Your nurse and pharmacist will check it every day. This will help you to better understand your medications and get into a routine. When you are ready to leave the hospital, we will give you prescriptions for all of the medications you need to take at home.

Completing the Self Medication Program is an important step before going home.

The Transplant Outpatient Pharmacy

The Transplant Outpatient Pharmacy meets the unique needs of transplant patients. You can fill out all of your prescriptions (both transplant and non-transplant) at the Transplant Outpatient Pharmacy after your transplant admission.

The staff at the Transplant Outpatient Pharmacy work closely with you, your transplant doctors, coordinators, and other members of your health care team to make sure you get the most out of your medications.

The Transplant Outpatient Pharmacy has many services and programs including refill reminders, personal medication schedules, and blister packaging to meet your medication needs. You may also book an appointment for a free MedsCheck. This is a one-on-one meeting with a Transplant Pharmacist to review of all of your medications.

Other services offered by the Transplant Outpatient Pharmacy include a free **Home Delivery Program**, which will ship your medications at no charge to your home or workplace anywhere in Ontario.

- Refills may be ordered 24 hours a day, 7 days a week using our automated online or phone prescription refill services.
- Our in-house medication reimbursement specialist will work with you to help you get the most coverage possible for your medications.
- For patients enrolled in the Ontario Drug Benefit program, the Transplant Outpatient Pharmacy waives the \$2 co-payment on all eligible prescriptions.

The Transplant Outpatient Pharmacy Website

There is a lot of new information to learn around the time of transplant. To help you answer any questions about transplant medications that come up before transplant, while in hospital, and even long after your transplant, we have some online programs and tools. Visit the UHN internet site any time to learn more about your transplant medications.

To visit the **Transplant Outpatient Pharmacy website**, please go to www.transplantpharmacy.ca.

On the website you can:

- Find answers to frequently asked questions about managing your medications and life after transplant
- Download a list of Drug Identification Numbers (DINs) from the Patient Toolbox for common transplant medications
- Download log sheets from the Patient Toolbox to help you manage common medical conditions such as high blood pressure or high blood glucose
- Prepare and download a personal medication schedule from the Patient Toolbox
- Get more information about the services offered by the Transplant Outpatient Pharmacy
- Refill your prescriptions at the Transplant Outpatient Pharmacy
- Enroll in the Transplant Outpatient Pharmacy Home Delivery Program.

The Transplant Medication Information Teaching Tool (TMITT)

The **Transplant Medication Information Teaching Tool (TMITT)** is an interactive internet-based teaching program to help you, your family, and/or your support person learn more about your transplant medications. You can learn at your own pace by choosing what you want to learn about.

Some of the features include:

- Brief and easy-to-follow audio-visual lessons on each medication
- Quiz questions to test your knowledge
- Printable information summaries for each medication

The TMITT program can be launched through the Transplant Outpatient Pharmacy website. Click on the link on the top of any page. You can also directly access the site by going to www.tmitt.ca.

Common medications after transplant

Information on medications that you may be taking after your transplant can be found in **Appendix 3** on page 135. Please read these information sheets for details about specific medications. You may also need to take other medications that are in this manual.

You will not be taking all of the medications listed here. Your transplant team will choose which medications are best for you. You may also need to take other medications to prevent or manage side effects from the anti-rejection drugs. Information about medications that treat common conditions such as high blood pressure, osteoporosis, and diabetes is not found in this guide. Please talk to your pharmacist for more information.

While taking anti-rejection drugs

Side effects from medications are common, especially right after your transplant. Your body getting used to the new organ and many new medications. Since each person responds differently to the medications, it will take some time for your transplant team to find the medication and doses that are right for you.

During the first day or two after transplant surgery, it is normal for recipients to:

- be tired
- have trouble concentrating
- have trouble sleeping

Your transplant team expects these side effects too and are trained to deal with them. Changing your medications or adding another one may help to reduce side effects. Talk to your transplant team if you have any questions about your symptoms.

Over-the-counter medications and herbal remedies

Many over-the-counter medications and herbal remedies can interact with your transplant medications and change your blood level of cyclosporine, tacrolimus, or other anti-rejection medications. They can lead to more side effects or even rejection. These medications include some antibiotics, non-prescription cold medications, or herbal remedies. Before you take any new medications or over-the-counter medications prescribed by another doctor, you **must** talk to your transplant team.

If you would like to take any herbal remedy (including herbal teas), always talk to your transplant team first. Herbal remedies are like medications and may interfere the medications you are already taking.

Pain medications

Do NOT take pain medications known as NSAIDs (non-steroidal anti-inflammatory drugs). This includes **ibuprofen** (the active ingredient in Advil® and Motrin® products) and **naproxen** (found in Aleve® and Naprosyn®).

- NSAIDs bother your stomach and raise the risk of bleeding.
- They may also cause your kidney not to work properly. Make sure that you read the label on all pain relief products very carefully and contact the transplant team if you have any questions.

If you are taking an 81 mg tablet of ‘baby’ Aspirin® once a day to prevent heart attack and stroke, this is fine if your doctor has asked you to take it. If you need to take medication for pain or headaches, acetaminophen (Tylenol®) is usually a safe choice. Talk to your transplant team before taking any other pain medication.

Chapter 12: Possible problems after transplant

Sometimes problems happen after your transplant surgery.

This does not mean that your transplant has failed. There is no need to panic. The transplant team will manage your recovery and deal with any problems.

When you are discharged, it is very important that your family doctor is part of your care. He or she can help with cancer screening and regular health exams.

For transplant-related illnesses, please call your Transplant Coordinator right away.

There are 2 major types of problems after transplant: rejection and infection.

Acute rejection

One of the main problems after transplant has to do with your immune system. The immune system is the body's defence system. Its main job is to protect the body from bacteria, viruses, and anything else that is considered "foreign".

Your transplanted kidney can be seen as "foreign" by your immune system. When the immune system attacks the kidney transplant, this is known as acute **rejection**. Acute rejections can be mild, moderate, or severe. It is important to treat acute rejection early to improve the chances that the kidney will recover.

When does acute rejection usually happen?

Most acute rejections happen in the first 3 to 6 months after the transplant. Also, most people do not have any symptoms when they have acute rejection, but their blood tests show a change in how the kidney is working. This is one of the reasons why regular blood tests are so important.

How does my transplant doctor know if I have acute rejection?

To find out if you have acute rejection, your transplant doctor will arrange for you to have a test called a **biopsy**. This involves putting a small needle into your kidney and getting a small piece of it to look under a microscope. Your transplant doctor will use the results of the biopsy to decide what kind of treatment you need.

Acute rejection:

- Happens in 10 to 15% of patients in the first year after transplant
- Is tested with a biopsy
- Does not mean you will lose your kidney
- Responds best when found and treated early

To prevent acute rejection, anti-rejection medications stop the normal immune response. The goal of these medications is to keep your kidney in good health for as long as possible.

The most common sign of an acute rejection episode is a higher serum (blood) creatinine level.

This is the main sign transplant nephrologists use to find acute rejection. Checking your serum creatinine level is done through regular blood tests after you are discharged from the hospital.

Other than an elevated serum creatinine, watch for these possible signs and symptoms of acute rejection at home:

- Pain or tenderness around the kidney
- Fluid retention (such as swollen hands and feet)
- Fever

Fever

- Let your Transplant Coordinator know if your temperature is over 37.5 °C (or 99.5 °F).
- You may be asked to go to the hospital or to the nearest emergency department.
- You will have a blood test done to see if the fever was caused by acute rejection. **Never wait for your temperature to drop back to normal.** Fevers caused by acute rejection can have temperatures that drastically go up and down.

Fluid retention (swollen hands and feet)

There are 4 signs of fluid retention:

1. **High blood pressure:** If you have a blood pressure monitor, check your blood pressure 2 times a day. Call your Transplant Coordinator if your levels are not normal. Your Transplant Coordinator can tell you what levels to watch.
2. **Weight gain:** It is normal to gain weight after having surgery. Let your Transplant Coordinator know if you have a large weight gain (one to two pounds or more) in 24 hours. Check your weight every day.
3. **Decreased urine:** If you are not urinating, please let us know right away.
4. **Swelling:** This may happen in your face, hands and feet.



If you have any of these signs, call your Transplant Coordinator right away. A sign of fluid retention could mean that your kidney is not working properly.

How acute rejection is treated

The treatment depends on:

- the type of acute rejection
- how serious the rejection is
- any other changes seen on the biopsy other than rejection
- the medications you are currently taking
- your medical history
- how long it has been since the transplant

The most common treatment for rejection uses an intravenous drug called **solumedrol**, which we give to patients who return to the hospital. Usually, one dose is given every day for 3 days.

During this time, we check you and if needed, give you larger doses of oral prednisone. Your doctor and nurses will talk with you about the acute rejection episode and the treatment.

After an acute rejection episode, you may receive other treatments in hospital or as an outpatient. You may also be on higher doses of your anti-rejection medications. You will probably have to do blood tests and come to clinic more often after an acute rejection episode.

Infections

What you need to know about infections:

- Anti-rejection medications decrease the body's ability to fight infections.
- Personal hygiene, such as hand-washing, is important.
- Eating well, getting plenty of rest, and exercising help you fight infection.
- Skin is a barrier to infection. Wash and dry any cuts or injuries.
- Tell your transplant team about any blisters, lumps, or growths.
- Let your transplant team know if you come in contact with chicken pox.
- If you have flu-like symptoms, please visit your family doctor.

There are 2 types of infections seen in transplant patients:

1. Infection of the incision.

This is not common but is more likely if you have diabetes or if you are overweight. Infections are treated with antibiotics which can help with healing of the incision. You may also need special dressings placed over the incision to help it heal.

2. Infection in another part of the body.

This mainly happens because of the anti-rejection medications. Infections are treatable but can also be serious and you may need to go back to the hospital. You will be treated with antibiotics or anti-viral drugs. In serious cases, you may need to decrease or stop one of the anti-rejection medications so your immune system can fight the infection.

Watch for these signs and symptoms of infection:



- **Fever.** Infection is the most common cause of a fever. (Let your Transplant Coordinator know if your temperature is over 37.5 °C or 99.5 °F).
- **Pain while urinating.** This may be a sign of a bladder or kidney infection. It can also happen before a fever.
- **Foul smelling urine.**
- **The sudden need to urinate.**
- **Coughing.** This may be a sign of a chest infection. It is commonly associated with a cold.
- **Pus leaking from the incision site.** This may be an infection of the incision.
- **Redness, swelling, or pain** around the incision may be a sign of infection.

Tell the transplant team if you have any of these symptoms.

Some other signs and symptoms of infection include:

- Sore throat
- Shortness of breath
- Change in the colour of your phlegm
- Cold sores
- Flu-like symptoms (such as severe fatigue, muscle aches)
- Rash

Side effects from medications are common, especially right after your transplant. Your body getting used to the new organ and many new medications. Since each person responds differently to the medications, it will take some time for your transplant team to find the medication and doses that are right for you.

Potential complications of anti-rejection drugs:

Cytomegalovirus (CMV)

- Up to 80% of people have been in contact with this virus before transplant.
- Everyone is screened for the virus including living donors.

When you have a healthy immune system, you don't usually get sick from this virus. When your immune system is suppressed, the virus can make you sick. You have a slightly higher chance of getting sick during the early stages of recovery because you are taking high doses of anti-rejection drugs. Fortunately, there are effective anti-viral medications for dealing with CMV.

Since many people have had CMV, you may get an organ from a donor that had CMV. If you have a higher risk for infection because your donor had CMV, we will start giving you medications to prevent CMV infection soon after your transplant.

CMV infection is most likely to happen within a few months after transplant. We do not test for CMV infection after the first few months.

CMV infection may lead to flu-like symptoms (such as fever, fatigue, and muscle aches) or may only be detected in a blood test (typically in earlier infections).

Multi-drug resistant infections:

Multi-drug resistant infections are becoming more common in the community as well as in hospitals. These infections don't respond to antibiotics. Two examples are MRSA and VRE. We try to reduce the problem of multi-drug resistant infections in our hospital by:

- Isolating patients at risk.
- Screening all patients when they are admitted to hospital.
- Only giving antibiotics when absolutely necessary.
- Washing hands or using hand sanitizer.

You can help to reduce infection by:

- Taking all your antibiotic prescriptions.
- Washing your hands and using hand sanitizer.
- Following the isolation signs posted on hospital doors. You may need to wear masks, gloves, or gowns.

Viral Hepatitis (B or C)

Donors are tested for hepatitis B and C viral infections. Organs from donors who have been exposed hepatitis B can be given to certain recipients who have also already been exposed or immunized. Donors with a history of Hepatitis C are not used at the Toronto General Hospital.

It is important that you protect yourself and visit your family doctor to get immunized while you wait for transplant. Everyone should be vaccinated against hepatitis B. No immunization is available for Hepatitis C.

Epstein Barr Virus (EBV)

EBV causes flu-like symptoms. Most people have been exposed to EBV and have immunity. Transplant recipients without any previous immunity will be given anti-viral medications to reduce the risk of EBV infection from the donor. You will be screened for immunity to this virus when you are doing your assessment.

West Nile Virus

If you have this infection, you probably will not have any symptoms or only minor flu-like symptoms. This virus is passed by insect bites, but can be passed through blood transfusions or organ transplants. Right now blood products and organ donors are screened for the virus.

During the spring and summer, when the risk of mosquito bites is high, you will need to protect yourself from biting insects by:

- Wearing insect repellent and long sleeved clothes
- Avoiding going outside during the early morning and at dusk

What you need to know about some new infections

As new infections come up, the transplant program will look at the risk to you. We will tell you about the best practices to lower your risk of infection. For example, with the H1N1 flu outbreak in 2009, we asked all recipients to get immunized for this virus plus the regular flu vaccine.

Travel can also expose you to other infections. You may need to be vaccinated before leaving for some countries. Do this early by calling a travel clinic for more information about these vaccinations.

Call the Medisys Travel Clinic at: 416-730-5700

Check the website at: www.medisys.ca/en-ca/travel-health

Travel clinics are not covered under provincial insurance. You can also check the Centers for Disease Control (CDC) website (www.cdc.gov) about travel precautions and infectious outbreaks.

Shingles

Shingles is a viral disease that causes rashes on the body. It happens because of an infection by the varicella zoster (VZV) virus, which also causes chicken pox. If you become infected, the virus is contagious and anti-viral medication will need to be started.

It is not safe to take the live shingles vaccine after your transplant since it may cause a varicella zoster infection. You can get the vaccine before the transplant if you are more than 50 years old. The cost of the vaccine may be covered by your drug coverage. You will need to be on hold on the waiting list for 4 weeks after the vaccine.

Polyoma Virus

This is a virus found in most people. The virus travels to the kidney where it remains inactive. The virus can become active when taking your anti-rejection medications. We regularly test for the virus with a blood test called a polymerase chain reaction (PCR). Tests are only done at the University Health Network.

Cancer

One of the possible effects of anti-rejection drugs is a greater chance of getting certain cancers.

Two important things that the immune system does are reduce the risk of cancer and control infection. When the immune system is weak, the chances of getting cancer increase.

Research studies show that the chances of getting these cancers, and others, are higher due to anti-rejection drugs:

- Lymphoma
- Skin cancer
- Cervical cancer (women)

These cancers may happen at any time after transplant.

Lymphoma

- A serious complication that may happen in the first year or many years after transplant.
- Treatment usually involves chemotherapy and reducing the dose of anti-rejection drugs.
- Can be linked to the total dose of medications used to treat acute rejection episodes.

Skin Cancer

- Reduce the chances of getting skin cancer by protecting your skin from direct sunlight.
- Wear a brimmed hat outside.
- Use sunscreen (and re-apply regularly) with an SPF of at least 50 on all exposed skin (including hands, face and ears) even during the winter.
- Avoid being in the sun between 11:00 am and 3:00 pm when the sun is at its brightest.
- Look for unusual moles or cuts on your body. Tell your doctor if you see any because skin cancer can be easily treated when it is found early.

Cervical Cancer in Women

- Starts as abnormal cells on the cervix.
- Women must have PAP smear tests every 3 years or as recommended by your family doctor to find these abnormal cells before they become cancerous.
- Finding cervical cancer early usually makes this type of cancer curable.

You have the same chance of getting other cancers not mentioned above as everyone else, but treating cancer is more complicated in transplant patients because you have to take immunosuppressants. The earlier cancer can be detected, the easier it is to treat.

For Women:

Do a breast exam every month and tell your doctor if you find anything unusual right away.

Once you reach the age of 50 years, have a mammogram every 1 to 2 years. Depending on you and your family history, you may need earlier check-ups. Please talk with your family doctor.

For Men:

Check your testicles every month and let your doctor know if you find any lumps right away. Men should visit their family doctor every year for a regular check-up. Talk with your transplant team about any of these complications.

Diabetes

Sometimes patients already have diabetes before transplant but some patients will develop it afterwards. Again, this is because of the anti-rejection drugs you are taking to protect the transplanted kidney. You have a higher chance of getting diabetes if your family has a history of diabetes and/or if your blood sugar was high before transplant.



Diabetes is a disease where blood sugar levels are higher than normal. There are two types: Type 1 and Type 2 diabetes.

Type 1 diabetes happens when the pancreas can't make insulin. Your body needs insulin to use sugars as energy.

Type 2 diabetes is the most common form of diabetes for people who have had transplants. It happens when the body can't make enough insulin or the body's cells can't use insulin properly.

The treatment of diabetes depends on how serious your diabetes is. If your blood sugars are only a little higher, it will be enough for you to carefully control the food you eat and/or take pills to help insulin work better in your body. In more serious cases of diabetes, you will need to start taking insulin and carefully control the food you eat.

Many patients are afraid of developing diabetes because people with diabetes have a higher chance of getting kidney and heart problems.

Carefully controlling your blood sugars can help to lower the risk of having kidney and heart problems.

Osteoporosis

Osteoporosis is a condition where the bones get weaker. This causes a greater chance of fractures or broken bones. The factors that cause osteoporosis include age, heredity, and menopause. Another factor in transplant patients is a drug called prednisone.

Osteoporosis can be found by a special x-ray test called the **bone mineral density scan**. The tests are usually done at 3 months after transplant and then every year after or as recommended by an osteoporosis specialist.

Watching what you eat and exercising are important for lowering the risk of osteoporosis. Supplements may sometimes be used as part of the treatment. There are also stronger medications available if a proper diet is not enough. Your transplant team and/or an osteoporosis specialist will choose the best therapy.

High blood pressure

Blood pressure is a measure of how hard your heart is pumping and how much blood is pushing through the blood vessels. Keep track of your blood pressure once you are discharged from the hospital because high blood pressure can cause damage to your transplanted kidney.



Many patients have high blood pressure (hypertension) before transplant but it is very common after transplant too. It may be a side effect of anti-rejection drugs or caused by other factors including age and medical history.

There are treatments available including blood pressure pills. Even if the pills do not seem to be working, you should never stop or change your medications on your own. Regular adjustments to your blood pressure pills may need to be made until your blood pressure is under control.

Ways to better control your blood pressure (along with medications) include:

- Watching your weight.
- Exercising regularly.
- Avoiding salty food and not adding salt to your food at the table.

Your doctor will change the medications to find the right treatment for you. If you have side effects that you feel are related to a blood pressure pill, always let your doctor know. Never stop or change any medication on your own.

High cholesterol

High cholesterol may be related to some of your anti-rejection medications. Other factors include diabetes, family history, and diet.

Your cholesterol levels need to be checked regularly after transplant. If you have high cholesterol, you may need to see a dietician to change your diet. If this does not reduce your cholesterol levels, you will need to take medications. It is important to control your cholesterol because high cholesterol levels have been linked to cardiovascular disease and stroke.

Coronary heart disease

It is important to take care of your heart after transplant. Patients have an increased risk for developing **coronary heart disease** (reduced circulation of blood to the heart). Like in the general population, **heart disease is the number one killer of kidney transplant patients.**

To reduce your risk:

- Eat foods low in sodium, cholesterol, and fat.
- Keep an ideal weight and exercise regularly.
- Don't smoke
- Drink alcohol in moderation: 2 drinks a day or less for men, and 1 drink a day or less for women.

Talk with your coordinator or doctor about any of these problems.



Delirium

Delirium is a condition which causes some patients to become confused in their thinking. Patients in hospital have a greater chance of developing delirium. Delirium can happen after major trauma such as a surgery or when there are changes in the balance of the blood. Delirium is a physical problem (a change in the body) than can affect how the mind works. It can start over a period of a few days and will often get better with treatment.

Clinical care staff check for delirium every shift. But, it is important for patients and families to know the symptoms and tell the staff if they see any changes in behaviour. Often small changes in the way someone is acting can be seen by patients themselves and those who know them best.

Below is a checklist of the common signs and symptoms of delirium.

Check ✓ for these common signs and symptoms of delirium:	
Disorganized thinking Saying things that are mixed up or do not make sense	
Difficulty concentrating Easily distracted or having difficulty following what is being said	
Memory changes Not able to remember names, places, dates, times or other important information	
Hallucinating Seeing or hearing things which are not real	
Having delusions Thinking or believing things which are not true or real	
Feeling restless Not able to stay still, trouble sleeping, climbing out of bed	
Changing energy levels Changes from being restless to being drowsy or sleepier than usual	

What if my kidney transplant fails?

Graft failure is when the transplanted kidney has failed. If this happens, a person must return to dialysis. Your Transplant Coordinator and Nephrologist will talk to you about what to do.

You may want to go onto the waiting list or find a suitable living donor. You and the donor will have the same tests done to determine suitability for another transplant. Your donor will also be tested to determine his/her health status and whether he/she is suitable to donate.

After one transplant, it may be harder to find a donor for you because you may now have antibodies against other people. This is measured with the panel reactive antibody or PRA test (see page 18 in Chapter 2). If this is the case, a recipient may need to consider other options for transplant (see "Special transplant programs" on page 31).

You can talk with your Transplant Coordinator and Nephrologist about all of these options.

Chapter 13: Taking Care of Yourself after Transplant

Taking care of yourself is a very important part of your transplant and can improve your long-term health.

Lab tests

After you are discharged, you need to have lab tests 2 to 3 times a week at the Toronto General Hospital (TGH).

Your Transplant Coordinator or Nephrologist will let you know if you have to do blood-work more or less often.

Important: Lab tests must be done at TGH soon after your transplant to make sure same-day results are used to change any medication doses.

Your Transplant Nephrologist will let you know when you can have blood tests done at your nearest Life Labs facility. You will receive a lab requisition form that is valid for 6 months.

You can find out where the nearest Life Labs centre to your home is by calling their phone number: 1-877-849-3637

Or checking on the internet at http://www.lifelabs.com/Lifelabs_ON/locations/default.aspx

We recommend that you only use Life Labs. Talk with your Transplant Coordinator if you can't go to a Life Labs.

Clinic visits at the ambulatory transplant clinic

The Ambulatory Transplant Clinic is located on the 12th floor, Peter Munk Building. You will visit the clinic soon after discharge. As you get better you will not need to visit the clinic as often. You will need to schedule your next appointment with the receptionist (see page 129). Try to come to appointments as scheduled.

To change an appointment date or time, please use Easy Call at 416-351-0793.

Remember:

- Before each clinic visit, check the Easy Call system and verify that there has been no change in your scheduled appointment.
- When you arrive for your clinic appointment, please check in with the receptionist.
- In between clinic appointments there is no drop-in service. Please do not come to see your Transplant Coordinator or Nephrologist unless you have called first on Easy Call and made an appointment to see them.

To continue getting prescriptions for your anti-rejection medications, you **must** be seen in clinic.

What you need to do before clinic:

- Complete your lab tests as requested by the coordinator
- Review your medication list at home
- Determine if you need any prescription refills
- Prepare questions for your transplant team

What you need to bring to clinic:

- Blue hospital card
- OHIP card (or provincial health card)
- Medication list and all medications (including bottles/packages)
- List of questions
- Calendar to record your next clinic appointments or tests
- Family member or support person (if you wish)

What you need to do during your clinic visit:

- Check in at the 12th floor, Peter Munk Building, Ambulatory Transplant Clinic Reception and notify them of your appointment and let them know if your contact information and address has changed
- Ask questions – bring a list if required
- Ask for your test results
- Review your medication list with your team - This is when you should ask for refills and any new prescriptions if needed
- Get a new requisition form for lab tests if needed
- Tell us about any health changes
- Find out if other tests need to be done between this appointment and the next

What you need to do when you leave the clinic:

- Make your next clinic appointment with the receptionist **before you leave**. The doctor will tell you when they want to see you again. Record your next appointment in your calendar
- Book your bone density and/or ultrasound tests as requested by your transplant team
- Get a new requisition form for blood work if you are using Life Labs

Prescription refills

Between clinic visits, contact your pharmacy to fax in a request for prescription refills. If there has been a dose change and there is not enough to last until your next transplant clinic appointment, ask your pharmacist to fax in a request to 416-340-3252.

It takes up to 3 working days to respond to your request for prescription refills. Whenever possible, please get your prescription refills at your clinic appointment.

You must tell us if you change your pharmacy so that we can update your information.

What if I have medical forms?

- If possible, ask your family doctor to fill out your medical forms
- There may be a cost for filling out forms that are not covered under the provincial health insurance plan
- Medical forms cannot be filled out during clinic visits
- Please complete the patient part of the form with your name
- Give the form to your Transplant Coordinator or Administrative Assistant
- **Please allow 4 weeks for forms to be filled in and returned to you**

What is a Telehealth Conference?

Telehealth is a live 2-way videoconference between you, your support person or family member, and members of the kidney transplant team. The Telehealth program was started for patients who live far from the hospital and (need travel more than 3 hours to TGH). Your doctor must approve this first. This appointment by videoconference is the same as a clinic appointment. You may still need to go to clinic visits in Toronto for issues that cannot be handled by Telehealth.

The Transplant Coordinator and Administrative Assistant will set up the Telehealth appointment. The Telehealth team in your area will contact you with your appointment and location. Once the appointment is made, it is very difficult to cancel and rebook. Please make sure to keep your appointment.

How can I prepare for a telehealth visit?

- Write down any questions or concerns so you can review them with the Transplant Team during your visit.
- Review your medications at home before the Telehealth visit. Bring a list of your medications with you to the appointment. Tell your Transplant Coordinator or doctor if you need to refill your prescription.

Your transplant logbook

We suggest you keep a log or diary of your health status. You can record your temperature, blood pressure, and blood sugar (if appropriate).

Here is an example of what your logbook should look like:

Sample logbook:

Date	Temperature	Blood Pressure	Blood Sugar

Temperature:

- Take your temperature once a day at the same time.
- Do not eat or drink anything for about 20 minutes before you take your temperature.
- Call us if your temperature is more than 38.5 degrees Celsius and tell us if you have any other symptoms.
- We may ask you to repeat your temperature in 2 hours.

Blood pressure (BP):

- You may need to buy a BP cuff to monitor yourself at home if you have high blood pressure.
- Your blood pressure may change because of medications or fluids.

Blood sugar:

- If you are using a monitor to measure your blood sugars, write the values in your log.
- This will be discussed with members of your team as needed.

Try to keep a record of your symptoms as needed. Your Transplant Coordinator may ask you to track your symptoms more closely.

Chapter 14: Life after Transplant

Family Doctor

Your transplant team at the Toronto General Hospital are kidney specialists. They can treat any transplant related sickness. In cases where you get sick but it is not related to your transplant, you must visit your family doctor. **This means that all patients must find a local family doctor.** If you do not have a family doctor, you must find one before a transplant can be scheduled.

Visit your family doctor for sicknesses such as the cold or a sore throat. The transplant team will work with your family doctor to make sure you are receiving the right care for the sickness and your transplant.

What if I don't have a family doctor?

The Ontario government through the Ministry of Health and Long Term Care has resources for finding a family doctor. This is only for patients with a valid OHIP card who are not currently enrolled with a family doctor.

Visit www.health.gov.on.ca for help finding a family doctor.

Getting vaccines

Please ask your family doctor for a record of your vaccinations.

Flu shots

Taking anti-rejection medications means you are more likely to get the flu. After your transplant, we strongly recommend that you and all the family members in your household get the flu shot each fall. Please call your family doctor's office to make an appointment. If you have just received your transplant and this vaccine is due, talk to your transplant team first. If you have an allergy to eggs, do not get the flu shot. This vaccine has a protein ingredient very similar to the protein found in eggs.

Pneumovax

Transplant recipients should also get vaccinated with Pneumovax for protection against pneumonia. Based on current guidelines, the Pneumovax vaccine should be received once before your transplant and then once every 3 to 5 years after that. Your family doctor can arrange for you to get this shot.

Tetanus

The tetanus vaccine is due every 10 years. Please call your family doctor's office to make an appointment.

Hepatitis B

After your transplant, being protected against hepatitis B is important. The hepatitis B vaccination is a series of 3 shots given over 6 months. We will tell you to start these shots if needed as soon as you are on the waiting list for a transplant. Your family doctor can give you these shots. If you did not complete the series of shots before your transplant, you will need to restart the shots after your transplant. Please wait 6 months before doing this. You may have to pay for this vaccine.

Human Papilloma Virus (HPV)

The HPV vaccine is suggested for young men and women less than 26 years of age. This vaccine may reduce the risk in women of developing cervical cancer. This virus can be transmitted by men through sexual intercourse.

Live Virus Vaccines

Recipients who are immunosuppressed cannot receive vaccines that contain a live virus. There is a risk that you will catch the illness you are trying to prevent with the vaccine. The vaccine for chicken pox (varicella) is an example of a live virus vaccine. Please check with your doctor before receiving any vaccines. This is also important if you need vaccinations before travelling.

Please refer to Appendix 2 that lists which vaccinations are recommended before and after transplant.

Dental care

Taking care of your teeth is an important part of your long-term health.

- Eating healthy will help you have strong healthy teeth.
- Brush your teeth at least 2 times a day and floss at least once a day.
- Use a soft bristled toothbrush.
- Check the inside of your mouth for any sores or swelling of your gums and let your dentist or family doctor know of any unusual mouth sores, swelling, or bleeding of the gums.
- Visit your dentist 2 times a year for a cleaning and an examination. Tell your dentist that you have had a transplant and your immune system is suppressed.
- Some people may need antibiotics for some dental procedures. Some antibiotics must be avoided because they interfere with cyclosporine or tacrolimus. We will give you a letter to take to your dentist with guidelines for patients with a kidney transplant.
- The dentist can call the kidney transplant office for information if they have any questions.

We ask you to delay any routine care which includes hygiene appointments, until you are at least 3 months after your transplant. This is due to the high level of immunosuppression and increased risk of infection during this period.

Diet and nutrition

Eating healthy by following Canada's Food Guide will help give you a balance of protein, fats, and carbohydrates and help you to maintain a healthy body weight.



Remember:

You cannot eat grapefruit or drink grapefruit juices after transplant. It interferes with the absorption of your immunosuppressive medications.

What you need to know about traveling

Try to travel or take vacations that are no longer than the time between your regular blood tests. When you plan a trip, please talk to your transplant team before you travel. You need to plan carefully before you travel so that you can enjoy your trip.

Here are some important tips for a worry-free holiday.

- Depending on the country you are travelling to, you might need vaccinations well before leaving for your trip. Arrange these vaccinations through a travel clinic.
 - You can check the Medisys website for more information about travel health at <https://www.medisys.ca/en-ca/travel-health>
 - In Toronto, call 416-730-5700 or check with a travel clinic in your local area. You will need to pay for this visit. Travel clinics are not covered by OHIP
- It is very important that you buy out-of-country health insurance. Your travel agent can help with this.
- We highly recommend that you buy airline cancellation insurance. If you have a complication from your transplant you might have to cancel your trip.
- Plan for your Transplant Coordinator to give you a **travel letter before your trip**. This includes a record of your medication, your most recent laboratory results, and emergency contact numbers.
- When travelling, always carry your medication with you in your carry-on luggage. **Never** put your medication with your luggage.
- Always take along a few extra days' supply of medication in case your return flight is delayed.
- Be prepared to return home if you become ill while travelling.

Pets

When you are on immunosuppressive medications you are at a higher risk of catching diseases from your pets.

Guidelines for contact with your pet:

1. Wash your hands after touching your pet, especially before eating
2. Keep your pet clean and well groomed
3. Avoid touching your pet's vomit, feces, urine and saliva by wearing gloves
4. Use a disinfectant to clean these fluids
5. Do not let a pet lick any of your wounds or your face
6. Keep your pet's vaccinations up-to-date at all times

Driving and seat belts

- Talk to your doctor about driving at your clinic appointment.
- You must not drive when still taking narcotic pain medication. You need to be strong and flexible enough to move your leg and foot on the pedals and be able to check your blind spot
- If your driver's licence was suspended before your transplant, it needs to be re-activated when you are fit to drive after your transplant. This can take several weeks to months.
- Always wear your seat belt when you are driving or riding in a vehicle. If the belt is uncomfortable where it crosses your incision, put a towel under the belt.
- We will not provide letters for the police to excuse you from wearing your seat belt.

Swimming

- Swimming is an excellent exercise once the incision is healed and you are strong enough to be in the water
- You will not be able to swim if you have a central line or peritoneal dialysis catheter
- You can swim in public pools
- You can swim in lakes, etc. as long as the water is clean

Hot tubs and saunas

- Both hot tubs and saunas can lower your blood pressure because of the heat, causing blood vessel dilatation
- Either should be used with caution in patients with heart disease or if you take blood pressure medications
- Hot tubs can be contaminated with bacteria which can cause skin infections
- Limit the duration you spend in hot tubs or saunas

Sunscreens

As a transplant recipient you are at a much greater risk of developing skin cancer. Taking immunosuppressant medication increases this risk. Skin cancer is the most common cancer seen in long term transplant recipients.

Here are some ways to help prevent skin cancer:

- Put on sunscreen with a SPF (sun protection factor) greater than 50. Protect your lips as well.
- Wear a hat, long sleeve shirts, and pants when you are out in the sun.
- Avoid the sun when possible between the hours of 11:00 am and 3:00 pm.
- If you are swimming or sweating heavily, put your sunscreen on again after drying off or if you are still sweating. Even if you use a waterproof sunscreen you must put it on again regularly.
- On cool, cloudy, or overcast days, 70 % to 80% of the sun's ultraviolet (UV) rays still reach the earth. You still need to be careful. Sitting in the shade or swimming underwater does not protect you. UV rays go through water.
- Put on your sunscreen even in winter months if you are outside for a while (for example skiing or skating).
- UV light is reflected from sand, concrete, snow and water; increasing your exposure.



- Exposure to UV light may cause cataracts. Protect your eyes with UV-filtering sunglasses (both UVA and UVB filtering).
- Checking your skin for moles every month is a good precaution. Use a mirror to check your back and the back of your legs. Look for any scaliness, changes in the colour or shape of moles, or any constant itching or oozing. If you are worried about your skin or a mole, or you are not sure, see your family doctor. You may need to be seen by a dermatologist.

Sexual activity

Changes to your interest in sex and intimacy are common. Please talk with your family doctor for more information.

Safe sex

Protect yourself from sexually transmitted infections (STIs) such as HIV/AIDS, genital herpes, Hepatitis B, and Hepatitis C:

- Getting STIs happens through sexual activity where body fluids pass from one person to another.
- Use a latex condom and contraceptive foam to greatly decrease the chance of catching a sexually transmitted disease or getting pregnant.
- Talk about safe sex with your partner.

Pregnancy

Pregnancy after a transplant may be at a higher risk. But it is possible for young women to have children after transplant. Talk with your transplant doctor who will refer you to a high-risk pregnancy specialist.

It is important to know that:

- Pregnancy may be complicated by medical issues requiring medication, treatment or staying in the hospital.
- The risk of developing severe high blood pressure is higher in pregnant transplant patients.
- The chance of rejection is higher in pregnant transplant patients.

- Some medications may be harmful to your baby. You should talk to your transplant doctor before trying to get pregnant so modifications can be made.

In some cases, the disease that caused kidney failure can come back in the transplanted kidney during pregnancy.

We strongly recommend that pregnancies in transplant patients be planned well in advance.

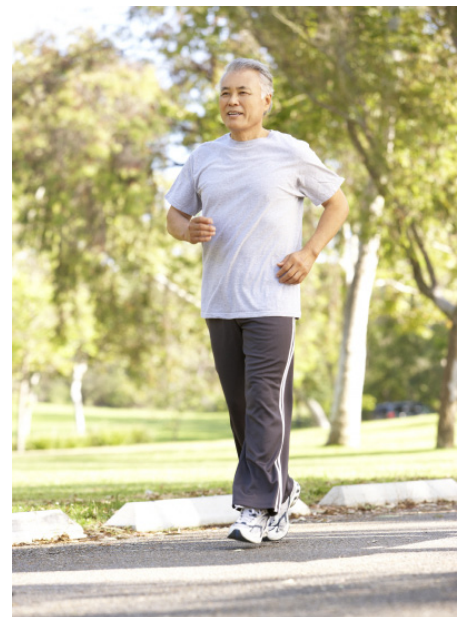
Birth control

To prevent pregnancy, use the **double barrier method**:

- Use condoms and contraceptive foam, or a diaphragm and contraceptive foam.
- The double barrier method is effective and has a low failure rate if used correctly.
- A woman must see a gynecologist to be fitted for a diaphragm.

Exercise and activities

- You must **not** lift more than 10 pounds for the first 3 months after your surgery.
- Lifting larger amounts may result in stress to your incision and can affect your healing – this may cause a hernia in the incision
- Walking is the best exercise – try to increase the distance and speed you walk
- In winter, many people walk in malls to avoid icy surfaces and cold conditions or they use a treadmill if they have access to one
- You can use small weights of 1 to 2 pounds to increase arm strength but be careful not to strain your shoulder joints. They are prone to strain due to muscle wasting



Returning to work

You should plan to go back to work after your transplant.

- Before you go back to work your transplant doctor needs to approve your health status
- The most important thing to think about is the physical activity and requirements of your job
- You may need to begin working part time initially if your job is physically demanding



Most people take 3 months off work after a transplant. This gives you time to recover from surgery and adjust to your transplant. In the absence of complications, we would not normally support a medical leave for longer than 3 months.

Chapter 15: If You Get Sick at Home

If you get sick before your next scheduled clinic appointment, you need to call your Transplant Coordinator using Easy Call. The coordinator will give you advice.

Leave a message on Easy Call between 8:00 am and 4:00 pm.

You may either be scheduled to attend the next clinic, see your family doctor or asked to go to your local Emergency Room.

Please call your Transplant Coordinator on Easy Call if you have gone to the Emergency Department or have been admitted at any hospital. Your Transplant Coordinator will tell the transplant doctor.

If there are concerns that cannot wait until the next business day, on weekends or after hours, the staff at Telehealth Ontario may also be able to help. We have partnered with them and provided staff there with specific information about transplantation. The service is free and available to all our patients. The toll-free number is:

1-866-797-0000

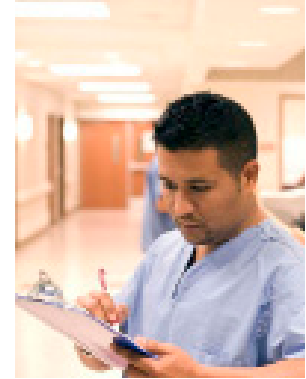
Let your Transplant Coordinator know if you have been started on any new medications.

In an emergency:

Call 911 in an emergency for an ambulance to take you to your nearest hospital.

Chapter 16: Research

The Kidney Transplant Program at the Toronto General Hospital, University Health Network is very active in kidney transplant research. Today patients still have rejection and other problems after transplant. This makes research an important part of the program.



During your time at Toronto General Hospital, a clinical research coordinator might ask you to take part in a study. You may also be asked for permission to have your personal health information and specimens become a part of our research database known as the Comprehensive Renal Transplant Research Information System (CoReTRIS).

We will not use your private information unless you agree first. Any personal health information will be held private. Taking part in research or not doesn't affect the quality of care you receive.

If you agree to take part in a study, the coordinator will explain all the details of the study to you. The coordinator will ask you to sign a consent form that has all the study information. You will be given as much time as you need to read and sign the form.

Chapter 17: Suggested Readings and Websites

Healthy Living or Lifestyle Readings:

Canada's Food Guide

 Website: www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php

Internet:

Organization: The Kidney Foundation of Canada – Central Ontario Branch

 Phone: 416-445-0373

 Website: www.kidney.ca

Organization: The National Kidney Foundation (USA)

 Website: www.kidney.org

Transplant and health books:

Visit The Peter and Melanie Munk Patient and Family Learning Centre and Library
Level 1 – Norman Urquhart (NU Building)

Hours: Monday to Friday 8:30 am to 4:00 pm. Closed weekends and holidays.

 Phone: 416-340-4800 Ext. 5951

 Website: www.uhnpatienteducation.ca

Email: tgpen@uhn.ca

Services:

- Information about many diseases and health conditions, treatments, and tests in different languages
- Over 250 books, manuals, guides, DVDs and videos for loan
- A large selection of materials on healthy lifestyle choices
- Customized health information searches that meet your needs
- Free Internet access and wireless Internet access
- Help to search the Internet for information that is valid and up-to-date
- Help to locate other healthcare services offered in the hospital or in the community
- Free monthly e-newsletter
- A place to relax and watch health information on a large LCD TV

Trained library staff and volunteers can help you find the information you need free of charge.

Chapter 18: Who to contact

Contact	Information
Pre-Transplant Assessment Office (for potential transplant recipients and living donors)	Toronto General Hospital – Peter Munk Building 12 th Floor (Room 12PMB100) 585 University Ave Toronto, ON M5G 2N2 Phone: 416-340-4800 extension 6385 Fax: 416-340-5209
Transplant Clinic Reception	Toronto General Hospital – Peter Munk Building 12 th Floor – Maria Bacardi Ambulatory Clinic 585 University Ave Toronto, ON M5G 2N2 Phone: 416-340-4800 extension 4113 Fax: 416-340-3252
Transplant Social Work Office	Toronto General Hospital – Peter Munk Building 11 th Floor (Room 11PMB100) 585 University Ave Toronto, ON M5G 2N2 Phone: 416-340-4800 extension 5655
Transplant Day Unit (TDU)	Toronto General Hospital – Peter Munk Building 12 th Floor (Room 12PMB) 585 University Ave Toronto, ON M5G 2N2 Phone: 416-340-4800 extension 5773 Open Tuesday to Friday from 7:15 am to 5:00 pm
Transplant In-Patient Unit	Phone: 416-340-5163
Post-Transplant Coordinator (using Easy Call)	Phone: 416-351-0793
Transplant Outpatient Pharmacy (TOP)	Phone: 416-340-4415 Fax: 416-340-5140 transplantpharmacy.ca
MOT Medication Reimbursement Specialist, Lucia Anghelache	Phone: 416-340-4800 extension 5715 Fax: 416-340-4162
Locating – Toronto General Hospital	Phone: 416-340-3155
UHN Patient Relations	Phone: 416-340-4907
Life Labs	Phone: 1-877-849-3637
Telehealth Ontario	Phone: 1-866-797-0000

Your Feedback

We want to know what you think

As a transplant patient, we care about what you think. Your feedback will help us improve the care we give to our patients.

If you have any suggestions about changes to this guide, please speak with your Transplant Coordinator. If you have any problems or concerns about the care you receive, please tell us.

In the hospital, you can speak with the Charge Nurse or the Nurse Manager for the inpatient area. When you are at home, you can speak with your Transplant Coordinator, the Manager of the Ambulatory Clinic, or your doctor.

If you prefer, the Patient Relations Department can also help you. The Patient Relations Department is pleased to hear both your concerns and your compliments.

Patient Relations can be reached at:

Patient Relations Office
1st floor – Room 401
R. Fraser Elliot Building
Toronto General Hospital
Phone: 416-340-4907

Appendix 1: Saying Thank You

Transplant recipients often wonder how to say “thank you” to their donors.

If your donor is a friend or relative, saying “thank you” can be done in the traditional way.

When your donor is an anonymous person whose organs were donated by their family at the time of their death, a “Thank You” can be difficult.

We encourage you to write to the donor’s family to express your thanks. It may be a challenge to write a letter, but many transplant recipients like the chance to express their gratitude. We have also found that such thank you letters or cards can be a comfort to donor families as they deal with their loss.

There is no right or wrong time to write to the family. Some recipients feel that they want to write right away but you might need time to recover from your surgery before you are able to write. We encourage you to write sometime within the first year after your transplant.

Under the Human Tissue Gift Act, the government of Ontario requires by law that we keep your identity and your donor’s identity private. For this reason, please do not include your name, email, where you live, your cultural background, religion, workplace, or where you had your transplant in your letter. Some things you may want to include are:

- How long you waited for your transplant
- How you felt while you waited
- How you feel now
- What you look forward to doing in the future

Many recipients want the donor family to know that they appreciate the courage it took to make the donation and that the donor family is often in their thoughts.

The letter can be as long or short as you like. Please remember that this is a letter of thanks. If you need some help with your letter, please ask your Transplant Team for advice.

When your letter is complete, give it to your Transplant Coordinator in an unsealed envelope so that it can be reviewed before being sent to the donor. Your coordinator will forward your letter to the staff at the Trillium Gift of Life program. The Trillium Gift of Life staff will then send your letter to the donor's family.

Sometimes the donor's families will send letters to recipients through the Trillium Gift of Life Program. If this happens, your Transplant Coordinator will let you know.

Appendix 2: Vaccines

Vaccines you need to have before your transplant

Vaccines you need	More information
Influenza Vaccine (flu shot)	Get this once a year during the flu season. Ask for the inactivated vaccine .
Pneumococcal	<p>If you had it before, check whether it was Pneumovax or Prevnar (most likely it will be Pneumovax if a family doctor gave you the vaccine).</p> <p>If you had this vaccine in the past 1 year, you are up to date. If not, you need to get Prevnar13, then Pneumovax (minimum 8 weeks after Prevnar13, but needs to be 5 years from the last Pneumovax).</p>
Hepatitis B	<p>If you had a positive titer result, you do not need the vaccine. Ask your doctor to check your titers regularly while you are on dialysis. Titers can decline over time.</p> <p>If you had a negative titer result, get 3 doses of the “Dialysis dose” or high dose vaccine at 0,1,6 months. Check anti-HBs to see whether they responded.</p>
Hepatitis A	You need 2 doses (don’t use the Twinrix vaccine)
Tdap	<p>If you had the tetanus vaccine in the past 10 years, you do not need this shot.</p> <p>If you did not have the tetanus vaccine in the past 10 years, you need a Tdap booster.</p>
HPV	<p>You need 3 doses of Gardasil HPV vaccine if you have not had it in the past and you are:</p> <ul style="list-style-type: none"> • a 45-year-old woman or younger • a 26-year-old man or younger • a 45-year-old man or younger who has sex with men

Vaccines you need	More information
Zostavax (LIVE) This vaccine is optional.	If VZV IgG+, You can get this vaccine but you have to be on hold for 4 weeks until the live virus is cleared from the body.
Varicella (LIVE)	If VZV IgG-, You can get this vaccine but you have to be on hold for 4 weeks until the live virus is cleared from the body.

These vaccines are only for some patients. Please ask your health care team for more information.

Meningococcal (Menactra or Menveo)	You should have the Meningococcal shot if you: <ul style="list-style-type: none"> • had a splenectomy • travelled to to a country with a high rate of meningitis • travelled to the Haiti • were in the military
Rabies	Get this shot if you have a pet or handle animals often.

After transplant:

- If you did not get vaccines before transplant, you can get them starting at 6 months after your transplant, **all except live vaccines** (vaccines made of living organisms)
- If you started a vaccine series before transplant but then you had a transplant, you should continue where it was left off starting at 6 months post-transplant. No need to repeat doses.

Where can I get my vaccines?

- Transplant ID Clinic (12th floor PMB at Toronto General Hospital)
 - Stocks most vaccines including: pneumococcal vaccines, Tdap, Varicella and can obtain dialysis-dose Hepatitis B, hepatitis A, Meningococcal
 - Also has TB skin testing available. Patients can be referred for vaccines/ TB skin test or a general ID pre-transplant evaluation.
- Transplant Outpatient Pharmacy
 - Stocks the flu shot at the during flu season
- Your family doctor

Appendix 3:

Your medications after transplant

The following pages give information about the medications that you will be taking after your transplant. These medications include:

- ADVAGRAF®
- AZATHIOPRINE
- CELLCEPT®
- CYCLOSPORINE
- DAPSONE
- MYFORTIC®
- NYSTATIN
- PREDNISONONE
- PROGRAF®
- COTRIMOXAZOLE
- SIROLIMUS
- VALGANCICLOVIR

ADVAGRAF[®]
(tacrolimus extended release)

GENERIC NAME	BRAND NAME	REASON FOR USE
Tacrolimus extended release Strengths: 0.5, 1 and 5 mg capsules	ADVAGRAF [®]	Tacrolimus is an <u>anti-rejection</u> drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. INCREASED BLOOD PRESSURE

Your blood pressure will be monitored. You may require treatment with blood pressure medications.

2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

This can include trembling hands, headaches, mood changes and trouble sleeping. This is usually related to the level of Advagraf[®] in the blood and usually subsides with time as blood levels are decreased.

3. HARMFUL EFFECTS ON THE KIDNEY

The level of Advagraf[®] in your blood will be closely monitored and the dose will be adjusted if needed. Your kidney function will be monitored with a blood test called creatinine.

4. GASTROINTESTINAL UPSET

This may include stomach upset and diarrhea. The degree to which this occurs is variable and will depend on how your body reacts with the medication.

5. DIABETES (Increased Blood Sugar)

Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

6. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

7. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

ADVAGRAF® (tacrolimus extended release)

DOSAGE ADJUSTMENTS

You will be advised to adjust your dose up or down based on the amount of Advagraf® in your blood. Blood tests are done just before your dose. On the days you are having bloodwork, you should **delay your dose of Advagraf® until after your blood is drawn**. Changes in dose are common so always check with your transplant team if you are unsure of your current dose.

STORAGE

Keep at room temperature – do not expose Advagraf® to extremes of temperature (direct sunlight or refrigeration).

INTERACTIONS WITH OTHER MEDICATIONS

- Many medications can change the level of Advagraf® in your blood. This may cause serious problems.
- Do not take **any** medications, including non-prescription drugs or prescriptions (given to you by anyone other than your transplant doctors), without first contacting your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase Advagraf® levels.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

TAKING YOUR MEDICATION

- Advagraf® (tacrolimus extended release) is taken once daily in the morning. In order to maintain a consistent amount of drug in your body, always take your dose at the same time every day.
- Always be consistent with respect to Advagraf® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Avoid grapefruit and grapefruit juice as these can increase Advagraf® blood levels.
- Do not get this medication confused with Prograf® (tacrolimus immediate release), which is a twice-daily formulation of tacrolimus.



**AZATHIOPRINE
(Imuran®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
Azathioprine Strength: 50 mg tablets	IMURAN®	Azathioprine is an <u>anti-rejection</u> drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. STOMACH UPSET

Upset stomach or vomiting may occur but usually decreases with time. Report this to your transplant team if this becomes problematic. Take with food or milk to help prevent stomach upset.

2. ABDOMINAL PAIN

If you have abdominal pain which is severe or lasts for more than one day you should report this to a doctor or your transplant team. Although uncommon, this may be a sign of a serious problem called pancreatitis, or inflammation of the pancreas.

3. YELLOW COLORATION OF SKIN, DARK URINE

These symptoms are rare but may be a sign of liver damage. Report these symptoms to doctor or your transplant team as soon as possible.

4. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

5. BLEEDING AND BRUISING

Try to protect yourself from injury. Notify your transplant team of any unusual bleeding or bruising.

6. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

7. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

AZATHIOPRINE

TAKING YOUR MEDICATION

- Azathioprine is taken once daily
- Take with food or milk to prevent stomach upset
- The dose prescribed may be any combination of 50 mg tablets or half tablets.

Examples: 100 mg = 2 tablets
75 mg = 1½ tablets
125 mg = 2½ tablets

- Changes in dosage may occur. Always check with your transplant team if you are unsure of your current dose.

INTERACTIONS WITH OTHER MEDICATIONS

- Azathioprine may interact with other medications and cause serious problems. For example, **allopurinol** is a drug used in the treatment of gout which can cause severe side effects if taken with azathioprine.
- Always speak to your transplant team before taking any new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.



CELLCEPT[®]
(mycophenolate mofetil)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Mycophenolate mofetil MMF Strengths: 250 mg capsules 500 mg tablets 200 mg/mL suspension	CELLCEPT [®]	Cellcept [®] is an <u>anti-rejection</u> drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. DIARRHEA

This side effect is common especially at higher doses. It can often be managed by taking smaller doses more frequently throughout the day. This should only be done on the advice of your transplant team.

2. STOMACH UPSET

Nausea, vomiting, and abdominal pain can sometimes occur. These effects usually decrease with time. Report this to your transplant team if any of these become problematic.

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

4. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

5. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

CELLCEPT® (mycophenolate mofetil)

TAKING YOUR MEDICATION

- Take this medication twice daily. Doses should be spaced 12 hours apart in order to maintain a consistent amount of drug in your body, e.g. 9:00 am and 9:00 pm. Always take your doses at the same times every day.
- Always be consistent with respect to Cellcept® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Capsules and tablets should not be cut, crushed or chewed.

INTERACTIONS WITH OTHER MEDICATIONS

Cellcept® may interact with other medications including:

- Products containing iron such as ferrous gluconate, ferrous sulphate, ferrous fumarate or multivitamins plus minerals
- Products containing magnesium such as Maalox® or Milk of Magnesia®
- Cholestyramine (Questran®), a cholesterol-lowering agent

All of these medications can decrease the absorption of Cellcept® if taken at the same time. It is important that these medications be spaced at least 2 hours apart from Cellcept® (and at least 4 hours apart in the case of cholestyramine).

Please speak with your doctor, pharmacist or transplant coordinator before taking **any** new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors. Your pharmacist or transplant coordinator can help you plan your dosing schedule to avoid these interactions.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.



CYCLOSPORINE (Neoral[®])

GENERIC NAME	BRAND NAMES	REASON FOR USE
Cyclosporine Strengths: 10, 25, 50 and 100 mg capsules 100 mg/ mL oral solution	NEORAL [®]	Cyclosporine is an <u>anti-rejection</u> drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. INCREASED BLOOD PRESSURE

Your blood pressure will be monitored. You may require treatment with blood pressure medications.

2. HARMFUL EFFECTS ON THE KIDNEY

The level of cyclosporine in your blood will be closely monitored and the dose will be adjusted if needed. Your kidney function will be monitored with a blood test called creatinine.

3. TREMBLING OF THE HANDS

This is usually related to the level of cyclosporine in the blood. This usually subsides with time as blood levels are decreased.

4. SWELLING OF THE GUMS

Good mouth hygiene and regular dental check-ups can minimize this problem.

5. GASTROINTESTINAL UPSET

This may include stomach upset and diarrhea. The degree to which this occurs is variable and will depend on how your body reacts with the medication.

6. DIABETES (Increased blood sugar)

Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

7. INCREASED HAIR GROWTH

Report this to the transplant team if it becomes bothersome.

8. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

9. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

CYCLOSPORINE (Neoral®)

DOSAGE ADJUSTMENTS

Cyclosporine is usually taken twice daily. Doses should be spaced twelve hours apart (e.g. 9:00 am and 9:00 pm) in order to maintain a consistent amount of drug in your body. You will be advised to adjust your dose up or down based on the amount of drug absorbed into your blood. Blood tests are usually done two hours after the dose is taken. Changes in dose are common so always check with your transplant team if you are unsure of your current dose.

STORAGE

Store this medication at room temperature. Do not expose to extremes of temperature (e.g. direct sunlight or refrigeration) as this may inactivate cyclosporine. Do not remove the capsules from their foil packaging until you are ready to take them.

INTERACTIONS WITH OTHER MEDICATIONS

- Many medications can change the level of cyclosporine in your blood. This may cause serious problems.
- Do not take **any** medications, including non-prescription drugs or prescriptions (given to you by anyone other than your transplant doctors), without first contacting your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase cyclosporine levels.

REMEMBER

Wear/carry identification (i.e. Medic-Alert) stating that you are immunocompromised.

This drug is available at no charge through a special program run by the Ontario Ministry of Health. In order to access cyclosporine free through this program it must be obtained from the Toronto General Hospital Outpatient Pharmacy.

CYCLOSPORINE PRODUCT INFORMATION

CAPSULES: Neoral®

- Usually supplied as 25mg and 100mg capsules (10 and 50mg also available)
- Dose may be any combination of these strengths – check strengths carefully
- Take with fluids e.g. water, juice, milk
- Avoid grapefruit as this can increase your blood levels of cyclosporine
- Capsules have an unpleasant skunk-like odour
- Remove capsules from the foil package **only when ready to take**

ORAL SOLUTION: Neoral®

- Supplied in a bottle with syringe
- Place syringe in bottle, draw up correct amount as indicated on scale: 100mg = 1 mL, 275mg = 2.75 mL, etc.
- Mix dose with ½ glass of milk or juice (use same type of fluid every time)
- Use only a glass, ceramic or china container **(no styrofoam, plastic or paper cups)** and only a metal spoon to mix **(no plastic spoon or straws)**
- Once opened use within 2 months



DAPSONE

GENERIC NAME

Dapsone
Strength:
100 mg tablet

REASON FOR USE

This medication is an antibiotic. It is used to prevent a type of pneumonia called PCP. You are more susceptible to this infection when your immune system is suppressed.

SIDE EFFECTS

1. SKIN RASH

This may be a sign of an allergic reaction. If this occurs, stop taking this medication and report this to your transplant team. A different drug may be prescribed.

2. SENSITIVITY TO SUNLIGHT

Your skin may burn more easily if exposed to the sun. Avoid excessive exposure to sunlight and wear protective clothing or sunscreen products on all sun-exposed areas, even in the winter.

3. YELLOW COLORATION OF SKIN, DARK URINE

These symptoms are rare but may be a sign of liver damage or a problem with your red blood cells. Report these symptoms to doctor or your transplant team as soon as possible.

4. FEVER

A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team **immediately**. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol®) may be used to control the fever.

HOW TO USE THIS DRUG

- This medication may be taken with or without food.
- Take this medication exactly as your doctor has prescribed. This may be once daily, or only on certain days of the week. Always follow the instructions given to you by your transplant team.



MYFORTIC[®]
(enteric coated mycophenolate sodium)

GENERIC NAME	BRAND NAME	REASON FOR USE
Enteric coated mycophenolate sodium Strengths: 180 mg and 360 mg tablets	MYFORTIC [®]	Myfortic [®] is an <u>anti-rejection</u> drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. DIARRHEA

This side effect is common especially at higher doses. It can often be managed by taking smaller doses more frequently throughout the day. This should only be done on the advice of the transplant team.

2. STOMACH UPSET

Nausea, vomiting, and abdominal pain can sometimes occur. These effects usually decrease with time. Report this to your transplant team if any of these become problematic.

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. Inform your transplant team if you develop symptoms of infection, feel very tired, or experience any unusual bleeding or bruising.

4. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

5. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

MYFORTIC[®] (enteric coated mycophenolate sodium)

TAKING YOUR MEDICATION

- Take this medication twice daily. Doses should be spaced 12 hours apart in order to maintain a consistent amount of drug in your body, e.g. 9:00 am and 9:00 pm. Always take your doses at the same times every day.
- Always be consistent with respect to Myfortic[®] dosing and meal consumption (i.e. if you take the medication with food, always take it with food).
- Tablets should not be cut, crushed or chewed.

INTERACTIONS WITH OTHER MEDICATIONS

Myfortic[®] may interact with other medications including:

- Products containing iron such as ferrous gluconate, ferrous sulphate, ferrous fumarate or multivitamins plus minerals
- Products containing magnesium such as Maalox[®] or Milk of Magnesia[®]
- Cholestyramine (Questran[®]), a cholesterol-lowering agent

All of these medications can decrease the absorption of Myfortic[®] if taken at the same time. It is important that these medications be spaced at least 2 hours apart from Myfortic[®] (and at least 4 hours apart in the case of cholestyramine).

Please speak with your doctor, pharmacist or transplant coordinator before taking **any** new medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors. Your pharmacist or transplant coordinator can help you plan your dosing schedule to avoid these interactions.

REMEMBER

Wear/carry identification (i.e. Medic Alert) stating that you are immunocompromised.



NYSTATIN		
GENERIC NAME	BRAND NAMES	REASON FOR USE
Nystatin Strength: 100,000 units per mL oral suspension	NILSTAT® MYCOSTATIN® (and generics)	This medication is an antifungal. It is used to prevent yeast infections in the mouth (also known as oral thrush), which appear as white spots or patches.
SIDE EFFECTS		
<ul style="list-style-type: none"> • Since this medication is not absorbed into the body, side effects are very unlikely. 		
HOW TO USE THIS DRUG		
<ul style="list-style-type: none"> • This product is a suspension. Shake the bottle well before taking each dose. • Measure the prescribed dose using the dropper supplied. • Swish it around in your mouth for at least one minute then swallow. • This medication needs contact time with the mouth and throat in order to be most effective. Do not eat or drink anything for 20 minutes after taking nystatin. • Nystatin is usually taken 4 times daily. It is easiest to take your doses after meals and at bedtime. 		



PREDNISONE

GENERIC NAME	REASON FOR USE
Prednisone Strengths: 5 mg and 50 mg tablets	Prednisone is a cortisone-like <u>anti-rejection</u> drug. This medication works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. STOMACH UPSET OR IRRITATION

Take prednisone with food or milk. An acid-reducing medication may be prescribed. Report any severe symptoms or blood in your bowel movements to a doctor right away.

2. WATER RETENTION

May cause swelling of the face, ankles or hands. You may need to restrict salt in your diet. A diuretic ('water pill') may be prescribed. This effect usually subsides as the dose is reduced.

3. FACIAL PUFFINESS

More common with higher doses. This usually subsides as the dose is reduced.

4. INCREASED APPETITE

Weight gain may occur if you overeat.

5. DIABETES (Increased blood sugar)

Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

6. SLEEP DISTURBANCES, NIGHTMARES, MOOD CHANGES

Take prednisone in the morning to minimize the effect on your sleep. These effects usually subside as the dose is reduced.

7. BRUISING

Your blood vessels may become more fragile which can cause easy bruising. Try to protect yourself from injury.

8. OSTEOPOROSIS (Thinning of the bones)

Your bones may become weaker which can increase your risk of fractures. You may be advised to increase calcium in your diet, do a weight-bearing exercise such as walking, or take calcium supplements or other medications to increase bone density.

9. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team **immediately**.

10. OTHER SIDE EFFECTS MAY INCLUDE

Increased hair growth, acne, cataracts, or menstrual irregularities.

PREDNISONE

TAKING YOUR MEDICATION

- Prednisone is taken once daily in the morning.
- Prednisone should be taken with food or milk to prevent stomach irritation.
- The dose prescribed may be any combination of 5 mg tablets or half tablets.

Examples: 20 mg = 4 of the 5 mg tablets

15 mg = 3 of the 5 mg tablets

12.5 mg = 2½ of the 5 mg tablets

- Some patients who are taking larger doses may also be prescribed the 50 mg tablets.

Examples: 75 mg = 1½ of the 50 mg tablets

60 mg = 1 of the 50 mg tablets plus 2 of the 5 mg tablets

- Typically larger doses are prescribed initially, followed by a gradual dose reduction or 'taper'. Changes in dose are common so always check with your transplant team if you are unsure of your current dose
- **Never stop taking this drug suddenly.**

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are taking prednisone and that you are immunocompromised.



PROGRAF®
(tacrolimus immediate release)

GENERIC NAME	BRAND NAME	REASON FOR USE
Tacrolimus immediate release Strengths: 0.5, 1 and 5 mg capsules	PROGRAF®	Tacrolimus is an <u>anti-rejection</u> drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. INCREASED BLOOD PRESSURE

Your blood pressure will be monitored. You may require treatment with blood pressure medications.

2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

This can include trembling hands, headaches, mood changes and trouble sleeping. This is usually related to the level of Prograf® in the blood and usually subsides with time as blood levels are decreased.

3. HARMFUL EFFECTS ON THE KIDNEY

The level of Prograf® in your blood will be closely monitored and the dose will be adjusted if needed. Your kidney function will be monitored with a blood test called creatinine.

4. GASTROINTESTINAL UPSET

This may include stomach upset and diarrhea. The degree to which this occurs is variable and will depend on how your body reacts with the medication

5. DIABETES (Increased blood sugar)

Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.

6. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

7. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

PROGRAF® (tacrolimus immediate release)

DOSAGE ADJUSTMENTS

You will be advised to adjust your dose up or down based on the amount of Prograf® in your blood. Blood tests are done just before your morning dose. On the days you are having bloodwork, always remember to **delay your morning dose of Prograf® until after your blood is drawn**. Changes in dose are common so always check with your transplant team if you are unsure of your current dose.

STORAGE

Keep at room temperature. Do not expose Prograf® to extremes of temperature (direct sunlight or refrigeration).

INTERACTIONS WITH OTHER MEDICATIONS

- Many medications can change the level of Prograf® in your blood. This may cause serious problems.
- Do not take **any** medications, including non-prescription drugs or prescriptions (given to you by anyone other than your transplant doctors), without first contacting your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase Prograf® blood levels.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

TAKING YOUR MEDICATION

- Prograf® (tacrolimus immediate release) is taken twice daily every 12 hours, *e.g.* 9:00 am and 9:00 pm. This is to ensure that you maintain a consistent amount of drug in your body. Always take your doses at the same times every day.
- Always be consistent with respect to Prograf® dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Avoid grapefruit and grapefruit juice as these can increase Prograf® blood levels.
- Do not get this medication confused with Advagraf® (tacrolimus extended release), which is a once-daily formulation of tacrolimus.



COTRIMOXAZOLE (Septra[®])

GENERIC NAMES	BRAND NAMES	REASON FOR USE
Sulfamethoxazole/ Trimethoprim <u>or</u> Cotrimoxazole Strengths: Single strength (400/80 mg) Double strength (800/160 mg)	SEPTRA [®] (and generics)	This drug is a combination of two antibiotics. It is used to prevent or treat a type of pneumonia called PCP. You are more susceptible to this infection when your immune system is suppressed.

SIDE EFFECTS

1. SKIN RASH

You may be allergic to the 'sulfa' part of the drug. If this occurs, stop taking this medication and report this to your transplant team. A different drug may be prescribed.

2. SENSITIVITY TO SUNLIGHT

Your skin may burn more easily if exposed to the sun. Avoid excessive exposure to sunlight and wear protective clothing or sunscreen products on all sun-exposed areas, even in the winter.

3. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.

4. FEVER

A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team **immediately**. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol[®]) may be used to control the fever.

HOW TO USE THIS DRUG

- This medication may be taken with or without food.
- Take this medication exactly as your doctor has prescribed. This may be once daily, or only on certain days of the week, or in some cases twice daily. Always follow the instructions given to you by your transplant team.



SIROLIMUS (Rapamune®)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Sirolimus Rapamycin Strengths: 1 mg tablets 1 mg/mL oral solution	RAPAMUNE®	Sirolimus is an <u>anti-rejection</u> drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ.

SIDE EFFECTS

1. INCREASED CHOLESTEROL LEVELS

Your cholesterol and triglyceride levels may increase which can lead to atherosclerosis and heart disease. Dietary changes or medications may be required to bring your cholesterol levels down.

2. DECREASED BLOOD CELL COUNTS

Your blood cell counts will be monitored closely. Inform your transplant team if you develop any symptoms of infection, if you feel very tired, or experience any unusual bleeding or bruising.

3. SKIN RASH, ACNE OR MOUTH SORES

A rash or acne may develop on your face or body. You may also develop sores inside your mouth. Inform your transplant team if these effects occur and are bothersome.

4. GASTROINTESTINAL UPSET

Stomach upset, diarrhea, or constipation may occur. The degree to which this occurs is variable and will depend on how your body reacts with the medication.

5. SLOW WOUND HEALING

Healing of wounds such as the incision from your surgery may be slow. Keep your incision site and any other wounds clean. If any signs of infection occur such as increased redness, swelling, or pus in the wound, report this to a doctor right away.

6. SWELLING OF THE HANDS, FEET, ANKLES OR LEGS

You may develop fluid retention and swelling of the extremities. If this occurs and becomes bothersome you should report this to your transplant team.

7. INCREASED SUSCEPTIBILITY TO INFECTION

Try to avoid close contact with people who have active infections. Report any symptoms of infection such as fever, sore throat, chills, or fast pulse to a doctor or your transplant team *immediately*.

8. INCREASED RISK OF DEVELOPING CANCER

The risk for developing certain types of cancers is higher. It is important to be aware of and report any changes in your body that could indicate a problem.

SIROLIMUS (Rapamune®)

TAKING YOUR MEDICATION

- Sirolimus is taken once a day. Try to take the dose at the same time every day in order to maintain a consistent amount of drug in your body. Tablets must not be cut, crushed or chewed.
- Always be consistent with respect to sirolimus dosing and meal consumption (*i.e.* if you take the medication with food, always take it with food).
- Your transplant team will adjust your dose up or down based on the amount of drug in your blood. Blood tests are done just before your dose is taken. **Always remember to delay your dose of sirolimus until after your blood is drawn.**

STORAGE

- Store sirolimus tablets at room temperature – do not expose to extremes of temperature (direct sunlight or refrigeration).
- Store sirolimus oral solution in the **refrigerator**. Protect from light, **do not freeze**.

INTERACTIONS WITH OTHER MEDICATIONS

- **Sirolimus must be taken at least 4 hours apart from cyclosporine.**
- Many medications can change the level of sirolimus in your blood. This may cause serious problems. Do not take any medications, including non-prescription drugs or prescriptions given to you by anyone other than your transplant doctors, without first speaking to your transplant team.
- Avoid grapefruit and grapefruit juice as these can increase the level of sirolimus in your blood and lead to side effects.

REMEMBER

Wear/carry identification (*i.e.* Medic Alert) stating that you are immunocompromised.

INSTRUCTIONS FOR SIROLIMUS ORAL SOLUTION

- Supplied as a 1mg/mL solution in a glass bottle with amber oral syringes and caps
- Keeping bottle upright, place syringe in the adaptor cap on top of the bottle and draw up the correct dose as indicated on scale: *e.g.* 3mg = 3 mL
- Add dose to ¼ cup of water or orange juice, stir well, and drink. Add another ¼ cup water or orange juice to container, stir well, and drink this rinse solution.
- Throw away the syringe after each dose.
- You may pre-fill your syringe to be used at a later time. Draw up dose as described above. Place a cap on the syringe and keep in the carrying case supplied. Dose may be kept at room temperature, but must be taken within 24 hours of preparation.
- Bottles should be stored in the refrigerator and used within 30 days of opening.



VALGANCICLOVIR (Valcyte®)

GENERIC NAME	BRAND NAMES	REASON FOR USE
Valganciclovir Strengths: 450 mg tablets 50 mg/mL oral solution	VALCYTE®	This medication is an anti-viral. It is used to prevent infections caused by viruses such as herpes virus and cytomegalovirus (CMV). It may also be used to treat infections caused by CMV.

SIDE EFFECTS

1. DECREASED BLOOD CELL COUNT

Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.

2. GASTROINTESTINAL UPSET

Diarrhea, nausea, vomiting, or stomach pain may occur. Taking the medication with food may prevent these side effects. If these symptoms are severe or last for more than one day, report this to your transplant team.

3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

This can include headaches or trouble sleeping. Report these symptoms to your transplant team if they become troublesome. Medications may be prescribed to help manage this.

HOW TO USE THIS DRUG

- If your doctor has prescribed a once daily dose of this medication it may be taken either in the morning OR the evening. Take the medication at the same time every day.
- If a twice daily dose of this medication has been prescribed, take it in the morning AND the evening, approximately 12 hours apart.
- Take this medication with food.

Your transplant team will adjust the dose of this drug according to your level of kidney function.

