



TORONTO PANCREAS  
TRANSPLANT PROGRAM

# Kidney/Pancreas Transplant Manual

## *Dedication*

*This manual is dedicated to the families of deceased donors who make Kidney and Pancreas transplants at our center possible.*

*A Kidney/Pancreas transplant comes with the hope for an improved quality of life and the possibility of living a longer and more normal life. Accepting a transplanted 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 your transplant team take the responsibility of caring for you and your transplant very seriously. We will endeavor to provide you with the best possible transplant care based on current research and our clinical expertise.*



## *CHAPTER ONE - Welcome to the Pancreas Transplant Program*

### **Our Philosophy Care**

- ❖ We believe that our work is possible because of the generosity of organ donors. Our work must honor 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 Soham & Shaila Ajmera Family Transplant Centre Program is to work in partnership 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 and ability of our multi-disciplinary team.
- ❖ We believe that all members of the health care team make an important and valuable contribution to the plan of care. Each member of the team is a dedicated professional who continually maintains a current knowledge base and consistently strives 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 their optimal state of the health in collaboration 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, available resources, and ethical principles.

### **Our Expectation of you**

Throughout your transplant experience in the Soham & Shaila Ajmera Family Transplant Centre Program at The Toronto General Hospital you have responsibilities as well:

- ❖ Work in partnership with the health care team to ensure the best possible treatment, rehabilitation, discharge planning and follow up care.
- ❖ Provide accurate information and share any concerns with your members of the health care team.
- ❖ Inform the team if you do not understand or cannot follow the health care recommendations.



## Your Transplant Team

The pancreas transplant team is a group of specially trained professionals who work together to help your transplant be a success. Our team will evaluate your health prior to listing for transplant. We will do tests such as blood work, x-ray and scans. When all your results are in, the team will work with you in the process of listing.

During your transplant journey, we will work together with you to help you care for your new organs, your health, and support you through this process.

### *Your transplant team includes:*

- ❖ Surgeons
- ❖ Nephrologists
- ❖ Nurses
- ❖ Social Workers
- ❖ Physiotherapists
- ❖ Occupational Therapists
- ❖ Transplant Coordinators
- ❖ Spiritual Care
- ❖ Pharmacists
- ❖ Administrative Assistants
- ❖ and most importantly... *YOU!*

**Transplant Surgeon** - The transplant surgeon is a doctor involved in the evaluation and selection. The surgeon may ask for more tests to better assess you pre-transplant as these tests may give the surgeon important information for your transplant surgery. The surgeon performs the transplant operation and manages the post-operative recovery and the surgical care and is also involved in your care over the long term.



**Transplant Nephrologist** - The Transplant Nephrologist is a doctor who is highly skilled in the diagnosis and treatment of kidney care. You will see one of our transplant nephrologists before you go on the transplant list. They will review your assessment results and answer your questions. This doctor, together with your family doctor will care for you after your transplant in the clinic setting.

**Cardiologist** - The Cardiologist is a doctor who specializes in the diagnosis and treatment of heart disease. You will be assessed by the cardiologist prior to listing to ensure that your heart health is at its best prior to surgery. You will be followed post-transplant by our cardiologist.

**Transplant Coordinator** - The transplant coordinator is a registered nurse who provides pre-transplant education and coordinates the transplant evaluation. They can provide support for you while you are on the waiting list. Post-transplant, the transplant coordinator monitors you and arranges your follow up care.

**Social Worker** - The Social Worker meets with all transplant candidates to review your situation and supports. They will work with you to plan for your transplant. They can advise you about available resources such as transplantation, housing and local accommodations, financial assistance and your medication coverage. They also provide supporting counseling for patients before and after transplant.

**Administrative Assistants** - The administrative assistants work closely with your transplant coordinator during the assessment and post-transplant period. They are pivotal to the program and are responsible for test bookings, clinic appointments and they can also relay concerns to the transplant team on your behalf.

**Pharmacist** - The transplant pharmacist works closely with your doctors and the transplant team while you are in the hospital to make sure that you receive the most appropriate medication therapy. After your transplant; while still in hospital, you will attend a Self-Medication Class taught by the Transplant Pharmacist to learn about your transplant medications. The Transplant Pharmacist also reviews all of your medications with you before you go home and answer any questions you may have. They will also provide you with a medication schedule to help you keep track of your medications. Once you are discharged, our transplant pharmacist is available to you in consultation for any questions or concerns you might have regarding your medications.



**Inpatient Resource Coordinator** - The Inpatient Resource coordinator is a registered nurse who ensures you are ready for discharge from hospital and that a smooth transition is made from being a hospital patient to a clinic patient. The inpatient resource coordinator communicates with the outpatient transplant coordinator about the events of your hospital stay.

**Spiritual Care** - Spiritual Care Professionals are part of the team that provides care to patients and families in the transplant program. They seek to nurture and celebrate spirituality by providing assistance that is sensitive to cultural and religious diversity.

**Transplant Infectious Disease Doctor** - The infectious disease doctor is a specialist who helps your transplant team to diagnose and treat infections. Some transplant candidates have unique concerns with respect to the risk of infection and may need to be seen both pre and post-transplant.

**Dermatologist** - The Dermatologist is a specialist in the care of skin problems. The dermatologist has an excellent knowledge in transplant patients specifically and can diagnose skin changes or issues that can happen post-transplant.

**Health Care Providers outside the Transplant Team** - Your Family Doctor will always be a very important member of your healthcare team. It is important you to have regular check-ups in addition to your visits with the transplant team. The transplant team and your local medical team will work together with you to provide care after your transplant.



## *CHAPTER TWO – Getting Ready for Transplant*

### **The Kidney and how it works**

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Kidneys are about the size of your fist. The kidneys are located at the back of your body, one on each side, a few inches above your waist. They are brown in color and have millions of tiny working units called nephrons.

- ❖ Fluid balance
- ❖ Waste Elimination
- ❖ Mineral regulation
- ❖ Hormone production

#### **Fluid Balance and Waste Elimination**

Blood flows continually through the nephrons in the kidneys. These nephrons filter out excess water, waste products and many other substances from your system. Waste and excess water is removed from your body as urine. Urine made in your kidneys passes down through tubes called ureters and into your bladder.

#### **Mineral Regulation**

Kidneys also regulate the amount minerals in your blood. Some of these minerals are calcium, phosphorous, sodium and potassium. There are others too. When you have the right amount of these minerals in your blood, they help with the forming bones and keeping your heart, muscles and other body functions working properly.

#### **Hormone Production**

When your kidneys are working well, they produce hormones. Two important hormones are Erythropoietin and Renin. Erythropoietin is a hormone that helps your body to make red blood cells and hemoglobin. Renin is a hormone that helps to regulate your blood pressure. Your kidneys will perform all of these functions until they are very diseased. One kidney can do the job of both. With one working kidney you can regulate minerals, remove waste, and produce hormones. This is why transplant patients receive only one kidney during transplant surgery. This is also why a living donor can still lead a normal life after donating one of their kidneys.



## The Pancreas and how it works

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The pancreas is located beneath your stomach and is attached to your small bowel. There are two main functions of the pancreas are to make:

- ❖ enzymes (special proteins) that digest food and;
- ❖ hormones in cells called “Islets of Langerhans”

The pancreas makes enzymes that help to digest all types of food. The hormones made in the pancreas include insulin – which is needed to change sugar into usable energy. When the pancreas does not make insulin, the person has Type 1 diabetes. This means that the Islets of Langerhans are destroyed and make little or no insulin. Type 1 diabetes is considered an auto-immune disease of which the cause is still unclear.

When a patient has Type 1 diabetes, his or her body is not able to control the blood sugar level in the body. From this, complications can happen. Diabetes can affect your:

- ❖ Eyesight
- ❖ Nervous system
- ❖ Blood vessels
- ❖ Heart
- ❖ Bowel function
- ❖ Blood pressure

The impact of diabetes on the blood vessels in your kidneys can cause kidney injury which is why you will be followed closely post-transplant by a nephrologist to ensure good kidney health.





## Why you may need a kidney and pancreas transplant

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Diabetic kidney disease can lead to the gradual loss of kidney function. When the kidneys stop working, they cannot do their job of eliminating waste, regulating minerals or producing hormones.

When enough nephrons are damaged, you will not have enough kidney function. You will need dialysis or a transplant. Dialysis is a life-saving treatment. But it does not replace all the complicated functions of real kidneys. A successful kidney transplant is able to perform all these functions. Because of this, a transplant has more advantages compared to dialysis. Patients gain more independence and generally have more energy with a transplant. Also, patients with a kidney transplant, on average, live longer than those on dialysis.

Kidney transplantation is still a treatment option for kidney disease. It is not a cure. You can get your new kidney from a living donor, or from a person who has died (deceased donor). The hope is that your transplanted kidney will last several years.

Outcomes are variable depending on individual risk factors. This will be discussed in detail with your transplant surgeon and nephrologist.

Type 1 diabetes managed by insulin does not replace normal pancreas function. Complications as a result of sugar fluctuations can occur despite careful management. A pancreas transplant allows for improved quality of life and may stabilize neuropathy. If a kidney and pancreas transplant has been recommended for you then there is no possibility of your kidney failure reversing or that your pancreas will recover normal function.

If your doctor is recommending that you consider having a kidney transplant it means that there is no chance that your kidneys will recover. Your doctor believes that this will be the best treatment for you. We will help you understand the benefits and risks of having a transplant. This will give you the information to make an informed decision. We will support you as you go through the process of deciding to have a transplant. The decision to proceed is up to you. We will support your choice whether you go forward with transplant or not.



## What are my Transplant Options?

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As transplants become more common, patients are more interested in receiving kidney and pancreas transplants. For patients with Type 1 diabetes and kidney failure, there are several options available.

### **Living donor kidney transplant followed by pancreas transplant**

Living donor transplant happens when someone gives you one of their kidneys. This can be a family member (parent, brother or sister, or child), more distant relative (for example, cousin, aunt or uncle), husband or wife, in-law, or even a friend. The person does not have to be related by blood to you at all. After being reassessed by the transplant team, and you have recovered from the kidney transplant (usually about six months), you may be placed on the list for pancreas transplant.

### **Simultaneous kidney and pancreas transplantation**

During this operation, you receive a kidney and a pancreas from a deceased donor. You have one operation, where both organs are inserted at the same time.

### **Deceased donor kidney transplant followed by pancreas transplant**

Some people received a kidney transplant at a time when pancreas transplantation was not as common. They can still receive a pancreas transplant, even if it is several years since their kidney transplant. Before going on the pancreas transplant list, these patients will go through a complete assessment including kidney function like they did during their first transplant.



## The advantage and disadvantages

There are advantages and disadvantages to kidney and pancreas transplant. Kidney/pancreas transplants are a treatment for kidney failure and diabetes, not a cure. We believe that the advantages of having a kidney transplant outweigh the disadvantages. The advantages and disadvantages are listed below:

### Advantages

- ❖ you do not have to be on dialysis
- ❖ you will not need insulin injections
- ❖ you have more energy
- ❖ your diet is less restricted
- ❖ you do not have fluid restrictions
- ❖ overall, you feel better

### Disadvantages

- ❖ you will need to take drugs for the rest of your life to prevent rejection
- ❖ you will come to the transplant clinic for follow up appointments
- ❖ you may have side effects from your medications

Talk to your doctor and transplant coordinator about these advantages and disadvantages. They will help you work through each issue and help you decide if dialysis and medical treatment or transplantation is better for you.

It is very important for you to think about all your options, and discuss them with your family and the transplant team. For example, some people are afraid to ask someone to be a live donor, because they think it is dangerous for the donor. In fact, the donors are assessed very carefully, so that their risk is very low (about the same as having your appendix removed). Other people don't know that an in-law, a friend or even someone in their church, synagogue, or mosque can donate a kidney. Please ask us any questions you might have.



## Who is suitable to have a kidney/pancreas transplant?

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Any patient can look into having a transplant. The team assesses each patient individually. The basic requirements are:

- ❖ You must want to have a transplant, and understand and accept the responsibilities after the transplantation
- ❖ You must complete an assessment which shows that you are able to safely tolerate and aesthetic and surgery, and that you do not have any other active medical problems
- ❖ You must not have an infection at the time a transplant becomes available
- ❖ You must not be receiving treatment for cancer. Your physician will decide what period of time has to pass before you can be assessed for transplant after cancer is diagnosed.
- ❖ If you are currently smoking you must be smoke free for approximately 3 months prior to listing. You must remain smoke free thereafter.

Our goal is to make your transplant as simple and as successful as possible. We will do everything we can to make your transplant work for you. We will include you in your care decisions. We will help you to understand your treatments and check up on you regularly to ensure that your treatment regime is working for you.

**We need your commitment too.** Having a transplant will change your life significantly. Before you make this choice you need to be prepared to make changes. After your transplant you must follow the treatment regime very carefully to have a successful transplant. This includes being part of your health care team, learning about your treatments, taking your medications and attending your clinic appointments.



## The Transplant Assessment Process

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The transplant assessment process helps to determine if you are a transplant candidate. An important part of this assessment is to try and ensure that it is safe for you to have a transplant. Your assessment includes different types of medical tests and interviews with members of the transplant team. We make sure that you do not have any other conditions or health problems that would put you at risk if you were to have a kidney/pancreas transplant. Sometimes your assessment will uncover a problem that makes transplantation a poor option for you. Or it can identify a problem that may need to be corrected before you become a candidate for a transplant.

**The Transplant Work-Up** - Several tests are routinely done during assessment. These include:

- ❖ Blood work - we take many tubes of blood to test your blood type, HIV, hepatitis, kidney and liver function. We routinely require blood tests to keep your assessment current)
- ❖ Chest X-Ray – to look at your lungs, diaphragm, and heart size
- ❖ Electrocardiogram – an electrical picture of your heart
- ❖ Echocardiogram – an ultrasound picture of your heart
- ❖ Exercise or Persantine Stress Test – a test to determine how your heart performs
- ❖ Iliac Doppler – a test to check how blood well blood flows to your legs and feet
- ❖ Abdominal Ultrasound – to show a picture of the major abdominal organs

**Consultation interviews** - As part of the assessment process, interviews will be arranged with several members of the transplant team. They may include:

- ❖ Transplant Surgeon
- ❖ Transplant Nephrologist
- ❖ Transplant Coordinator
- ❖ Social Worker
- ❖ Transplant Psychiatry
- ❖ Cardiologist
- ❖ Anesthesiologist



## Infection Risks with Transplantation

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The risk of infection related to transplantation needs to be considered when choosing whether or not to proceed with kidney and pancreas transplantation. We hope this helps transplant candidates make an informed decision about transplant surgery. Please speak to your doctor or transplant coordinator if you have any questions about the information below.

Infections are an unavoidable risk of transplantation. They are the most common complication after transplantation. The risks of developing an infection must be balanced against the benefits of a transplant.

Transplant patients are at greater risk for infection because the anti-rejection drugs given after transplant affect their immune systems. Bacteria, viruses, fungi, or other organisms can cause infections. Most infections can be successfully treated.

We try to minimize the risk and impact of infections in part by:

- ❖ routine testing of the donor and of blood products
- ❖ giving anti-infective medications at the time of surgery and post transplants and,
- ❖ monitoring and testing recipients

Our knowledge of the infection risk with transplantation continues to grow. Over time, we will continue to learn about new infections that are currently unknown. Wound infections, abscesses, pneumonia and urine infections are potential complications of any surgery. Some, but not all, of the infections risks associated with transplantation discussed below:

**Multi-drug Resistant Bacteria** - Some patients in hospital have developed bacterial infections that are resistant to standard antibiotics. Some specialized antibiotics may be effective in this situation. We try to reduce the risk of multi-drug resistant bacterial infections in our transplant unit by only giving antibiotics when absolutely necessary.

**Viral Hepatitis (Hepatitis A B, C)** - Donors are tested for the presence of hepatitis B and C infections. As with other viral infections, testing is accurate but not 100% effective in avoiding disease transmission. Organs from donors who have been exposed to the hepatitis B or C virus are sometimes knowingly given to recipients who have also been previously exposed to this virus and have developed immunity.



**Cytomegalovirus (CMV)** - CMV can cause flu-like symptoms, pneumonia, hepatitis, and other illness. Most people have already been exposed to this virus and have some degree of immunity. Since CMV is very common in the general population, you have received an organ from a donor that is positive for CMV. Transplant recipients who are at high risk of developing CMV infection will be given medications to reduce the risks of CMV infection.

**Epstein - Barr virus (EBV)** - EBV also causes flu-like symptoms. Rarely, it can cause a disease similar to a lymphoma (a type of blood cancer). Fortunately, most people have been exposed to EBV and have partial immunity. Transplant recipients without any previous immunity will be given medications to reduce the risks of EBV. Reasonably effective treatment is available if an EBV infection develops or recurs post-transplantation.

**SARS (Coronavirus)** - SARS is potentially transmissible with a transplanted organ. There is no proven method available to test donors for SARS at this time. We try to reduce the risks of SARS transmission by checking donors with a screening questionnaire and by not retrieving organs from hospitals that have had uncontrolled spread of SARS.

**West-Nile Virus** - Most patients with this infection have no symptoms or minor symptoms. Sometimes the infection can produce permanent brain or nerve damage. This virus is transmitted by insect bites, but also through blood transfusions or organ transplantation. It is a fairly new problem in Ontario. We do not yet know the likelihood of contracting this infection but a very small number of our transplant recipients have become infected. Although most have recovered, others have become disabled or have died. Currently, blood and organs from donors with symptoms suspicious for West-Nile infection are excluded.

**AIDS (Human Immune Deficiency Virus)** - All donors are tested for HIV. The testing is very accurate but again, not 100% reliable for preventing HIV transmission with blood organ donation. There is a brief period of time during the beginning of HIV infection when the virus testing could be negative but the donor could still be infectious.

**Polyoma Virus** - A transplanted kidney may become infected with the Polyoma Virus. This infection can be acquired from the donor organ or through environmental exposure to this agent. This virus sometimes irreversibly damages kidney grafts. There is no effective treatment other than to reduce immune suppression.



**Unknown Infections** - Transplant recipients may be at risk of acquiring previously unknown infections due to their weakened immune system. It is possible such an infection may be acquired from the donor. Every effort is made to ensure that donors with symptoms suspicious for any type of known or unknown infection are excluded.

## Cancer Screening

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The Canadian Society of Transplantation recommends that potential transplant recipients be screened for cancer. These guidelines should be followed through your family doctor's office as listed below:

**Cervical Cancer** - Every woman should be screened for cervical cancer. The test is cervical cytology smears – PAP smear test. This should be done every year. Women, 30 years of age or older, may be screened every 2-3 years if they have had 3 normal smears in a row.

**Breast Cancer** - Beginning at age 40, woman should have a mammogram every 1-2 years. Clinical breast examination and breast self-exam are encouraged.

**Colorectal Cancer** - Patients with no personal or family history of colorectal cancer should be screening at the age of 50. This can be arranged through your family doctor's office.

## Following your Evaluation

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If you are deemed a suitable candidate for transplant, you will be contacted and given a clinic appointment to discuss and review the following:

- ❖ Results of the assessment testing
- ❖ Review and signing of the surgical consent, at which time a copy will be given to you
- ❖ Blood work will be drawn for antibodies and tissue typing and any other updates needed
- ❖ You will be given a schedule for these tests in future
- ❖ Review telephone numbers that you may be reached at
- ❖ We will review reasons for placing you on hold on the transplant list





## *CHAPTER THREE – The Cost of Transplantation*

### **The Cost of Transplant Medications**

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When you are discharged from the hospital after your transplant, you must be ready to pay for your medications.

These costs can range from \$200 - \$4,000 per month.

If you have not registered with Trillium and paid the deductible, you will need to pay by

- ❖ using your drug benefit card to directly bill your insurance company (if your company offers this option)
- ❖ VISA or MasterCard
- ❖ Cash

**NOTE:** The Transplant unit will not provide you with medications to take home. Toronto General Hospital **does not** have a drug assistance plan for Transplant patients.



## The Trillium Drug Program

Many transplant drugs are expensive and unusual. These drugs can cost hundreds or thousands of dollars. Even the best insurance programs may not completely cover the costs of these medications.

The Trillium Drug Program, funded by the Ontario Government, is available to all Ontario residents, under 65 years of age, to help pay for such medications. The Trillium Drug Program also covers recipients who are on social assistance, Ontario Disability or have Home Care drug cards.

We encourage all Ontario recipients under the age of 65 to register for the Trillium Drug Program *BEFORE* being listed for transplant.

There is no cost to register with the Trillium Drug Program. The application takes only a few minutes to complete. Being registered with Trillium does not interfere with your private drug coverage. Trillium may assist you with drug costs that are not covered or only partly covered by your private drug plan. You can get applications at any Ontario pharmacy, online, or through your social worker. Your social worker will provide you with further details about his program. The website to download the application for the Trillium Drug Program is:

[http://www.health.gov.on.ca/english/public/forms/form\\_menus/odb\\_fm.html](http://www.health.gov.on.ca/english/public/forms/form_menus/odb_fm.html)

As a transplant recipient you must keep your registration active with Trillium. You must renew your registration with Trillium every year in August.

**Seniors** - Recipients over the age of 65 years are covered automatically with the government drug plan under the seniors benefit plan.

If you have any further questions you can contact your social worker or Trillium Directly at:

PO Box 337, Station D  
Etobicoke, ON, M9A 4X3  
24hour line: 1-800-575-5386  
Fax: 416-642-3034  
e-mail: [Trillium@resolve.com](mailto:Trillium@resolve.com)



## Drug Coverage – Private Insurance

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The following points are things to consider prior to listing for transplant:

- ❖ Who is the provider of your private drug coverage (Manulife, Sunlife?)
- ❖ What is the percentage of medication costs covered by your private insurance?
- ❖ Is payment of medications automatic or do you have to pay up-front and get reimbursed later?
- ❖ Are there any yearly maximums for drug coverage?
- ❖ Are there any lifetime maximums for drug coverage?

If you pay for your medications up front, how do you plan to pay for your transplant medications? You must have a payment plan in place prior to transplant.

You should submit a medication list to your insurance company for pre-approval. One will be provided for you at time of listing by your transplant coordinator.

If your transplant team needs to request special approval for medications that your private plan does not pay for, we can only do so with Trillium in place. Therefore, advanced application and approval to these programs will prevent any delays in providing unexpected treatments.

## Financial Information

Having a transplant can have an impact on your finances. It is important for you to know this and plan ahead. Our income may change and you may have new expenses. Every situation is unique. Use the following information as a guide to see if there are opportunities for financial support.

Transplant patients may be eligible for financial help from sources such as:

- ❖ Insurance – Employment or Sickness Benefits
- ❖ Employment and Retraining Funding
- ❖ Canadian Pension Plan – Disability (CPP-D)
- ❖ Ontario Works (OW)
- ❖ Ontario Disability Support Program (ODSP)

It is important to know how these programs may assist you with important financial support. Please contact your transplant social worker for assistance and details about these programs to see which ones you may qualify for.



## Insurance

**Employment Benefits** - Some transplant patients are able to return to the job or position they had before transplant. Depending on your employer and the amount of time you are off sick, you may have short or long term disability benefits. Your employer will be able to tell you more about this.

**Sickness Benefits** - If your work does not have STD/LTD or the payment is low, you might qualify for Employment Insurance (EI) sickness benefits. EI sickness benefit gives you 15 weeks of income. Contact your local EI office for more information about qualifying.

**Employment and Retraining Funding** - Some patients may return to work after transplant but need to change their job. In this case, patients may qualify for an Ontario government program for vocational assessment and rehabilitation. This program is for patients who have physical problems that prevent them from finding or keeping their job.

Unfortunately there is a long waiting list. Once you are accepted into the program, you qualify for financial assistance for retraining costs and a living allowance.

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

**Canada Pension Plan – Disability (CPP-D)** - If you are permanently unable to work after your transplant and you paid into CPP, you can apply for CPP benefits. CPP approves 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 several weeks to process. Benefits are not retroactive. Some restrictions may apply.

**Ontario Works Assistance (OW)** - You can apply for Ontario Works if you have a low income, few assets and are temporarily not able to work. Your total family income determines if you are eligible. Drug benefits are included. You will have to contact your local OW office for assessment.



**Ontario Disability Support Program (ODSP)** - If your doctor states you are permanently disabled and cannot return to work, you may qualify for the Ontario Disability Support Program. This program is also for patients with low family income and few assets. Drug benefits are included. You will have to contact your local ODSP office for assessment.



## Other Financial Considerations

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After your transplant you will have expenses related to doctor and clinic visits. These will be out of pocket expenses. We will describe a few below and offer some brief tax tips to help you recover some of these costs.

**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. It is worth looking at the costs of nearby lots if you will be coming to TGH often. Consider taking public transit (TTC) or Go Transit whenever possible.

**Wheel Trans** - If you live in Toronto and are physically disabled, you can apply for Wheel Trans. This service is available to people who are not mobile enough to use the regular transit system. To get a Wheel Trans number, you must have an interview with the TTC. Call 416-393-4111 to set up an appointment.

**Housing** - Sometimes patients need to arrange for a place to stay locally during the post-transplant period. Talk to your social worker about this. We can give you a list of places to stay.

**Travel** - For patients living in Northern Ontario, the Northern Health Travel Grant provides some financial assistance for travel to medical appointments. As a patient, you must pay the cost of travel and then apply for reimbursement you will need to have your local doctor fill out their section of the travel grant form, and then bring this form to your TGH specialist to fill out their section.

Social Assistance (OW/ODSP) may help you with travel costs, no matter where you live. You must apply at your local office for help.

**Tax Tips** - Check the Revenue Canada Agency Website or ask your accountant for information about deductions on your income tax related to your illness and your transplant. The web site is:

<http://www.cra-arc.gc.ca/menu-e.html>

Here is a partial list that may be helpful. Remember to keep all your receipts for all your expenses. You cannot claim for anything if you have already received reimbursement, unless that reimbursement is claimed as income. You may need a medical letter to support your claim for some items.



## Medical expenses that you may be able to claim include:

- ❖ Long distance calls to the hospital
- ❖ Any diagnostic procedures you had to pay for
- ❖ Any payments you made to the hospitals not covered by your provincial health insurance
- ❖ Prescription drugs that you paid yourself, including any portion not covered by your private insurance or the Trillium Drug Plan
- ❖ Fees paid to doctors for completing medical or insurance forms
- ❖ Ambulances
- ❖ Parking for hospital and clinic visits
- ❖ Outside of Canada Medical expenses – not covered by provincial health insurance
- ❖ Cost of housing, if you relocate immediately following your surgery
- ❖ Home care services not covered by provincial health insurance
- ❖ Premiums paid to private or government drug plans

The list of eligible expenses is extensive and you should refer to the Revenue Canada Website for a full list.

You may claim expenses for yourself, your spouse and, with some limitations, your dependents. You can claim expenses for any twelve-month period ending in the current tax year.

## Travel Expenses

- ❖ If you travel more than 40km one way for medical appointments, you may be able to claim transportation costs: train, bus, or taxi costs
- ❖ If you use your own car, you can claim a reasonable amount for travel, approximately \$0.50/km. Check with Revenue Canada. This amount may change over the years
- ❖ You will need to prove the number of trips you made to the hospital for appointments. Keep a travel log with mileage that you travelled.
- ❖ If you travel more than 80km one way for medical appointments you are also able to claim reasonable expenses for meals (\$51/day) and accommodation as well.



# Legal Information for Patients

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## Powers of Attorney

It is important that you think about your situation and make plans for your powers of attorney. There are two basic forms for Powers of Attorney.

- ❖ Powers of Attorney for Personal Care
- ❖ Powers of Attorney for Finances

## Powers of Attorney for Personal Care

Your power of attorney (PoA) for personal care is a person that you choose to make decisions about your care when you are not able to make them yourself. This person is also called your Substitute Decision Maker.

To appoint a power of attorney, you need to create a legal document called Powers of Attorney for Personal Care decisions.

If you do not assign a PoA for personal care, the law states who can make decisions, in the following order of priority:

- ❖ spouse
- ❖ adult children
- ❖ 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.

Sometimes patients have a PoA for health care decisions that is different than their usual substitute decision maker. If this applies to you, make sure this is clearly stated in your PoA document.

Give copies of you PoA document to your doctor, your PoA and the hospital when you have your transplant.





## Powers of Attorney for Finances

Your power of attorney for finances is a persona that you choose to make decisions about your finances when you are not able to make them yourself.

To appoint a Financial PoA, you need to create a legal document called Powers of Attorney for Finance decisions. This legal document states who will be responsible for making financial decisions, payments, etc., if you are unable to do so.

## Advance Care Planning

Advance Care Planning is also known as advance directives and living wills. Decisions about your healthcare need to reflect your wishes and values. There may be a time in the future when you are unable to make decisions about your medical care and treatment. This situation may be temporary or permanent; it could happen suddenly or gradually.

If you were unable to make decisions for yourself, there are two important things we need to know:

1. What are your specific wishes regarding your healthcare?
2. Who would you want to make decisions for you?

It is important to answer these questions now, while you are capable of making a decision. This helps to ensure that your wishes will guide your care.

Advance care planning helps to clarify how you wish to be cared for and gives someone you trust the authority to act on your wishes. This person is also known as a Substitute Decision Maker. This is the only person we would ask to make decisions, in the event that you are unable to do so.

Please talk about your care wishes with your family and anyone else who might make a decision for you in the future. We are always happy to answer any questions you have about advance care planning.

There are guides that you can use to help you at:

<http://www.citizenship.gov.on.ca/seniors/english/programs/advancedcare/docs/AdvancedCare.Guide.pdf>



## *CHAPTER FOUR – Waiting on the List*

### **Waiting on the List**

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While you are on the active waiting list, yearly updates of all testing will be done through your dialysis unit or family physician's office. This will ensure that you are still medically safe to undergo transplant surgery.

There are 2 goals for the waiting period for transplantation.

1. Maintain your health as you wait for transplant surgery
2. Identify and manage any new problems that may arise.

While you are on the list, you will occasionally be asked to come to the clinic to see your coordinator and transplant nephrologist. These clinic appointments are excellent opportunities for you to ask questions or clarify misconceptions regarding transplant you may have heard while waiting on the list. You may contact your transplant coordinator to set up an appointment if you feel the need for additional information.

### **Your Place on the Waiting List**

The waiting list is generated based on specific criteria. At any time there are over 100 patients in Ontario waiting for a kidney and pancreas transplant. There is one computerized network or database for all transplant centers across the province. This database contains information about organ identification and sharing. The **Trillium Gift of Life Network (TGLN)** is the organization that takes care of the organ sharing system in the Toronto region. They also support donor families and organize the organ donation process with transplant centers.

The wait time for a kidney and pancreas transplant varies from a few months to several years. This can be a very stressful and discouraging time for you. You are waiting for a transplant under circumstances over which you have no control. There are many unknowns.

You may also be experiencing fear; this is normal and it is okay to be scared. 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. Talk to them. Ask them your questions.



## Maintaining Contact

When a kidney and pancreas becomes available time is critical and we need to get in touch with you right away.

We must know how to contact you at all times. For this reason you need to provide your transplant coordinator with all your contact information.

- ❖ Home number and address
- ❖ Work number
- ❖ Cell phone number
- ❖ A nearby friend or relative

**You must inform your coordinator immediately if:**

- ❖ any of these contact numbers change
- ❖ you will be out of reach for a period of time (e.g. Travel)
- ❖ you are ill or have an active infection
- ❖ you are hospitalized for any reason

We will need to place you on hold should the above circumstances happen however, you will not lose your place on the waiting list and will be re-activated once appropriate.



## Deceased Donor Process

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

Deceased donors are individuals who have recently died from severe injury causing brain death, the donor is identified and declared brain dead and the next of kin is approached for consent to donate their loved one's organs and tissues for donation and transplantation.

The organ donor is tested to make sure the organs are suitable for transplant. Tests include blood tests, virus testing, x-rays and scans. After testing, organs are assigned to the most appropriate patient on the wait list. After the transplant program accepts the organ, the donor is taken to the operating room. A specialized team of surgeons then works carefully to remove the organs for donation.

### Are the kidney and pancreas suitable for transplantation?

Blood type is an important part of transplantation. People are identified as blood type A, B, AB, or type O. Blood type affects how long people will wait.

- ❖ type O is the most common
- ❖ the next most common blood type is A
- ❖ Only a small percentage of the population has type B or type AB blood

Not every kidney/pancreas that becomes available will be right for you. Blood type is not the only thing that matters. For every donor and recipient, we look at 4 things. These are:

- ❖ blood type
- ❖ genetic typing
- ❖ cytotoxic antibodies
- ❖ viruses

**Blood Type** - Your blood type must be compatible with the blood type of the donor. The factor i.e. 'positive' or 'negative' in the blood group does not have to match.



**Genetic Typing** - Genetic typing is also called tissue typing. It gives us information to find an appropriate match for you. Most of our donors are recipients are not well matched. In living related donors, we often find some similarity in the typing. Currently, we type and match six significant separate areas on your chromosomes. Deceased donors often match none of these numbers or at best one out of the six. Genetic typing is complicated to explain. Your transplant team will explain in detail if you would like.

**Cytotoxic Antibodies** - We test all recipients to see if they have antibodies that could react against the tissue of their donor. To do antibody testing, our lab mixes your blood cells with the blood cells of the donor. If the results come back negative, it means that there are no antibodies and the match is OK. A positive test means that there are antibodies. A transplant between you and this donor is not possible. Once on the deceased donor list, you will have blood drawn for this every 3 months. You are tested against 20-30 random people to determine how easy or difficult you are to match. The results are given as a percentage. If you are given results of 10% you are reacting against only 2 of 20 people are fairly easy to match. If you are given a percentage of 90%, you are reacting against 18 of 20 people and are therefore more difficult to match and have a higher risk of rejection.

**Viruses** - We test all donors and recipients for several viruses including AIDS and West Nile Virus. If the donor carries these viruses they are automatically turned down.

➤ **CMV**

- All recipients and donors are also screened for a virus called CMV. Eighty percent of the adult population in Canada is positive for this virus, meaning that at some point, they were exposed to it. In some cases we will give a CMV positive kidney and pancreas to a CMV negative individual but we will give you extra medications for a period of six months to try to keep you from getting ill as a result of being exposed to this virus. This strategy has worked relatively well. CMV is a virus that may cause flu-like symptoms in normal individuals but which can cause serious illness in a transplant patient.



➤ **EBV**

- Epstein-Barr virus, frequently referred to as EBV, is a member of the herpes virus family. It is one of the most common human viruses. As many as 95% of adults between 35-40 years of age have been infected. EBV also establishes a lifelong dormant infection in some cells of the body's immune system. All recipients and donors are tested for EBV. About 75% of the population is EBV positive and some people are EBV negative. Individuals who are EBV negative are at increased risk of developing some types of cancers. If you are EBV negative you will have this issue explained in more detail by your transplant nephrologist.

For those receiving a deceased donor kidney and pancreas the physician will look at these four matching categories every time an organ of your blood type is available. He will also consider such things as medical priorities. Everyone on the list is treated fairly using all the information available.

The race and sex of the donor and recipient do not matter. Deceased donors must however be:

- ❖ free of heart disease
- ❖ free of infection
- ❖ free of chest trauma

Even if all these tests are ok, there are still times when your transplant may not happen. Even though the initial testing may look good, the final approval must come from the surgeon after he has looked at the kidney and pancreas to be transplanted. So, you may go through the process of getting the call to come for surgery; you get ready for surgery, and then have you surgery cancelled. This is a false alarm. This can be very disappointing. It is for your protection.

**Trillium Gift of Life Program (TGLN)** - TGLN is the government service that keeps track of organ donation and distribution. This program is responsible for the allocation, retrieval, and transplantation of the organs. Our branch of the TGLN is the largest and busiest in Canada. TGLN is an integral part of the Soham & Shaila Ajmera Family Transplant Centre Program. The TGLN program is first to be notified about a potential organ and tissue donor. They use a matching system to find a transplant recipient. A recipient coordinator will call you when a transplant becomes available.



## What is a False Alarm?

A false alarm happens when a coordinator calls you to come for your transplant and then 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. Keep in mind that false alarms can happen.

Once you arrive at the hospital, things move at a hectic pace as you move through the procedures to prepare you for the transplant. In the middle of this, you are told that the transplant surgery cannot be done.

The surgery can be cancelled for many reasons:

- ❖ We may have found a problem with the donor at the last minute
- ❖ One of your last minute tests has unusual results so the operation cannot safely proceed and,
- ❖ We may have found that there is a problem matching an organ to a recipient.

You and your family may feel shock, disappointment and sadness when this happens. Hopefully, you will be called again soon, for another possible organ transplant. If you, or any members of your family are having difficulties coping with the false alarm experience, let your coordinator know. They will be able to refer you to someone on the transplant team who can help you deal with your feelings.

In accordance with the *Ontario Human Tissue Gift Act*, The Toronto General Hospital and the Soham & Shaila Ajmera Family Transplant Centre Program do not support or accept payment of any kind from recipients, organizations or any party for organs for transplantation.

It is against the law to buy, sell or otherwise deal in, directly or indirectly, any tissue for transplant or any body part or parts of the body for therapeutic purposes, medical education or scientific research.

If at any time you are approached by a person to purchase or sell an organ for transplant, please immediately contact:

Patient Relations at 416-340-4907



## How Long Will I Have To Wait?

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How long you will wait for a transplant depends on:

- ❖ your medical status
- ❖ your length of time waiting
- ❖ your blood group
- ❖ organ availability

In general, as the number of patients requiring transplant increases, so does the wait time. We can talk to you about the average wait time for someone with your blood type. It is difficult to give you the exact time that you will wait. This is because we do not know when an organ that is a good match for you will be available.

**It is important to remember the following while you wait:**

1. Live your life to the fullest that you are able. Do not wait by the phone, but rather, do as much as you can, ensuring all the time that we are able to reach you if we need to.
2. You must ensure the transplant team has the up to date contact information to reach you if a kidney and pancreas becomes available. Provide all relevant information including cellular phones, alternate telephone numbers. Give the team up to date information if you move or change jobs.
3. Tell your transplant coordinator if you are going away for the weekend or on vacation. Give them the numbers where they can reach you if a transplant becomes available.
4. 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 dietician has given you. If you are overweight, try to lose weight. Obesity increases your surgical risks.
5. If you are ever ill, either with a bad cold or an infection or other complications related to dialysis, let your Transplant Assessment Coordinator know. Your dialysis nurse will also keep them informed, but it's good if you communicate directly with the transplant coordinator yourself. Illness usually means you go on temporary hold. When the illness is resolved, you will be reactivated after review with the transplant physician.





## Staying Healthy While You Wait

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### Vaccinations

Vaccinations are important for your health. We recommend:

- ❖ A flu shot every year in the fall. You can get this from your family MD or a health clinic
- ❖ The Pneumovax vaccine every 5 years
- ❖ Hepatitis B Vaccine or TwinRix (hepatitis A and B combined). Except for recipients who have previously been exposed to or immunized for Hepatitis B. Ask your coordinator
- ❖ Varicella Vaccine (chickenpox) is recommended for any adult who tests negative. Except for recipients who have previously been exposed to or are immunized for Varicella. Ask you coordinator.

**Dentist** - Good oral hygiene is important before transplant. Regular check-ups and cleanings are recommended.

**Smoking** - All transplant recipients are **REQUIRED** to be smoke free (tobacco and other substances) for a period of at least 3 months prior to listing. If you are having problems with quitting and staying smoke free, speak with our social worker or coordinator who can recommend programs that can help.

**Travelling/out of town trips** - If you need to travel outside approximately 3 hours outside of your normal residency, please speak with your coordinator. You may need to go on hold on the list while you are away.



## *CHAPTER FIVE – The Call*

### **The Call for Transplant**

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When a kidney and pancreas become available from a deceased donor we need to contact you right away.

Once you are chosen as the most suitable recipient, the transplant programs recipient on call coordinator will work to reach you by calling your contact numbers in this order

- ❖ home phone number
- ❖ alternate phone numbers that you provide

*\*Messages will be left where answering machines are available. \**

Time is critical when an organ becomes available. If the coordinator cannot reach you after **1 hour**, another recipient must be selected.

If you are unable to reach the person who called you, contact the **Transplant Inpatient Unit at 416-340-5163**. Ask to speak to the Charge Nurse.

Tell the nurse that you are waiting for a kidney/pancreas transplant. The charge nurse will put you in touch with the recipient on call coordinator.

**Refusing to come in when called for transplant will mean that you are immediately placed on hold and must contact your transplant coordinator to discuss your situation.**

The call to come into hospital for transplant may come at any time of the day or night. The recipient on call coordinator will identify themselves and asks you a few questions. They will ask:

- ❖ How are you feeling?
- ❖ If you have any fever or flu symptoms
- ❖ If you have had an recent surgery, blood transfusions or infections
- ❖ In you are taking any antibiotics or have had any new medications prescribed
- ❖ If they have no concerns regarding your present condition they will ask you to come to hospital as soon as possible.

***Do not drink or eat anything from the time that you are called in for transplant. It is very important that you follow these instructions.***



## Coming to the Hospital

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Once you are called in for kidney/pancreas transplant there is an urgent need to make sure you arrive at the hospital quickly and are ready for surgery.

- ❖ It is your responsibility to arrive at the hospital when called
- ❖ Estimated time of arrival will need to be discussed with the coordinator on call
- ❖ If you live outside the Toronto area, specific plans need to be made ahead of time
- ❖ If weather or traffic delays your trip to the hospital, call the transplant in-patient unit to advise them of the situation. **416-340-5163**

We expect you to arrive at the hospital as soon as possible after getting the call for transplant. We want you to arrive safely to hospital.

Depending on the time that you are called to the hospital, you will either go to the Admitting Department or the Emergency department. The coordinator who calls you will tell you which entrance to use.

**Between 7 am to 11 pm Monday -Friday go to:**

Admitting Department

Toronto General Hospital, 200 Elizabeth St., Ground Floor, East (Eaton) Wing

**Between 11 pm and 7 am Monday – Friday & Weekends go to:**

Emergency Department

Toronto General Hospital, Elizabeth St. Entrance

Once you arrive at the hospital, you will be admitted to the transplant unit where the nurses will prepare you for surgery.

**We will:**

- ❖ Do blood work and a chest x-ray
- ❖ Start an intravenous line (IV)
- ❖ You will not be given anything to eat or drink



## What to Bring to Hospital?

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### Bring these items to hospital:

- ❖ Toronto General Hospital blue identification card
- ❖ Ontario Health Care (or provincial health card from another province)
- ❖ An accurate list of all medications or bring the medications with you in their original packages

After your surgery, you will go to the Acute Care Unit on the 10<sup>th</sup> floor of the Clinical Science Building. You do not need any of your personal belongings here, and we want to lessen the risk that such items are lost in hospital.

Personal belongings will not be needed until you are transferred back to the Transplant Unit on the 7<sup>th</sup> Floor. At this later time, your family may bring personal items to hospital such as:

- ❖ Toiletries, i.e. soap, shampoo, comb, toothbrush etc.
- ❖ Dentures, hearing aids or glasses
- ❖ Your drug card if you have one
- ❖ A pair of slippers with a closed in heel or running shoes
- ❖ Lip and skin moisturizer (the hospital tends to be very dry)
- ❖ A small overnight bag
- ❖ A bathrobe that opens all the way down the front

### Do not bring:

- ❖ Any valuables such as rings, watches or jewelry
- ❖ Large amounts of cash
- ❖ Any large electrical equipment that needs to be plugged in (you may bring an electrical razor or hair dryer)
- ❖ Laptop computers



## *CHAPTER SIX – Your Transplant Surgery*

### **The Surgical Phase**

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When you are ready for surgery, one of our staff will take you to the pre-operative care unit. Here, an operative room nurse will come to see you and later, take you into the operative room. Once you are settled in the operating room, the anesthesiologist gives you your anesthetic to put you to sleep. While you are asleep, your transplant team will put in several drains, lines and tubes. We will talk about these in the post-operative phase.



## The Surgical Phase

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When you are ready for surgery, one of our staff will take you to the pre-operative care unit. Here, an operative room nurse will come to see you and later, take you into the operative room. Once you are settled in the operating room, the anesthetist gives you your aesthetic to put you to sleep. While you are asleep, your transplant team will put in several drains, lines and tubes. We will talk about these in the post-operative phase.

Your family can wait in our waiting room until your surgery is over. This is located on the 3<sup>rd</sup> floor of the clinical science building. The nurses will direct your family during your surgery. Your surgeon will talk to them once the operation is finished.

- ❖ Your surgery will take approximately 5-6 hours
- ❖ Your incision will be in the middle of your abdomen. It will be approximately 10-15cm long.
- ❖ **Attaching your new kidney:** The surgeon places your new kidney in your left side; the artery and vein from your new kidney (renal artery/renal vein) is attached to the iliac artery and iliac vein which also supplies blood to your leg. The ureter (the tube that takes urine away from your 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 will be removed 6 weeks after transplant.
- ❖ **Attaching your new pancreas:** The surgeon places your new pancreas in your right side; the artery and vein from your new pancreas is attached to the iliac artery and the inferior vena cava. The duodenum is attached to your intestine.
- ❖ You will have 1-2 drains (Jackson-Pratt drains) in your abdomen to help drain excess fluids away from your new organs.
- ❖ If you are a peritoneal dialysis patient, your PD catheter will be removed during the surgery.



## The Post-Operative Phase

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After your transplant, your new kidney may or may not function immediately.

- ❖ If your new kidney works immediately, you will not need dialysis any more.
- ❖ If your kidney does not work immediately, you will continue on dialysis until your new kidney recovers from being moved. Once it starts to work dialysis will not be needed.
- ❖ Having dialysis treatments will not prevent your kidney transplant from functioning.
- ❖ In most patients, the new pancreas begins producing insulin immediately and there is no need for injections to control blood sugar levels.
- ❖ You will have blood tests every day. This tells us how your transplants are working and gives us the information that we need to adjust your medications properly.
- ❖ You will have other tests to check your transplants, such as an ultrasound.

Your family can wait in our waiting room until your surgery is over. This is located on the 3<sup>rd</sup> floor of the Munk building. The nurses will direct your family during your surgery. Your surgeon will talk to them once the operation is finished.

After your transplant surgery, you will be in the hospital for 7-10 days. You will receive care in several different places. The chart below shows where you will be at different stages of your care.

### Stage of your care

*Getting ready for transplant*

*Immediately after your transplant*

*When you are starting to recover*

*Completing your recovery*

### Where you will have your care

*Soham & Shaila Ajmera Family Transplant Centre Unit*

*Post Anesthetic Care Unit (PACU)*

*Multi-Organ Acute Care Unit*

*Soham & Shaila Ajmera Family Transplant Centre Unit*

You begin your hospital stay on the **Soham & Shaila Ajmera Family Transplant Centre Unit** then go to the operating room. Immediately after your transplant surgery our care team will take you to the **Post Anesthetic Care Unit (PACU)**. Here you will have your blood pressure, breathing and other things checked.



Once you wake up from the aesthetic, we will take you to the **Multi-Organ Acute Care Unit (ACU)**. You will be on a heart monitor and blood pressure machine; many intravenous and pumps will be giving you medications. The average stay in the ACU is 2-3 days. While you are in the ACU, your family is invited to visit you for short periods.

When you are ready to leave the ACU, we take you to a regular room on the **Soham & Shaila Ajmera Family Transplant Centre Unit**. This is where you will stay for the rest of your time in the hospital. All of our new transplant patients stay here.

During your time in hospital, we request that you pick one person to be your family spokesperson. This person is responsible for calling to see how you are doing. Then all other family members and friends can call your spokesperson. This will help us make sure that we are giving information about you to the right person. It will also allow the nursing staff the time they need to take care of you and other patients.

## **Pain Management**

Recipients are often concerned about whether they will have pain after surgery and how that will be dealt with. Here are the answers to some of recipients more commonly asked questions. Feel free to speak to your coordinator if you have any further concerns.

### **Will I have pain after surgery?**

Yes, most recipients have pain after surgery. Pain medicine is a priority in your care. It will help relieve your discomfort; you can expect to feel pain in the area of the incision. You may also feel stiffness and aches in other areas. We encourage you to use the pain medicine. It will help you start moving around, sitting, and walking sooner. This is an important part of your recovery.

### **How will my pain be managed?**

We will work with you to manage your pain. Since you will be taking pain medicine only for a short period of time, you do not need to worry about becoming dependent on it. You will be monitored daily by pain specialists in the hospital to ensure that your pain control is enough to ensure you can still move comfortably. You will have an intravenous that is connected to a patient controlled analgesia (PCA). This pump holds the pain medication. When you feel like you need something for pain, you press the button attached to the PCA pump. The pump delivers pain medication through your IV.





## Can I overdose on pain medication?

The patient controlled analgesia (PCA) has a safety feature that we set to stop you from getting too much medication. We program a safety timer called a lockout.

## Are there side effects of pain medications?

Some recipients have side effects from pain medication. They can include nausea, vomiting, sleepiness or itching. If any of these happen to you, tell your nurse.

## What happens when I don't have an IV?

Once you are able to drink fluids, we will give you pills to help control your pain. Pills take longer to work than IV medication. This means that it is important to tell your nurse when you are beginning to feel uncomfortable.

## How else can I control my pain?

**Relaxation breathing**– gets the attention away from your pain because you are focusing on your breathing. You take slow deep breaths, in through your nose, and out through your mouth.

**Visualization**– Visualization involves imagining yourself without pain. To begin, close your eyes and imagine yourself in a place or time that brought you happiness. It may be on a beach, in a forest, anywhere that brings you peace.

**Massage**– Massage can help to decrease your pain. Massage is something your family or partner can do to help relieve your pain. Gently rubbing your shoulders, back or arms can relieve tension.

## Delirium

Delirium is a condition which causes some patients to become confused in their thinking. Patients who are hospitalized are at a greater risk for developing delirium. Delirium can occur after major trauma such as a surgery or with disturbances in the balance of the blood. As well, delirium is a physical problem (a change in the body) that can alter one's psychological state (change in how the mind works). Delirium can start over a period of a few days and will often improve with treatment.



Clinical care staff monitor for delirium every shift however it is important for patients and families to be aware of symptoms and report changes in behavior to their clinical care provider to ensure early detection. Often, subtle changes in behavior are best recognized by patients and those who know them best. Below is a checklist that can help to identify common signs & symptoms of delirium.

*What are the signs and symptoms of delirium?*

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

The caregiver should notify the nurse or physician if they notice any of the above changes in their loved ones.



## The Hospital Stay

**Multi-Organ Acute Care Unit** - The ACU is on 10A Munk Building. You will be admitted here for 2-3 days as your condition improves.

**What to Expect in the ACU** - You will have several monitors and pieces of equipment attached. These include the heart monitor, IVs, pumps and urinary catheter. These will gradually be removed as you get better.

**Visiting the ACU** - Visiting is still limited to immediate family only, TWO people at a time. There is a designated rest period in the ACU is from 3pm – 5pm. No visiting is allowed during this time. Please refer to the signs posted on the doors. You are asked to check in at the nursing desk for security reasons.

**Soham & Shaila Ajmera Family Transplant Centre Unit** - You will complete your recovery on the MOTU on 7th floor, Munk Building. The staff will help you recover, gain strength, and learn how to manage with your organ transplant.

The MOT has private and semi-private rooms. Private rooms are first given to recipients based on medical needs. For example, if a recipient needs isolation, they will be given a private room first. Otherwise private rooms are given on a first come first served basis. Even if you have private coverage, this does not mean that you will be in a private room if none are available. Our priority is your medical needs. Your request for accommodation will be taken into consideration whenever possible. Recipients who need a private room for medical reasons, but do not have insurance coverage; do not pay extra for their room.

Sometimes we need to move recipients from room to room. This can be unsettling and inconvenient for you. We move recipients only when we need to in order to meet the needs of all our patients. We take the right precautions to make sure that all our recipients receive the best care possible.

**What to expect from the transplant unit** - The Soham & Shaila Ajmera Family Transplant Centre unit (MOT) at Toronto General Hospital includes recipients who have recently had a liver, bowel, lung, heart, kidney and pancreas transplant, who have been readmitted for various medical reasons or who are waiting for transplant.



## Staff of the Soham & Shaila Ajmera Family Transplant Centre Unit

**Nurses** -The nurses on the MOT unit are specially trained to care to transplant patients. They work 12 hour rotating shifts.

**Medical/Surgical Staff** -The surgeons, fellows and residents will see you each day while you are in the hospital. The doctors may change during your hospital stay.

**Nurse Practitioners** -Nurse Practitioners have advanced training and a graduate degree. They work with the transplant team to assist in your care and recovery.

**Other Staff** -You will meet other staff during your recovery on the unit including a physiotherapist, social worker, and pharmacist. They are an important part of the transplant team in getting you ready for discharge home.

### Guidelines of the Transplant Unit

- ❖ Visiting hours are from 10 am to 9 pm.
- ❖ All visitors must sign in at the reception desk and wear a 'visitor' sticker while on the unit. This is for patient safety.
- ❖ We recommend only two visitors in a recipient's room at one time. We encourage the recipient and family 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.
- ❖ Children under 12 are discouraged from visiting in the recipient's rooms because of the risk of infection to the child. An adult must supervise children who are visiting. If children are restless visitors will be asked to visit with the recipient in another part of the hospital.
- ❖ Staying overnight for family and friends is not allowed on the transplant unit.
- ❖ Visitors for recipients in isolation must fully respect the precautions in place to protect the recipient, themselves, and other people on the unit. This may mean wearing a gown, gloves and/or mask when entering the room.
- ❖ Visitors with signs of fever or the flu are not allowed on the unit.
- ❖ Visitors are asked to wash their hands on entering and leaving the recipient's room and the Transplant Unit. Hand sanitizer is available throughout the hospital.
- ❖ Visitors may be asked to temporarily leave a recipient's room in order for staff to provide personal care or discuss confidential matters with the recipient. Visitors may also be asked to leave if the recipient in the next bed needs extra medical care.



## Flowers

Cut flowers or plants are not allowed on the transplant unit. They can carry a significant infection risk to transplant patients.

## Planning for Discharge

Members of the kidney/pancreas transplant team will see you daily. You and your family will be advised several days in advance of your expected discharge date. Please make sure that all preparations have been made for you to go home. Your discharge team will help the process of transfer, provide you with further information and answer any questions you may have.

## The First Two Weeks

After your transplant we will focus on:

1. Monitoring your kidney and pancreas function
2. Watching for signs of rejection and infection
3. Adjusting your immunosuppressive medications
4. Recovery and rehabilitation
5. Teaching you about living with a transplant
6. Reassurance

## Monitoring for Rejection

Rejection happens when your body's immune system recognizes your new organs as foreign. If rejection happens and is left untreated, it can damage your transplant. Blood tests will be done frequently, and possibly biopsies will be needed to monitor for rejection.

## Blood Clots (thrombosis)

Thrombosis is a blood clot in one of the deep veins in the body. It is an early complication that can occur within 24 hours of a kidney/pancreas transplant. A thrombosis in one of your own veins can be treated with medication designed to thin the blood. A thrombosis in the transplanted pancreas itself usually results in pancreas failure and it could be removed.



## **Pancreatitis**

Pancreatitis is an inflammation (swelling) of the pancreas and is common in the first few days after surgery.

Symptoms of pancreatitis include:

- ❖ A dull pain in your abdomen
- ❖ Nausea (feeling sick)
- ❖ Vomiting

## **Eye Disease**

Most patients notice their vision gets worse in the first three months after a pancreas transplant, and then it starts to improve after 2-3 months. Steroids are a part of the immunosuppressant treatment any pre-existing cataracts may get worse following a transplant.

## **Fluid Retention**

Fluid retention (edema) is more likely to occur for several days after a simultaneous kidney and pancreas transplant. This can cause swelling of your feet and ankles.

## **Abdominal Abscess**

An abdominal abscess is a serious complication that can occur on to six months after the surgery. Symptoms include abdominal pain and a high temperature. A computerized tomography (CT) scan will often be used to determine whether an abdominal abscess is present. They can be treated using a combination of antibiotics and surgery to drain away the collection.

## **Adjusting Immunosuppressive Therapy**

After your transplant you will start immunosuppressive drugs. These are drugs that stop your immune system from rejecting your new kidney and pancreas. It is important that we have you on the right doses of these drugs. It is normal to have many changes in your drugs until we find the correct balance.



We will adjust your dosages based on:

- ❖ Blood test results
- ❖ Symptoms
- ❖ Side effects to the medications
- ❖ Biopsy results

### **Education and Teaching**

During your 10 days in hospital, the transplant unit nursing staff and your transplant team will give you information about taking care of yourself now that you have a new kidney and pancreas. 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 and the physiotherapist 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 questions and tell us if you are wondering about anything.

### **After Discharge**

You will be expected to attend clinic once per week at first. There may also be additional unscheduled clinic appointments depending on your health. Blood work will be required twice per week at the Toronto General Hospital for the first two weeks to ensure the drug levels in your body are adequate. Blood work will eventually be completed locally at a LifeLabs location. Your coordinator will help you locate one close to your home.

### **Limitations at the Time of Discharge**

You will not be able to lift anything that weight more than 10 pounds for the first three months post transplant. This is to ensure that your incision heals well and limits your risk of developing a hernia.



## **Patient Education**

We believe that it is very important for you to have the information and knowledge to care for yourself at home after your surgery. There are 2 key areas which we focus on – these are the self-medication program and self-care and monitoring education. Every patient participates in both of these programs and we encourage you to have a support person attend with you.





## ***CHAPTER SEVEN – Going Home after Transplant***

### **Medications**

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All transplant patients are required to take medications every day for the rest of their lives. This section details some of the common drugs that are prescribed after transplant and special instructions that will need to be followed if you are taking these medications. It will also describe the various educational programs and tools that you can use to help you learn more about these medications.

#### **Your Home Medications**

When you are admitted to the hospital, your Transplant Pharmacist will speak to you to obtain a complete home medication history. It is important for you to bring in all of your home medications including all prescription medications and any over-the-counter products, eye drops, puffers, creams, etc. If you have a medication list, please bring this in as well. Your Transplant Pharmacist will review all of your home medications with you to make sure that everything you need is ordered for you in the hospital. There may be many changes to your medication regimen after your transplant. Your Transplant Pharmacist will provide you with a medication schedule. They will review all the changes with you to help you understand how to take your medications correctly at home. You will receive prescriptions for any new medications. 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 home medications as described above. This will help your Transplant Pharmacist to ensure that you continue to receive all of the medications you need while in hospital.

#### **The Self Medication Program**

After your transplant, you will be taking medications to help prevent rejection and manage other health issues. The Self Medication Program is designed to help you learn more about your transplant medications so that you will be able to take them correctly and safely when you go home.

After your transplant you will attend a Self-Medication Class taught by one of the Transplant Pharmacists. Your family members or support person can attend with you. These classes are usually held on the Transplant Unit every Monday, Wednesday and Friday afternoon. You must attend a class before you can be discharged from the hospital after your transplant. During your recovery in hospital, your nurse and pharmacist will make sure you are scheduled to attend a class. Plan to attend a class as soon as you are transferred to the Transplant Unit.



### In 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 side effects that may occur with each medication

In these classes the Transplant Pharmacist will answer any medication-related questions you may have. Once you have taken the class, you will be responsible for taking some of your transplant medications on your own. You will be given a one week supply of each medication to keep at your bedside. You will be given a special form to record when you have taken each dose. Your nurse and pharmacist will check your progress daily. This will help you to better understand your medications and get into a regular routine. At the end of the week, your medication bottles will be collected and refilled. When you are ready to leave the hospital, you will be given prescriptions for all of the medications you will need to take at home.

Completing the Self Medication Program is an important step towards going home and your participation is vital to your successful discharge.

### The Transplant Pharmacy Website

There is a lot of new information to learn and process around the time of transplant. Important questions about the transplant medications may arise before transplant, while in hospital, and even long after a transplant. Your Transplant Pharmacist will answer these questions and assist you in learning about your new medications while you are in the hospital. We have also developed some online programs and tools that can be accessed at any time on the UHN public internet site that will help you learn more about your transplant medications.

The **Transplant Pharmacy website** is located on the UHN public Internet site. To visit the website, please follow these instructions:

1. Go to [www.UHN.ca](http://www.UHN.ca)
2. Click on the “our programs” link
3. Click on “Soham & Shaila Ajmera Family Transplant Centre”
4. Click on the “Out-Patient Pharmacy” link

On the website you will find answers to Frequently Asked Questions regarding *Managing Your Medications* and *Life After Transplant*



## Transplant Medication Information Teaching Tool (TMITT)

The Transplant Medication Information Teaching Tool (TMITT) is an interactive internet-based teaching program to help you and your family or support person learn more about your transplant medications. This tool is flexible and designed to allow you to learn at your own pace by selecting the specific medications and material you want to learn about.

Some of the features include:

- ❖ Content that is divided into brief and easy to follow 'lessons'
- ❖ Ability to customize your own learning experience
- ❖ Unique audio-visual format
- ❖ Interactive quiz questions to test your knowledge
- ❖ Printable information summaries for each medication

### Common Post-Transplant Medications

Information on common post-transplant medications can be found in *Appendix I* at the back of the manual. Please refer to these information sheets for details regarding your specific medications. These are medications that *may* be prescribed for you after transplant. You may also need to take other medications that are not discussed in this manual.

Your Transplant Pharmacist will teach you about your transplant medications in the Self Medication Class. They will also review all of your medications with you when you are discharged from the hospital and will give you a medication schedule to follow when you are at home.

You will not be taking all of the medications listed here. Your transplant team will choose the combination of medications that is best for you. You may also be prescribed other medications to prevent or manage side effects from the anti-rejection drugs. Medications to treat common conditions such as high blood pressure, and osteoporosis, are not described here.

### While Taking Immunosuppressive Drugs

Side effects from medications are common, especially right after your transplant. Your body is adjusting to the new organ, as well as many new medications. Everybody responds differently to the medications. It will take time for your transplant team to establish the right drug combination and doses for you.



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

- ❖ be tired
- ❖ be confused and disoriented
- ❖ have difficulty concentrating, and
- ❖ have difficulty sleeping

It is important to remember that your transplant team expects these side effects and are trained to deal with them. Adjusting your medications or adding another drug may help to reduce side effects. Talk to your transplant team if you have questions or concerns about your symptoms.

### **Drug interactions**

Many drugs can interact with your transplant medications. Before you take any new medications including any over the counter products or medications prescribed by a non-transplant doctor, you **MUST** speak to your transplant team. For example, some antibiotics, non-prescription cold medications or herbal remedies can interact with your transplant medications to cause unwanted effects.

### **Vitamins/herbal remedies**

If you would like to take a multi-vitamin or any herbal remedy, please talk to your transplant team first. Herbal remedies are like drugs and may interfere with your medications so proper precautions need to be taken.

### **Pain Medications**

Do not take pain relief medications known as NSAIDs (non-steroidal anti-inflammatory drugs). These include ibuprofen (the active ingredient in Advil and Motrin products); naproxen, which is found in Aleve and Naprosyn. If you need to take medication for pain or a headache, acetaminophen (Tylenol) is usually a safe choice. Talk to your transplant team before taking any other pain medication.



## Self-Care and Monitoring at Home

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As you recover from your transplant, it is important that you know what to watch for at home and what important issues you should report to your transplant coordinator. You will be going for regular blood tests and attending clinic as well and further information is obtained by these assessments. Part of the information you are given is covered by 4 video presentations which you and your family are required to watch. The rest will be covered by the discharge nurse and this written information.

Complications are not uncommon, and most can be treated by procedures and medication adjustments. Early detection of complications and avoiding them if possible are important to the success of your transplant.

### 1. Monitoring for Rejection

Your immune system protects you from foreign proteins such as bacteria and viruses. Your immune system also recognizes your new liver as a foreign protein and will try to reject it. Immunosuppressive medications are meant to prevent this, but it is difficult to know exactly which medications and what dose to give you to prevent this complication from ever occurring in you. Rejection is less likely to occur if you take your medications correctly, and do your blood tests with the correct timing, but it can still occur. Having a rejection episode does not mean your kidney or pancreas are destroyed. We do try to avoid rejection if at all possible as it results in the need for additional medications. Lab test results are the key way we monitor for signs of rejection. The signs and symptoms we ask you to watch for at home and to report are:

- ❖ fever of 38<sup>o</sup>C or more (check your temperature periodically for the first month)
- ❖ fatigue
- ❖ dull ache in the area of your abdomen where the your transplants are
- ❖ sudden weight gain of a kilo or more in 24 hours (weigh yourself daily if you have scales)



## 2. Monitoring for Infection

Your immune system also protects you from infections. Your immunosuppressive medications interfere with your ability to fight infections, thus detecting and treating infections promptly is important. Signs and symptoms of infection that we ask you to watch for at home and report are:

- ❖ fever of 38<sup>o</sup> C or more (check your temperature daily for the first month and thereafter when you feel unwell)
- ❖ chills and flu-like symptoms
- ❖ redness and pain around your incision
- ❖ redness and pain on any part of your skin - such as your legs especially if the skin is broken
- ❖ cough - especially with colored sputum
- ❖ pain when you pass urine
- ❖ diarrhea
- ❖ rash or sores

It is important to take precautions to avoid infection. The most important thing you can do is remember to **wash your hands**. This is the single most important way to avoid infection – after using the bathroom, after touching doors in the mall, grocery carts etc. You can carry a small bottle of hand sanitizer to use if a sink is not readily available. Avoid contact with people you know are sick or who have infections. This does not mean that you can't go out to public places such as restaurants, church or malls – but remember to wash your hands. You will get the same type of infections such as colds as people without transplants. We do not recommend that you take antibiotics unless we are sure you have an infection.

## 3. Activity

Remember the following about activity after discharge:

- ❖ You can shower – even before your incision staples are removed. We do not recommend that you take a bath until your incision is completely healed.
- ❖ You should not lift more than 10 pounds for the first 3 months – lifting more than this amount may cause stress on the incision and result in a hernia. For the same reason avoid abdominal strengthening exercises or upper body exercises such as sit-ups and push-ups for the first 3 months. This means that even grocery bags must not weigh more than 10 pounds.
- ❖ If you have small children you will not be able to lift them for 3 months
- ❖ You can walk as soon as you are able and this is excellent exercise. At first you may only be able to walk short distances but the goal should be to gradually increase the distance and pace at which you go.



#### 4. Avoiding Skin Cancer

Transplant patients are at increased risk for skin cancer as a result of taking immunosuppressive medications. It is important to remember that the sun exposure you have had in the past is an additional risk factor for developing skin cancer. It is therefore important to decrease additional risk by taking precautions against sun exposure. The following are important points to remember:

- ❖ Avoid sun exposure between the hours of 10:00 AM and 3:00 PM when the sunlight is most intense
- ❖ Use sunscreen when you are going to be in the sun at any time – use a product with a sun protection factor (SPF) of 30 for good protection.
- ❖ Select a product that blocks both UVB (shorter rays) and UVA (longer rays). For example PABA only filters UVB rays.
- ❖ Consider using a stronger product on very susceptible areas – face, ears, scalp
- ❖ Use a lip balm with sun screen
- ❖ Wear a hat with a wide brim
- ❖ Apply the sunscreen 30-60 minutes before going outside
- ❖ Reapply sunscreen if swimming or perspiring profusely
- ❖ Overcast days do not protect you – 70-80 % of the UV rays still come through
- ❖ Wear UV-filtering sunglasses – UV light can cause cataracts
- ❖ Outdoor winter activities such as skiing can still expose you to sun damage
- ❖ Be a mole-watcher and report concerns – watch for moles that grow or change color, watch for moles with irregular borders, watch for moles that are itchy or ooze.
- ❖ Report any new skin lesions that are growing, which scale or bleed

#### 5. Nutrition

- ❖ Diet is an important part of helping you rebuild your muscles and to help with healing after surgery.
- ❖ Before your transplant you may have been on a very salt restricted diet to try to avoid fluid retention. Following your transplant, salt restriction can be less strict although we still advise that you are careful about the amount of salt in your diet as it may contribute to high blood pressure – a common complication post-transplant.
- ❖ Your immunosuppressive medications may contribute to the development of high cholesterol.
- ❖ We advise you to follow a healthy diet such as Canada's Food Guide. You can get a copy from the discharge nurse or look it up on the internet.



## Planning for Discharge

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### Communication after Discharge

We have a special communication system called “Easy Call” that we use both to receive messages from you and also to send messages to you after transplant. One of the secretaries from the clinic will meet with you and review the system before you go home. Important points about the system to note:

- ❖ This is an efficient system that can be accessed from anywhere in the world at any time of the day.
- ❖ The system will not work if you have a rotary phone or if you have “call privacy” on your phone.
- ❖ If English is not your first language you must have someone who speaks English and is able to access messages for you.
- ❖ We pick up messages from you from 8:00 AM to 4:00 PM Monday to Friday. You can leave messages at any time.
- ❖ We can send you messages by activating the computer to call your phone with a “hail” or “urgent” message. We use this when we want to tell you about a medication change or an appointment. Your phone will ring hourly until you pick up the message, but will not ring between 10:00 PM and 08:30 AM.
- ❖ You should also check regularly for messages – in the first 3 months check daily and thereafter check weekly as well as a couple of days after a blood test.
- ❖ We will still call you directly if we need to discuss something with you in greater detail – for example if you report an illness. If you want us to call directly, then leave this information with your message.
- ❖ If you change your telephone # you must let us know right away or the system will not work.
- ❖ **DO NOT USE EASY CALL in an EMERGENCY** – After hours if you need immediate advice or have an urgent health problem call.
- ❖ **Telehealth Ontario @ 1-866-797-0000** or go to your nearest emergency department.  
Make sure that another family member or friend knows how to use the system





## **Out of Town Patients**

If you live more than 2-3 hours outside Toronto, then you will be advised to stay in the city for the first few weeks after discharge if you are able to do so. This period is a time when you need to be closely monitored and it is a time when complications are common so it is safest if you can stay nearby. If you need a list of accommodations located near the hospital our social worker can provide you with one. Planning for this should take place before you are admitted for transplant.

## **Home Care**

If you have a dressing on your incision or have a special reason to need a nurse to visit, then we can arrange a visiting nurse. This is not a routine practice for all patients. Each patient is assessed at the time of discharge regarding the need for home care.

## **Paying for Medications**

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

## **Transportation**

It is your responsibility to make arrangements for a ride home from the hospital by 11:00 AM on the day of discharge. You will also need to plan for rides to clinic and to the lab for blood tests. It is also likely that you will need to make extra trips to hospital for additional blood tests or scans after discharge. These test arrangements are often made suddenly and you need to have a plan about how you will travel to the hospital should one of these situations arise.

## **Clinic and Blood tests after Discharge**

You will be given a date and time for your first clinic visit before you go home. You will also be given a schedule for lab tests that need to be done prior to the clinic visit. We will give you a new blood requisition for your lab as the tests that are done may be different and will also include a drug level each time. At each clinic visit you are given further instructions to guide you until the next clinic.



## Post-Discharge 'to do' List

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### Complete your “Contacts” List

Please complete this list and bring it to your first clinic. This is important so that we have accurate phone information so that we can contact you when necessary. This list also includes the information about your pharmacist and family doctor.

### Complete Medic Alert Bracelet Form

If you need assistance completing this form, you can bring it to your first clinic. We do recommend that you have a Medic Alert bracelet.

### Thanking Your Donor family (see Appendix 3)

It is important to do this when it feels right but it is very meaningful to the donor family to receive a note from you. If you need assistance, please ask us in clinic.

### Expectations Post Kidney/Pancreas Transplant

In addition to your regular clinic visits, you will be followed post-transplant with specific blood tests at 3 months, 6 months and yearly thereafter. These include yearly glucose tolerance tests, abdominal ultra sounds, chest x-rays, and cardiac testing, including echocardiogram and stress tests. These tests are part of our program and help us ensure that your general health is monitored closely.

We depend on your commitment to the program.

### Annual Check Ups

You need to take care of your whole body, not just your new organ and therefore annual health examinations (check-ups) with your family physician are very important. Women require yearly gynecological check-ups with annual PAP smears and breast cancer screening done. Men should be checked annually for testicular cancer and enlargement of the prostate gland.



## Clinic

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Location: 12<sup>th</sup> Floor Munk Building (Munk Elevators)

You will be given a date and time for a follow up appointment to see your transplant doctor and nurse coordinator in clinic. Generally, patients are seen within a week after discharge but this can vary slightly, depending on your post-operative course in hospital, length of stay and general health. We initially see our new transplant patients every 1-2 weeks in clinic. Clinics become less frequent as your health stabilizes over time.

It is important to attend all scheduled appointments, as routine clinic assessment is an essential part of your follow-up. If you need to change your appointment, please call *Easy Call* (416-351-0793 + your PIN #), at least 72 hours in advance. Missed appointments or “No Shows” will be documented in your chart.

**We ask that you bring the following to your clinic appointments:**

- ❖ Your OHIP card and blue hospital card
- ❖ Your medication list.
- ❖ A list of the medications which require renewal prescriptions
- ❖ Contact information (see previous page) &/or changes in contact information. Once you are further out from your transplant date, it is important to keep us updated with any changes to your personal information, new family doctor, change in pharmacy etc.
- ❖ A list of concerns or questions.

**We will review the following in clinic:**

- ❖ We will ensure your medications and medication list match with the list in your chart. We will assess for side effects and effectiveness of these medications.
- ❖ We will adjust medications if required.
- ❖ Review your most recent blood work.
- ❖ Review any questions or concerns you may have.
- ❖ Physical assessment to assess fluid retention, wound healing, blood pressure etc.
  
- ❖ Staples are usually removed two weeks after surgery.
  
- ❖ Review the plan of care until your next clinic appointment.



At the end of every clinic you will be given:

- ❖ A prescription - for your transplant medications, which should provide enough of a supply to last until your next scheduled appointment. It is important to drop off your prescriptions at the appropriate pharmacy after each clinic. If you don't need a particular medication filled, simply ask the pharmacist to keep the prescription "on file". When you need a refill, please call the pharmacy directly.
- ❖ An Appointment for your next clinic - You will be asked to take your clinic chart to the reception desk, where you will be given a card with the date of your next appointment and a schedule for your blood work.
- ❖ New lab requisition(s) for your local lab – each requisition is valid for 6 months.



## Monitoring and Tests in the Post-Transplant Period

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### Regular blood work

It is essential to help us monitor your kidney and pancreas transplant and overall health. We are able to assess for the following by monitoring your blood work.

### Rejection

An episode of rejection of a kidney or pancreas transplant is detected by blood work. A rejection episode may also be accompanied by other symptoms such as an increase in temperature but often no visible signs or symptoms are present. *Doing your blood work as advised by your transplant team is vitally important in detecting this complication early.*

### Assess Drug Levels

We have guidelines for the blood drug levels we aim for. Early after transplant you will need higher blood drug levels as this is the time you are at a greater risk for an acute rejection. Over time, this risk becomes slightly less and we usually can reduce the target level you need to avoid rejection and reduce the risk of side effects. *Medications can only be adjusted safely if the blood work has been done regularly and with correct timing depending on the drug you take. If you are not sure what correct timing is, please ask us for advice.*

### Drug side effects

The absence of rejection will indicate that you are adequately immunosuppressed but we also watch for side effects of these medications by reviewing your blood work. We monitor for drug side effects such as, low white blood cell counts and increased potassium.

### Blood work on Clinic day

New transplant patients require blood work on the day of clinic. We have a blood technician in the clinic area on the 12<sup>th</sup> floor and blood tests are done soon after you arrive in the clinic. We will let you know if we plan to do labs when we remind you about clinic.

Please bring your morning dose of *Tacrolimus* to take after the blood work has been drawn. (This applies to every set of blood work).



### **Blood work drawn at the local lab (Lifelabs)**

In between your clinic visits, you will be given a blood work schedule. Unless otherwise advised, these labs should be drawn at a Lifelabs site close to your home. We urge you to use Lifelabs as they have a computer link with Toronto General which enables our team to see the majority of results the same day they are drawn. You can call Lifelabs at 416-675-3637 or toll free at 1-877-849-3637 to find a location close to your home. You can also find this information online at [www.Lifelabs.com](http://www.Lifelabs.com). Other labs are not linked to our computer and results are not received as quickly. If a Lifelabs is not available in your area, please discuss this with your coordinator prior to doing blood work at the local lab.

There are several different scans that may be ordered to investigate changes in your blood work or clinical health. Some of the common ones we order include:

### **Abdominal ultrasound**

If your transplant organ tests become elevated, this is often the first test which is ordered to further assess if there is any change within the kidney or pancreas. This test uses sound waves to detect any changes within the blood flow to the kidney and pancreas.

### **CAT (CT) Scans**

CTs may be booked if there is a change in blood work or your health which require further investigation. It is important to let your team know if you have any history of reaction to seafood or intravenous dye as special preparation for the test may be required prior to the test, or sometimes a different test may be necessary instead of a CT scan.

### **Glucose Tolerance Test**

Six months post-operatively a 2 hour glucose tolerance test will be scheduled. This test allows us to monitor your pancreas function, measure the insulin production and it's response to glucose in your blood stream. This test will be performed yearly post-transplant.



## Care by Other Health Care Professionals

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### Family Physician or Primary Care Provider

It is important that you have a family doctor to provide your overall health care on an ongoing basis. Initially, you will see your transplant team very regularly but it is important to remember that we are your transplant specialists and our focus of care is on your transplant.

We recommend that you see your family doctor within a month after discharge.

### **Anti-rejection medications should only be adjusted by your transplant specialist.**

Family doctors may have questions about what medications are acceptable for you. We have included a medication reference sheet ([Appendix 5](#)) as well as a summary of information on vaccinations ([Appendix 6](#)) at the end of this manual for your own reference and we will be forwarding a post-transplant care manual to your family doctor through the mail. If your family doctor has other questions about medications we encourage them to contact our office for additional information. Your family doctor will also be copied on all blood work done at Lifelabs (your local lab).

### Dentists

Good dental care is an important aspect of maintaining long term health, however, we ask you to delay any routine care which includes hygiene appointments, until you are at least 3 months post-transplant. This is due to the high levels of immunosuppression and increased risk of infection during this period. If there additional questions, the dentist can contact us for additional information.



## Complications in the Early Post-Transplant Period

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### Rejection Episodes

The goal of immunosuppression is to prevent organ rejection. Rejection occurs when your immune system recognizes the new liver as “foreign”. Your body then attacks this foreign presence resulting in increased inflammation of the pancreas, commonly known as rejection. The likelihood of rejection is greatest early after your transplant surgery, and as such, you will require higher doses of the anti-rejection medications during this period.

To prevent rejection, it is important for you to take your medication as instructed and to do your regular blood work.

Acute rejection may still occur despite careful attention to your medications, but it is important to know that acute rejection is almost always successfully treated if diagnosed early. Treatment for rejection may involve an increase of anti-rejection medications and/or intravenous steroids (prednisone) given in our outpatient day unit. In some cases, admission to hospital is required to treat the rejection with more potent intravenous immunosuppressive drugs.

Here are a few more facts about rejection:

- ❖ Rejection is common after transplantation. 15-20% of all transplant patients have 1 or 2 episodes of rejection
- ❖ Rejection is confirmed by a pancreas or kidney biopsy and monitoring for signs and symptoms of rejection
- ❖ Rejection must be treated promptly
- ❖ If you experience rejection, it does not mean that you will lose your transplant or that it will be permanently damaged.

### Wound Infection

Your incision is an area for potential infection until it heals. As noted earlier in this booklet, your risk for infection is increased as a side effect of your anti-rejection (immunosuppressive) medications. Your incision will be examined at each clinic appointment but it is important for you to monitor and report any increase of redness or swelling, pus along the incision or fever to your transplant coordinator. While the staples are still in and until the incision is healed, you may have a shower but avoid baths unless the water comes to below the incision line.





## General Infections

When you are on immunosuppressive drugs, your body cannot fight infection as well as it could before. This increases your risk of getting an infection. Common places for you to get infections are in your lungs, and urinary tract. The information below will help you to fight infection:

- ❖ Good oral and personal hygiene are important to help to fight infection.
- ❖ Eat well, get plenty of rest and exercise regularly to increase your resistance to infection
- ❖ Do not go near people who are sick or have infections, especially during your first 3 months after transplant.
- ❖ Watch any broken skin for signs and symptoms of infection.
- ❖ Call your transplant team immediately if you have flu-like symptoms.

After your surgery it will be difficult to know whether or not the discomfort experienced are from the surgery or from a possible rejection. Once the incision has healed, you should not normally feel pain. If you experience a brief feeling of pain or tenderness, it is usually due to a muscle pull or spasm. This is not serious. If you have prolonged discomfort, call your transplant coordinator. It may be a sign of infection or rejection.

## Biopsies

A pancreas or kidney biopsy is a procedure where your doctor takes a tiny piece of your transplant graft and sends it for testing. He inserts a needle through your skin into your transplant to get this tiny specimen. Your team will talk to you about the risks. One of the main risks is that any biopsy can cause bleeding. To prevent this you must not take aspirin or blood thinners within 5 days of the biopsy.

- ❖ This procedure is generally carried out in the interventional radiology department at Toronto General Hospital, under ultrasound guidance.
- ❖ You will be able to go home on the same day as your biopsy, so please bring an escort to take you home
- ❖ Wear loose clothing so that you are more comfortable after your biopsy
- ❖ To prepare yourself for your biopsy you need to stop eating and drinking for 4 hours before you come to the hospital for your procedure.
- ❖ The procedure takes about 30 minutes



## Long-Term Complications

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### Rejection Episodes

Although it is more common in the early post-transplant period, rejection can occur at any time – even many years after your surgery. Two things which you can do and which are important in trying to avoid rejection are taking your immunosuppressive medications exactly as prescribed and doing blood test monitoring as instructed.

Remember that other medications including herbal medications, as well as grapefruit and pomegranate juice can interfere with the absorption and metabolism of immunosuppression meds. It is important that you confirm that any new medication you are prescribed does not interact with the ones we prescribe.

Signs of rejection as previously reviewed in this manual; however, it is possible to have rejection without symptoms and that is why it is vital that you continue monitoring your transplanted organs by doing your blood work as advised. Abnormalities can be detected in blood test results when there are no other symptoms present.

Acute rejection can be treated as described in ‘early post-transplant complications’. Sometimes just adjusting your immunosuppression medications or their doses can restore normal kidney and pancreas function and stop the rejection process. It is important that you do blood level testing of immunosuppression medications accurately with Tacrolimus. Your tacrolimus level should be taken 24hrs after you have your morning dose of Advagraf. If levels are not done accurately your medication doses could be adjusted when in fact they should not be adjusted.

Chronic rejection can also develop – this can occur if labs are not monitored regularly or if medications are missed. This type of rejection is much less common and more difficult to treat. Missing doses of immunosuppression medications can result in chronic rejection. It is important to know that the most common cause of late rejection episodes is the failure to take your medications correctly.

The only way to confirm rejection is to do a pancreas or kidney biopsy.



## **Hypertension (High Blood Pressure)**

This health issue may be present pre transplant and is quite common post-transplant. Left untreated, high blood pressure can lead to problems with your heart, kidneys and brain i.e. 'stroke'. Diet – reducing salt intake, exercise and weight control can correct hypertension in some cases. Often, however medications are required.

## **High Cholesterol**

Many factors can contribute to high cholesterol such as can age, hereditary factors, diet/exercise and other medical conditions. Some of the anti-rejection medications may also affect your cholesterol levels. We monitor your cholesterol with your scheduled blood work. Regular exercise also helps reduce your cholesterol. If diet and exercise are not effective, treatment with medication may be required. High cholesterol levels must be treated as part of the health plan to decrease the risk of heart disease and stroke.

## **Hernias**

Hernias can occur along the incision line if the layers beneath the skin do not heal properly. This results in an area of weakness, where the abdomen appears to bulge. To prevent the development of a hernia, do not lift more than 10 lbs. or do any abdominal exercise for the first 3 months after transplant. If a hernia is problematic a year after transplant, your team can refer you to a general surgeon to assess if a repair is appropriate.

## **Infections**

### *Cytomegalovirus/CMV:*

This is a viral infection you can get after transplant. It is most common in the first year after transplant as that is when you are on highest doses of immunosuppression medication, but can occur at other times. CMV is a virus most people have been exposed to before transplant but if you were not (this would have been tested in your pre transplant assessment) you would be at higher risk for developing a CMV infection after transplant. Patients at higher risk for this infection are given medication to prevent this for the first 6 to 12 weeks after transplant. Symptoms of CMV can be vague and can include; fever/chills, extreme fatigue, diarrhea. If you are in a high risk group be on the lookout for these symptoms particularly in the first few months after completing the preventative medication. Contact your coordinator as soon as possible if you have these symptoms. A blood test can be arranged to diagnose a CMV infection.



## Infection prevention

- ❖ Frequent hand washing.
- ❖ Avoid touching your face before washing your hands.
- ❖ Avoid people you know have active infections, particularly in the first 3 months after transplant
- ❖ Good oral and personal hygiene
- ❖ Practice a healthy lifestyle; eat well, get enough rest and exercise regularly
- ❖ Get the flu shot every fall
- ❖ Get the Pneumovax vaccine every 5 years

## Osteoporosis

Osteoporosis or osteopenia are conditions where bones are weakened and more prone to fracture. Prednisone, as well as other risk factors can make you more prone to this problem. There are interventions to prevent or treat this. You most likely had a bone mineral density (BMD) test to check for this pre transplant and should continue to be monitored for this after transplant. We monitor your bone mineral density during the first year post-transplant and if more convenient for you, we encourage further monitoring through your family doctor's office.

## Cancer

Transplant recipients have a moderately increased risk for developing cancers. This is thought to be related to the effects of long term use of immunosuppression medications. It is that much more important for a transplant recipient to have regular check-ups with routine screening – the frequency of these tests would not differ from the non-transplant population.

## Heart Health

We will monitor your heart health on a yearly basis. This is to ensure that any possible complications from long-standing diabetes can be dealt with in a pro-active manner. You will be assessed by your cardiologist here at the Toronto General Hospital yearly if there are issues present or every two years should your heart health remains stable.



## Commonly Asked Questions

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### Symptoms to Report to the transplant office

- ❖ Fever of 38 degrees centigrade
- ❖ Diarrhea (may be a medication side effect or a sign of illness) especially if accompanied by cramping or with blood in the stool
- ❖ Vomiting that lasts more than 12 hours (may affect your drug levels if you can't keep pills down)
- ❖ New rashes
- ❖ Itching
- ❖ Pain, especially in your abdomen
- ❖ Headaches
- ❖ Dizziness
- ❖ Cough and coloured sputum

### Staple Removal

- ❖ Usually removed 2 weeks after surgery
- ❖ Removed by your nurse in the transplant clinic
- ❖ Removal causes minimal discomfort as the staples only close the thin upper layer of tissue – there are dissolving stitches in the muscle layers beneath the incision
- ❖ Small supporting tapes called steri-strips are often placed on the incision for a few days after the staples are removed
- ❖ If there are stitches in drain sites, they are usually removed at the same time as the staples

### Driving

- ❖ Discuss readiness for driving in clinic
- ❖ Must not drive when still taking narcotic pain medications
- ❖ Need to be sufficiently strong and flexible enough to move your leg/foot on the pedals and be able to check your blind spot
- ❖ If driving license was suspended pre-transplant this needs to be reactivated when you are fit to drive post-transplant. This process may take several weeks.

### Wearing Seatbelts

- ❖ All patients should wear their seatbelt
- ❖ If the belt causes discomfort where it crosses your abdomen, place a towel under the belt
- ❖ We will not provide letters for the police to excuse you from wearing the belt



## Exercise and Lifting Restrictions

- ❖ You must 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 the 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 1-2 pounds to increase arm strength but be careful not strain your shoulder joints. They are prone to strain due to muscle wasting

## Swimming

- ❖ Swimming is excellent exercise once the incision is healed and you are strong enough to be in the water
- ❖ You can swim in public pools and lakes

## 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

## Diet

- ❖ You should eat a healthy diet and avoid junk food
- ❖ Canada's food guide provides excellent advice re foods, food groups and portion sizes
- ❖ It is not uncommon to gain weight after transplant and it is better to avoid this – losing weight is as challenging for transplant patients as it is for everyone

## Avoiding Infections

- ❖ Hand washing is the single most effective way to avoid infections – wash after using the bathroom, wash your hands after touching such things as grocery cart handles or door knobs etc.
- ❖ You can go to public places such as restaurants or malls as soon as you go home from hospital as long as you wash your hands, there is no need to wear masks
- ❖ Avoid people with obvious infections such as friends with cold or flu symptoms but keep in mind it is impossible to avoid all infections. If members of your household have infections, try to avoid physical contact but there is no need to move out of the house



### Increased nasal secretions

- ❖ Transplant patients all experience an increase in clear nasal secretions
- ❖ This occurs especially when eating and when eating or drinking hot drinks and food and when they eat spicy food
- ❖ The cause is unknown but it does not mean you have a cold or infection
- ❖ This may continue for life

### Prescription renewals

- ❖ We ask that you always get enough prescriptions in clinic to last until your next clinic visit
- ❖ If you do need a prescription before you come to clinic, then we ask you to give us enough time to have the prescription signed and faxed
- ❖ Check your bottles to see if there are repeats on the prescription before calling us for renewals

### Immunizations/Flu Shots/Pneumovax vaccine

- ❖ We recommend that all patients receive the annual flu vaccine to protect from influenza
- ❖ We suggest that you be at least 6 months post-transplant before receiving this vaccine as it will be less effective when your medication doses are highest
- ❖ We recommend that all patients get pneumovax which protects against one particular kind of bacteria which causes pneumonia
- ❖ People with normal immune systems receive this vaccine once in their life but in transplant patients it needs to be given every 5 years
- ❖ Transplant patients can receive some other immunizations but it is important to remember that no vaccine with live virus or bacteria can be given.
- ❖ It is believed that some vaccines may not be as effective as they are in those with normal immune systems but that transplant patients do benefit from them
- ❖ All immunizations and vaccines are given by the family doctor, we do not do immunizations in the transplant clinic

### Insurance Forms

- ❖ We will complete disability insurance forms after transplant in the first 3-6 months after transplant
- ❖ It will take at least 30 business days to have these completed



## Returning to Work

- ❖ Most patients are ready to return to work 3 to 6 months after their transplant surgery
- ❖ This may vary somewhat depending on the type of work done prior to transplant – for example if the work involved heavy lifting and the patient is very debilitated prior to the surgery it may a little longer to get strong enough to return to work
- ❖ Transplant patients can do any type of work – we have patients who work in construction, nursing, teaching, medicine, farming and factory work
- ❖ We usually recommend that if at all possible that the return to work be “graduated” – part time for the first few weeks and gradually increased to full time
- ❖ Many people are nervous about returning to work especially if they have been sick for some time but one of the goals of transplant is to return patients to active lives including work

## Pain Medications

- ❖ Most narcotic pain medications are safe and most people need some type of pain medication in the first 2-4 weeks after surgery
- ❖ It is important to gradually decrease this type of pain medication to avoid becoming dependent on the pain meds
- ❖ Tylenol (acetaminophen) is a safe medication to take for minor pain, headaches etc in small amounts when necessary. The maximum amount of this drug in 24 hours is 2000 mg (equal to 6 of the regular 325 mg strength or 4 of the extra 500 mg strength)
- ❖ You must not take anti-inflammatory medications (“NSAIDs”) such Advil, Motrin, and ibuprofen – these meds are not good for your kidney and can cause stomach irritation. If you uncertain if a medication you are considering is in this category ask your transplant coordinator. Some drugs in this class are given by prescription and should be avoided as well.
- ❖ The transplant doctors will not prescribe any narcotic medications in clinic.

## Over the Counter and Herbal medications

- ❖ In general we do not recommend that you take herbal or naturopathic medications because we are not certain of the effect they may have on absorption or metabolism of the immunosuppressive medications.
- ❖ These medications vary in the amount of active ingredients they contain and this adds more uncertainty to their effect on your body
- ❖ Stomach antacids are safe – use according to the package instructions
- ❖ Some cold and allergy medications can affect your blood pressure or heart rate and you should review the with the pharmacist or transplant coordinator before you use them





### Medications to avoid

- ❖ Most antibiotics are safe to use and the only group we try to avoid is the erythromycin family of drugs because they affect the levels of your immunosuppression. If it is essential that you have something in this group, then please let us know as we may need to temporarily adjust the doses of your drugs
- ❖ If you have diarrhea we do not recommend that you take anti-diarrhea medications such as Imodium. There are many reasons to have diarrhea and the cause of this needs to be assessed first before using these medications

### Pets

- ❖ It is safe to have pets such as cats and dogs in your home
- ❖ It is better to avoid cleaning a litter box, but if you are the only care provider, wear gloves when cleaning litter or picking up waste
- ❖ Birds may carry various fungus and bacteria which can cause serious infections and are not ideal pets for transplant patients
- ❖ Fish and fish tanks may have bacterial and fungal organisms which can cause serious infections. Avoid cleaning tanks and handling fish if possible but if necessary wear gloves

### Sexual Activity/Birth Control

- ❖ It is safe to resume sexual activity as soon as you feel physically able after transplant
- ❖ Precautions for practicing safe sex (condoms) are important after transplant because you are immunosuppressed and thus more prone to infection
- ❖ The safest method of birth control in the first year after transplant is the barrier method – condoms and contraceptive foam or jelly
- ❖ Some oral birth control methods or intrauterine devices (IUDs) can be used after transplant but this must be discussed with your transplant coordinator first

### Pregnancy/Planned Parenthood

- ❖ For female patients, it is possible to have children after transplant. However we do not encourage you to get pregnant.
- ❖ The rate of birth defects in the child is higher when an immunosuppressed patient gives birth
- ❖ It may be necessary to stop or change medications such as some blood pressure pills as they can affect the baby's development and growth
- ❖ We monitor blood tests more often during pregnancy as drug doses may need to be adjusted
- ❖ If a male patient is considering a family a review of medications is helpful to review any impact current medications may have on sperm



## Travelling

- ❖ Before you consider travelling you should discuss it with your transplant care team especially if the trip is outside Canada and it involves making reservations. If a trip needed to be cancelled and we did not know about it, we would not be able to verify you were given permission to travel when your health was stable
- ❖ You should always purchase trip cancellation insurance
- ❖ Things to consider include how long is your trip and how frequent are your blood tests – you may have to do labs while you are away and this can be expensive and will not be fully covered by our health insurance, or are there any upcoming tests or appointments that conflict with the time you plan to be away
- ❖ Trips to some locations place you at added risk for infections such as malaria. For this reason we do recommend that you are seen in travel clinic at least a month before your trip.
- ❖ You should ask us to give you a “travel letter” – this is a summary of your medications and lab results to carry with you. This verifies that you have a reason for the medication you are carrying and provides basic information for health providers if you become ill while you are away.
- ❖ Make sure you have sufficient medication with you plus an additional 2 weeks in case of a delay in your return
- ❖ You must always put your medication in your carry-on luggage – your checked luggage can get lost.

## Smoking

- ❖ Our policy is to remain smoke-free both pre and post-transplant.
- ❖ Cancers related to smoking include cancer of the bladder, kidney, larynx, cervix, stomach and pancreas
- ❖ If someone in your family smokes we recommend that they not smoke in the home or around you as there is also significant risk in second-hand smoke
- ❖ These precautions also apply to marijuana

## Telehealth Ontario

- ❖ We are available to provide advice Monday through Friday during business hours to answer your questions
- ❖ Should you need advice after hours or on weekends or holidays, Telehealth Ontario is a free confidential service available 24 hours a day where you can speak to a registered nurse to get health advice and information.
- ❖ We have given them basic transplant information as a reference for them
- ❖ The telephone number to reach them is 1-866-797-0000



## Urgent Situations

- ❖ If you experience chest pain, shortness of breath or symptoms of a stroke, you need to seek urgent care by calling 911
- ❖ For safety reasons, you will be taken to the nearest hospital and although you always feel safer coming to Toronto General it is usually not safe to delay care by coming downtown. Other centers are able to treat urgent situations such as these. If the other hospital staff need additional information they can contact our doctor on call for advice
- ❖ If you develop a fever or other illness and feel weak and dizzy you should be seen in your local emergency

## Re-Transplant

- ❖ In some cases a second transplant will be considered if the first graft is failing – or if there was a circulation problem with the first graft
- ❖ The same assessment tests are completed for a second graft as were done to see if the patient is suitable for a first transplant
- ❖ The surgery for a second transplant is more challenging for the surgeons because of the scar tissue related to the first surgery



## Feedback

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As a patient with us, we care about what you think. Your feedback is important to help us improve the care we provide to our patients.

If you have any problems or concerns with the way in which your care was provided, please tell us. In the hospital, you can speak with the Charge Nurse or the Nurse Manager for the inpatient area. When discharged, you can speak with your transplant coordinator or physician.

If you would prefer, the Patient Relations Department can help resolve issues. The Patient Relations Department would be pleased to hear both your concerns and your compliments.

### They can be reached at:

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

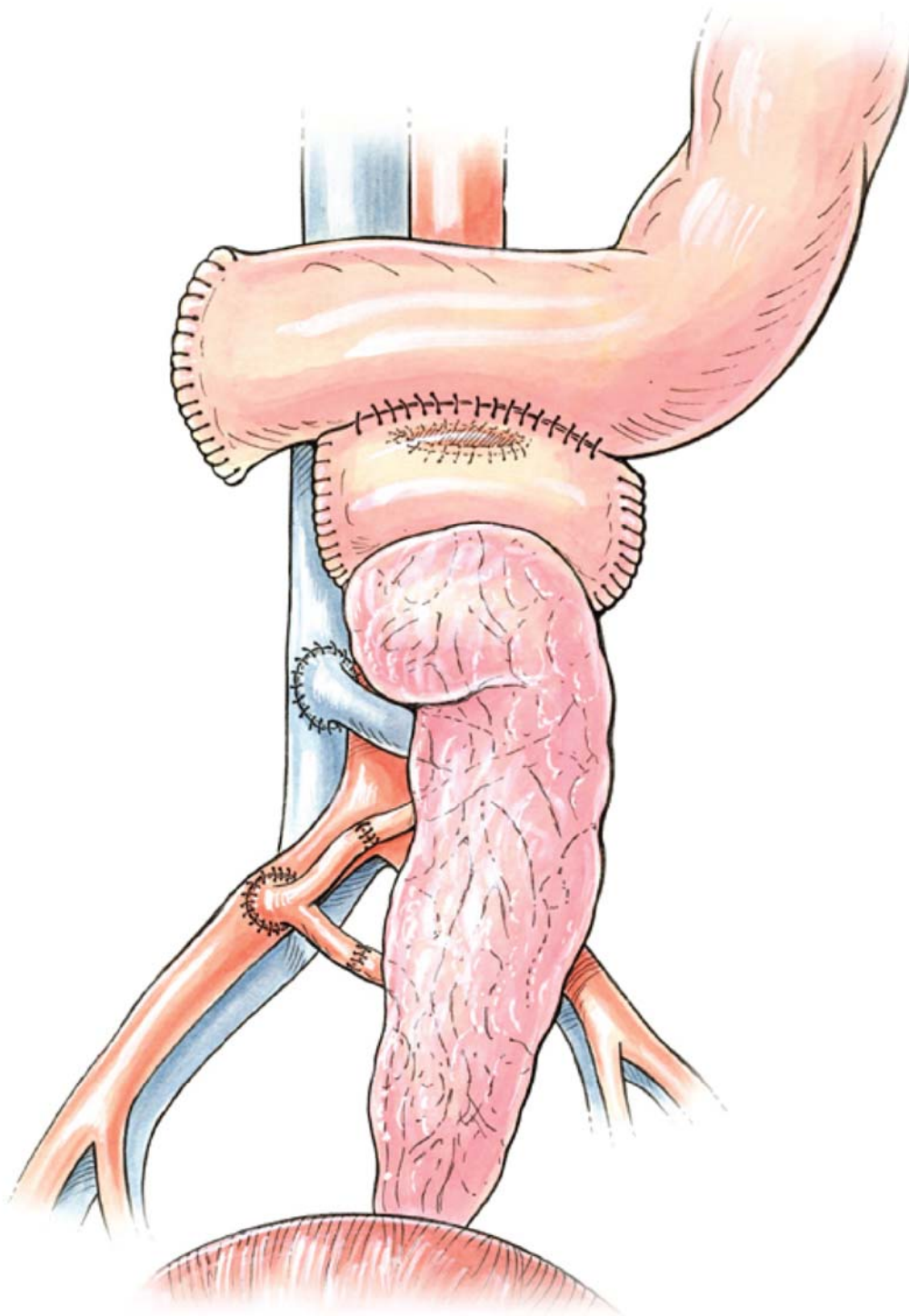


## Important Telephone Numbers

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Contact	Telephone Number
Emergency	911
Easy Call	(416) 351-0793
<i>Your Easy Call PIN</i>	
Pharmacy - Toronto General Hospital	(416) 340-4075
Transplant Coordinator via Easy Call	(416) 351-0793
Transplant Clinic	(416) 340-4800 x 4113
Telehealth Ontario	1-866-797-0000
Locating – Toronto General Hospital	416-340-3155
Transplant In-Patient Unit	416-340-5163
Patient Relations – UHN	416-340-4907
Registered Dietician – EatRight Ontario	1-877-510-5102
Life Labs	1-877-849-3637
Transplant Assessment Office	416-340-4800 x 6637
Transplant Social Work Office	416-340-4800 x 5655





## Appendix 1 - Medication Profiles

<b>ADVAGRAF® (tacrolimus extended release)</b>		
GENERIC NAME	BRAND NAME	REASON FOR USE
Tacrolimus extended release <b>Strengths:</b> 0.5 mg, 1 mg, 3mg and 5 mg capsules	ADVAGRAF®	Tacrolimus is an anti-rejection drug. It works to suppress specific cells of your immune system in order to prevent rejection of your transplanted organ.
<b>SIDE EFFECTS</b>		
<p><b>1. INCREASED BLOOD PRESSURE</b> Your blood pressure will be monitored. You may require treatment with blood pressure medications.</p> <p><b>2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM</b> 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.</p> <p><b>3. HARMFUL EFFECTS ON THE KIDNEY</b> 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.</p> <p><b>4. GASTROINTESTINAL UPSET</b> 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</p> <p><b>5. DIABETES (Increased blood sugar)</b> Your blood sugar (glucose) levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.</p> <p><b>6. INCREASED SUSCEPTIBILITY TO INFECTION</b> 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 <i>immediately</i>.</p> <p><b>7. INCREASED RISK OF DEVELOPING CANCER</b> 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.</p>		



## PROGRAF® (tacrolimus immediate release)

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

### SIDE EFFECTS

#### 2. 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.





## PREDNISONE

GENERIC NAME	REASON FOR USE
Prednisone <b>Strengths:</b> 5 mg and 50 mg tablets	Prednisone is a cortisone-like anti-rejection 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.



## SIROLIMUS (Rapamune®)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Sirolimus Rapamycin Strengths: 1 mg tablets 1 mg/mL oral solution	RAPAMUNE®	Sirolimus is an anti-rejection 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.



## CELLCEPT® (mycophenolate mofetil)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Mycophenolate mofetil MMF <b>Strengths:</b> 250 mg capsules 500 mg tablets 200 mg/mL oral suspension	CELLCEPT®	Cellcept® is an anti-rejection 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.



## MYFORTIC® (enteric coated mycophenolate sodium)

GENERIC NAME	BRAND NAME	REASON FOR USE
Enteric coated mycophenolate sodium  <b>Strengths:</b> 180 mg and 360 mg tablets	MYFORTIC®	Myfortic® is an anti-rejection 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.



## AZATHIOPRINE (Imuran®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Azathioprine <b>Strength:</b> 50 mg tablets	IMURAN® (and generics)	Azathioprine is an anti-rejection 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.



## COTRIMOXAZOLE (Septra®)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Sulfamethoxazole/ Trimethoprim or Cotrimoxazole  <b>Strengths:</b> Single strength tablet (400/80 mg) Double strength tablet (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.
<b>SIDE EFFECTS</b>		
<p><b>1. SKIN RASH</b> 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.</p> <p><b>2. SENSITIVITY TO SUNLIGHT</b> 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.</p> <p><b>3. DECREASED BLOOD CELL COUNTS</b> 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.</p> <p><b>4. FEVER</b> A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team <i>immediately</i>. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol®) may be used to control the fever.</p>		
<p><b>HOW TO USE THIS DRUG</b> ● 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.</p>		



## DAPSONE

GENERIC NAME	REASON FOR USE
Dapsone <b>Strength:</b> 100 mg tablet	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.



## NYSTATIN

GENERIC NAME	BRAND NAMES	REASON FOR USE
Nystatin  <b>Strength:</b> 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

- Since this medication is not absorbed into the body, side effects are very unlikely.

**HOW TO USE THIS DRUG** ● 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.





## VALGANCICLOVIR (Valcyte®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Valganciclovir  <b>Strengths:</b> 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.
<b>SIDE EFFECTS</b>  <b>1. DECREASED BLOOD CELL COUNT</b> 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.  <b>2. GASTROINTESTINAL UPSET</b> 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.  <b>3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM</b> 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.		
<b>HOW TO USE THIS DRUG</b> ● 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.		



## PANTOPRAZOLE (Pantoloc®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Pantoprazole  <b>Strength:</b> 20mg and 40mg tablets	PANTOLOC® (and generics)	This drug is used to prevent and treat heartburn, and stomach or intestinal ulcers, by decreasing the amount of acid produced by the stomach.
<b>SIDE EFFECTS</b>		
<ul style="list-style-type: none"> <li>● Side effects may include headache, constipation or diarrhea. ● Generally this medication is well tolerated. Contact your doctor if any side effects continue or are bothersome.</li> </ul>		
<b>HOW TO USE THIS DRUG</b>		
<ul style="list-style-type: none"> <li>● If your doctor has prescribed one dose of this medication every day it may be taken in the morning or at night. If you experience heartburn during the night you should take this medication at bedtime. ● If it is to be taken twice daily, take it in the morning and at night.</li> <li>● Doses may be taken without regard to meals.</li> </ul>		
<b>SPECIAL INSTRUCTIONS</b>		
<ul style="list-style-type: none"> <li>● Swallow tablets whole with a glass of fluid such as water or juice. ● Tablets must not be chewed or crushed.</li> </ul>		



## RANITIDINE (Zantac®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Ranitidine  Strength: 150 mg tablets	ZANTAC® (and generics)	This drug is used to prevent and treat heartburn, and stomach or intestinal ulcers, by decreasing the amount of acid produced by the stomach.
<b>SIDE EFFECTS</b>		
<ul style="list-style-type: none"><li>● Side effects may include headache, dizziness, constipation, nausea and abdominal pain.</li><li>● Generally this medication is well tolerated. Contact your doctor if any side effects continue or are bothersome.</li></ul>		
<b>HOW TO USE THIS DRUG</b>		
<ul style="list-style-type: none"><li>● If your doctor has prescribed only one dose of this medication every day, it may be taken in the morning or at night. If you experience heartburn during the night you should take this medication at bedtime.</li><li>● If it is to be taken twice daily, take it in the morning and at night.</li><li>● Doses may be taken without regard to meals.</li></ul>		



## METHYLPREDNISOLONE (Solumedrol®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Methylprednisolone Sodium Succinate <b>Strengths:</b> Various (injection only)	SOLUMEDROL® (and generics)	This is an intravenous anti-rejection drug. It works to suppress your immune system in order to prevent rejection of your transplanted organ. It may also be used to treat an episode of rejection.

### SIDE EFFECTS

1. **INCREASED BLOOD SUGAR LEVELS** This medication may cause high blood sugar (glucose) levels, which are difficult to control in patients with existing diabetes or those who are prone to developing diabetes. Your blood sugar levels will be monitored. You may require treatment with medication if your blood glucose levels remain persistently high.
2. **SLEEP DISTURBANCES, NIGHTMARES, MOOD CHANGES** These effects usually subside as the dose is reduced.
3. **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.
4. **STOMACH UPSET OR IRRITATION** An acid-reducing medication may be prescribed. Report any severe symptoms or blood in your bowel movements to a doctor right away.
5. **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*.

This medication is given through an intravenous (IV) line. It is commonly used in hospital right before and after transplant. Prednisone is a very closely related medication which is available in an oral tablet form. Most patients will receive a prescription to continue on oral prednisone therapy when they leave the hospital after transplant.



## RABBIT ANTI-THYMOCYTE GLOBULIN (Thymoglobulin®)

GENERIC NAMES	BRAND NAMES	REASON FOR USE
Rabbit anti-thymocyte globulin <b>Strength:</b> 25mg/5mL injection	THYMOGLOBULIN®	This is a potent intravenous medication that may be used in the first few days following a transplant to prevent rejection. It may also be used to treat an episode of rejection.

### SIDE EFFECTS

1. **ALLERGIC REACTIONS** This medication is derived from rabbit serum. Allergic reactions are unlikely, but if they occur the drug will be stopped and antihistamines and steroids will be given. Pre-medications are usually given before each dose to prevent allergic reactions.
2. **FEVER AND CHILLS** This effect is more common during the infusion of the first dose. Pre-medication will be given and the drug will be infused very slowly in order to limit this effect. If fever or chills do occur the infusion will be slowed or stopped temporarily. These effects do not last long and will respond to treatment with acetaminophen (Tylenol®).
3. **DECREASED BLOOD CELL COUNTS** Your blood cell counts will be closely monitored while you are on this medication. If a decrease does occur the dose of this medication may be reduced or it may be stopped temporarily.
4. **INFECTION** This medication is a powerful anti-rejection drug and that will cause suppression of your immune system. You will be much more susceptible to developing an infection, both during treatment and for a period of time after the medication has been stopped. To avoid the risk of serious infection this drug is used for the shortest period of time possible. 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*.



## GANCICLOVIR (Cytovene®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Ganciclovir Strength: 50mg/mL injection	CYTOVENE®	This is an anti-viral medication that is given intravenously to prevent and treat infections caused by the herpes virus or cytomegalovirus (CMV).

### SIDE EFFECTS

1. **DECREASED BLOOD CELL COUNTS** Your blood cell counts will be monitored closely. It may be necessary to stop or interrupt treatment until your blood cell counts recover.
2. **PAIN AT INFUSION SITE** This medication is infused slowly through a large vein to limit this effect.
3. **EFFECTS ON THE CENTRAL NERVOUS SYSTEM** This can include headaches or trouble sleeping. Medications may be prescribed to help manage these symptoms if they occur.

### HOW TO USE THIS DRUG

- This drug is given intravenously (IV). In some cases treatment may continue for up to several months. If this is necessary, a special long-term IV (midline catheter or L-Cath) may be inserted so that you do not have to have multiple peripheral IVs inserted during the course of treatment.
- Many patients may be converted to a very similar medication called valganciclovir (Valcyte®) which is available in an oral tablet form. Your transplant team will determine if this is an appropriate option for you.

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



## ACYCLOVIR (Zovirax®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Acyclovir <b>Strengths:</b> 200mg, 400mg and 800mg tablets	ZOVIRAX® (and generics)	This is an anti-viral medication used to prevent and treat infections caused by the herpes family of viruses, such as shingles or severe cold sores.

### SIDE EFFECTS

1. **STOMACH UPSET, NAUSEA, VOMITING, DIARRHEA** Taking this medication with food can help to prevent these effects. If these symptoms are severe or last for more than one day, report this to your transplant team.
2. **EFFECTS ON THE CENTRAL NERVOUS SYSTEM** Tiredness, headache, tremors or confusion may occasionally occur. While still uncommon, these effects are more likely with the use of higher doses of intravenous acyclovir. In rare cases acyclovir may trigger seizures in those who have seizure disorders.
3. **ALTERED KIDNEY FUNCTION** This effect is rare and is more likely to occur with use of intravenous acyclovir. You may be instructed to increase your fluid intake while you are on this medication. If you experience any pain in your side (between ribs and hip) or kidney area of your back, report this to your transplant team.

### HOW TO USE THIS DRUG

- This medication is usually taken 3 to 5 times a day. Always follow the dosing instructions given to you by your transplant team.
- This medication may be taken without regard to meals, although taking it with food can help to prevent stomach upset.
- You may be instructed to increase your fluid intake while you are on this medication.

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



## *Appendix 3 - Saying Thank You*

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Transplant recipients often wonder how to say “Thank you” to their donor.

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. Although it may be a challenge to write a letter, many transplant recipients welcome the opportunity 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 immediately. 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 we keep your identity and your donor’s identity confidential. For this reason, we ask that you do not include your name, where you live, your cultural background, religious affiliation or 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 are looking 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 wish. Please remember this is a letter of thanks. If you need some help with your letter, do 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 then forward your letter to the staff at the Trillium Gift of Life program. It is the Trillium Gift of Life staff that sends your letter to the donor family.

Occasionally donor families will send correspondence to recipients through the Trillium Gift of Life Program. If this happens, your coordinator will let you know.





## Appendix 4 - Medication Reference for Other Providers

Most conditions affecting liver transplant recipients are treated as they are in any other patient with the following cautions and exceptions

Avoid	<ul style="list-style-type: none"> <li>• All NSAIDs – worsening of (subclinical) Tacrolimus-induced renal dysfunction and G.I. irritation</li> <li>• Macrolide antibiotics (e.g. Erythromycin) inhibition of drug metabolizing enzymes in the liver with significant increases in the Tacrolimus levels. Azithromycin seems to be an exception and has minimal impact on the levels and thus is acceptable</li> </ul>
Vaccines	<ul style="list-style-type: none"> <li>• <b>NOT</b> to receive vaccines with live virus or bacteria thus no herpes zoster vaccine, MMR etc.</li> <li>• Annual flu shot is recommended preferably after the first 6 months post-transplant to improve benefit</li> <li>• Pneumovax recommended q 5 years for all patients rather than single dose in lifetime</li> </ul>
Antibiotics	<ul style="list-style-type: none"> <li>• No contraindications except macrolides (see above) and rifampin. Rifampin induces the drug metabolizing enzymes in the liver and therefore causes a marked decrease in Tacrolimus levels. If it is used close monitoring of the Tacrolimus levels and respective dose adjustment is necessary</li> </ul>
Cholesterol Rx	<ul style="list-style-type: none"> <li>• Lipid lowering meds well tolerated</li> <li>• Agent we have most experience with is atorvastatin – start at lowest possible dose due to potentiation effect with immunosuppressives , - increase dose gradually if necessary</li> <li>• Limited experience with rosuvastatin (Crestor), but has been used, again starting with the lowest possible dose</li> </ul>
HTN	<ul style="list-style-type: none"> <li>• Follow usual guidelines with some caution related to diuretics, ACE inhibitors and ARBs due to commonly encountered baseline renal dysfunction and risk for hyperkalemia</li> </ul>
Gout	<ul style="list-style-type: none"> <li>• Colchicine in small doses the usual choice since no NSAIDs allowed: Brief course of prednisone acceptable.</li> <li>• If recurrent acute attack: Allopurinol acceptable.</li> </ul>
Seizures	<ul style="list-style-type: none"> <li>• Many antiepileptics such as phenytoin and carbamazepine induce the drug metabolizing enzymes in the liver and therefore cause a marked decrease in Tacrolimus levels. If these drugs have to be used, close monitoring of the levels is advised and respective dose adjustment if necessary</li> </ul>
Erectile Dysfunction	<ul style="list-style-type: none"> <li>• No specific transplant concerns, use usual risk assessment</li> </ul>



## Appendix 5 - Vaccine Reference

Vaccine	Inactivated/ live attenuated (I/LA)	Recommended before transplant	Recommended after transplant	Monitor vaccine titers
<b>Influenza</b>	I	Yes	<b>Yes *</b>	No
	LA	No	<b>No</b>	No
<b>Hepatitis B</b>	I	Yes	<b>Yes</b>	Yes
<b>Hepatitis A</b>	I	Yes	<b>Yes</b>	Yes
<b>Tetanus</b>	I	Yes	<b>Yes</b>	No
<b>Pertussis (Tdap)</b>	I	Yes	<b>Yes</b>	No
<b>Inactivated Polio vaccine</b>	I	Yes	<b>Yes</b>	No
<b>Pneumovax</b>	I	Yes	<b>Yes **</b>	No
<b>N. meningitis (MCV4)</b>	I	Yes	<b>Yes</b>	No
<b>Rabies</b>	I	Yes	<b>Yes</b>	No
<b>Human papilloma virus (HPV)</b>	I	Yes	<b>Yes</b>	No
<b>Varicella (live-attenuated; Varivax)</b>	LA	Yes	<b>No</b>	Yes
<b>Varicella (live-attenuated; Zostavax)</b>	LA	Yes	<b>No</b>	No
<b>BCG</b>	LA	Yes	<b>No</b>	No
<b>Smallpox</b>	LA	No	<b>No</b>	No



\* In new patients we recommend that the flu shot be delayed until 6 months post-transplant to improve response

\*\* Repeat dose every 5 years

Reference: Danzinger-Isakov L, Kumar D et al. Am J Transplant 2009;9(Suppl 4):S258-S262

Note: Reference Information courtesy of Dr. C. Rotstein MD FRCPC FACP, Co-Director Transplant Infectious Diseases, University Health Network



# *Special Thanks to...*

The Kidney and Pancreas Transplant Program Team

**Dr. Trevor Reichman, MD, FRCS(C)**  
Director, Pancreas Transplantation  
Professor of Surgery

**Dr. Jeffrey Schiff, MD, FRCP (C)**  
Medical Director, Pancreas Transplant  
Associate Professor

**Dr. Ian McGilvray MD, PhD. FRCS (C)**  
Transplant Surgeon  
Associate Professor

**Dr. Markus Selzner, MD**  
Transplant Surgeon  
Associate Professor

**Dr. Gonzalo Sapisochin, MD**  
Transplant Surgeon  
Assistant Professor

**Dr. Peter H. Seidelin, MD, FRCPC**  
Cardiologist

**Andrea Norgate, RN, BScN, ENC(C)**  
Transplant Coordinator

**Anila Yousuf, RN(EC), MScN, BScN, BSc**  
Nurse Practitioner

**Cynthia Godinez**  
Administrative Assistant

**Narges Tzogas**  
Administrative Assistant

