



TORONTO PANCREAS
TRANSPLANT PROGRAM

Islet Cell Transplant Manual

Dedication

This manual is dedicated to the families of deceased donors who make Islet Cell transplants at our center possible.

An Islet Cell 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 Islet Cell 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.



Chapter Two – What is an Islet Cell Transplant?

What Are Islet Cells?

Type 1 diabetes develops in people because they are unable to produce the hormone insulin. Insulin is made by specialized cells found in clusters called the Islets of Langerhans (or simply 'islets').

Islet cells produce insulin when blood glucose levels in the body are high, bringing them down again, and stop producing insulin when blood glucose levels are low.

If you think that the above mentioned description represents you, then an islet cell transplant might be a suitable option. The main reason to have an islet cell transplant is recurrent, severe, disabling hypoglycemia despite the best medical therapy, which may include a trial of insulin pump therapy.

What is an islet cell transplant?

Islet cell transplantation involves extracting islet cells from the pancreas of a deceased donor and implanting them in the liver of someone with Type 1 diabetes. First islets are extracted from the pancreas of someone who has died and given consent for their organs to be used for transplantation. If this process produces a suitable number of good quality islets, they can be offered to someone in need of a transplant.

Donor islets are injected into a vein within the liver (the portal vein) and after a period of around two to six weeks, they start to produce insulin. At this time, the transplant patient will become aware that their blood glucose is easier to manage. Most people require two transplants (involving two hospital admissions) to get the maximum benefit from the procedure.

At the time of the transplant the recipient must take anti-rejection drugs to make sure that their immune system does not reject the newly transplanted islet cells. These drugs must be taken for the rest of the transplant patient's life and have known side effects, which are discussed in detail in the appendix at the end of this guide.



Who might be suitable for an islet cell transplant?

- People with Type 1 diabetes who have experienced two or more severe lows within the last two years, and have impaired awareness of hypoglycemia.
- People with Type 1 diabetes and a functioning kidney transplant.

Who might NOT be suitable for an islet cell transplant?

- People whose BMI (body mass index) is greater than 30
- People with poor kidney function. For example, those with an estimated glomerular filtration rate (GFR, the rate at which fluid filters through the kidney) of less than 60ml per minute, which can be worsened by the anti-rejection medications.
- Women who are planning a pregnancy (because the long term effects of some anti-rejection drugs on unborn children is uncertain)
- Other people with less common health issues - your medical team will discuss these with you.

What are the likely benefits of an islet cell transplant?

The goals and likely benefits of an islet cell transplant are to:

- reduce the frequency of severe lows
- improve awareness of lows
- improve quality of life
- reduce the fear of lows
- reduce the risk of long-term complications of diabetes



Will I still have to take insulin after an islet cell transplant?

For most people, the simple answer is 'yes'. The goal of an islet cell transplant is NOT to eliminate the need for insulin injections, although it can be of great benefit when this happens. In some cases, transplant patients will have freedom from insulin injections for up to one year and very occasionally for more than five years. Others will need to continue with some level of injected insulin from the start.

Results worldwide suggest that the majority of people who receive an islet cell transplant have to continue taking insulin, but their dose is usually around half of that required before their first transplant. Results show that five years after an islet cell transplant, around nine out of ten transplant patients will need to resume treatment with insulin by pump or by injection. It is important to realize that islet cell transplantation is not an effective treatment for people whose aim is to stop insulin therapy.



Chapter Three – What Other Treatments Options Are Available?

Understanding treatment options

It is important that you have sufficient information to help you make a decision about whether or not to undergo an islet cell transplant. Before you pursue a full clinical assessment to see if you are suitable for an islet cell transplant, you should be familiar with the risks and benefits of this therapy and other available therapies.

Several treatment options are available. They are listed here in order of increasing complexity.

- Revision of your insulin regimen and overall diabetes management
- An insulin pump
- An islet cell transplant or a whole organ pancreas transplant

Your medical team will discuss the risks and benefits of these alternatives with you to help you to decide on your best option.

Enhanced Standard Therapy

People with Type 1 diabetes who are using a very simple, inflexible insulin injection regimen (such as twice daily injections) may benefit from learning how to use their insulin more effectively. If you have not been taught how to count the carbohydrates in different meals and to change your insulin doses in response to food intake, activity levels and glucose results, then the islet cell transplant team will discuss this with you.

If you are already using the best available insulin injection therapy, then the option of an insulin pump may be discussed with you. This can be a safe and highly effective way of dealing with problematic lows in people with Type 1 diabetes.

Most people with Type 1 diabetes who are referred to an islet cell transplant centre with problematic lows are able to reduce the number of lows they experience by working with their healthcare team to adjust their insulin regimen, and/or use an insulin pump. Ultimately these people can overcome problematic lows without needing an islet cell transplant and therefore without the risks of undergoing an operation and taking anti-rejection medications.



Whole organ pancreas transplant

A whole organ pancreas transplant can be a very effective way of managing Type 1 diabetes and reducing the risk of severe lows. A successful whole organ pancreas transplant usually results in normal glucose levels, so that the transplant patients can, for the most part, eat what they like, when they like, and do not require insulin injections.

The main drawbacks of a whole organ pancreas transplant are the risks of surgery. A whole organ transplant is also a much bigger operation compared to an islet cell transplant.



Chapter Four – The Transplant Assessment Process

How do get referred for islet cell transplantation?

In order to receive an islet cell transplant you will require a referral by your Family Doctor or your Endocrinologist. Your team will need to confirm that all possible alternative options have been explored to help you achieve stable blood glucose levels and avoid severe lows. Once the islet cell transplant team receives the referral, they will contact you and provide you with some information about what is involved. They will then arrange an outpatient appointment where you will meet the medical and nursing staff so that they can assess you in more detail and give you further information about the procedure. They will perform blood tests at that time.

What happens if I decide to go ahead with the islet cell transplant?

If you are keen to proceed with an islet cell transplant and the team deems you suitable to proceed, further tests will be arranged. Your islet cell coordinator will try to minimize the number of hospital visits you will need, but you must be prepared for at least four additional visits to the hospital during this phase of preparation. Your hospital visits will include the following:

- ❖ 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 dopplers – 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
- ❖ Cardiologist

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 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, i.e. Illness or vacation



Infection Risks with Transplantation

The risk of infection related to transplantation needs to be considered when choosing whether or not to proceed with islet cell transplantation. We hope this helps transplant candidates make an informed decision about transplant. 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 may receive 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. Reasonably effective treatment is available if a CMV infection develops or recurs post-transplantation.

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.

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.

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.



Chapter Five– The Cost of Transplantation

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



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.

Drug Coverage – Private Insurance

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.



Chapter Six– The Call

When islet cells 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. **

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 an islet cell transplant. The charge nurse will put you in touch with the recipient on call coordinator.

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.



Chapter Seven – The Procedure

What happens when I'm called in for transplant?

The islet cell transplant team will telephone you to let you know that a suitable islet donor has become available. They will ask about your general health. If all is well, you will be admitted to hospital for approximately 5-7 days. When admitted, you will be seen and examined by your medical team and you will have a series of blood tests. At this time, an intravenous tube (IV) will be inserted into a vein in your arm. Insulin and fluids containing glucose will be given to you through this tube in carefully adjusted doses to keep your blood glucose as close to normal as possible.

If your glucose level goes low, you will be given more glucose and your insulin drip will stop until your level goes back up. Lows are unlikely to happen because your blood glucose and the insulin dose you receive will be checked and adjusted at least every hour. This drip will be kept running for the first 48 hours after the transplant to help you achieve near-normal glucose levels

Anti-rejection drugs will be given once the medical team has final confirmation that the transplant will be going ahead. These drugs are given through a vein.

What does the transplant procedure involve?

The transplant procedure will take place in the interventional radiology department. You will be given a local anesthetic injection to numb a small area of skin on the right side of your abdomen. The radiologist will use ultrasounds and x-rays to identify your portal vein, which is located within the liver. Using a needle, the radiologist will insert a plastic tube (a catheter) through your liver and into the portal vein. The islets are then injected slowly into the portal vein over a period of 15-30 minutes.



What happens after the procedure?

After the transplant, you will be transferred back to the transplant ward where you will be closely monitored. This will include hourly checks of your blood glucose, and checks for signs of bleeding. Your blood glucose will be controlled via the drip in your arm that will provide insulin and glucose and aim to keep your blood glucose levels as close to normal as possible. You will be treated with medicine to thin the blood, and this will require blood tests to be done approximately every four hours until this medication is stopped (usually within 48 hours of the transplant procedure). You will be allowed to eat and drink after about four hours, which will be covered by doses of short acting insulin as usual.

The day after your transplant you will have an ultrasound scan of your liver to check for any signs of bleeding or clots within the portal vein. You will have additional blood tests on a daily basis to monitor your kidney, liver, and the levels of anti-rejection drugs in your system. After your transplant you will stay in hospital for about 5 days but may need to stay longer if you experience any complications.

During your hospital stay, you will be seen frequently by members of the transplant team and by the pharmacist, who will help to explain the details of your medication including the important anti-rejection medications.

Will I continue to take insulin?

It may take 6-12 weeks before the transplanted islets work properly, and it is likely that you will make no major changes to your usual insulin doses when you leave hospital after an islet cell transplant. However, some transplant patients start to see a reduction in their insulin requirement 2-3 weeks after the procedure. You will be asked to monitor your blood glucose seven times per day, and keep in close contact with your transplant coordinator. We would expect your insulin requirement to come down by one quarter or one half during the first three months after the first transplant.

After your first islet transplant we would not expect you to stop taking insulin. However, after your second transplant it is possible that you may be able to stop taking insulin and stay off it for a few months. However, most islet cell transplant patients continue to take a small amount of insulin - usually about half the dose that they were taking before their first transplant. Taking small dose of insulin after an islet cell transplant may be beneficial to the transplant and extend the length of time that it continues to work.



Chapter Eight – After Your Transplant

How often will I need to attend the clinic?

Your transplant coordinator will need to see you very often for the first few weeks after transplant, which can be very demanding for some people. These visits are needed because your medication doses, including your insulin doses, will need to be changed frequently in the early stages. This can also be done with your coordinator through phone calls or e-mail.

How often will I need to check my blood glucose?

High blood glucose levels could harm the transplanted islet cells, and so your transplant coordinator will work with you to keep your glucose levels as close to normal as possible after your transplant. To help you achieve this, they will ask you to check your blood glucose levels several times per day, (before every meal, two hours after your meals and also at bedtime) for the first few weeks after your transplant. After several weeks, the number of blood glucose checks per day can be reduced as your glucose levels improve, and your insulin dose is reduced. Your coordinator will also ask you to keep a written record of your blood glucose levels and your insulin doses, and you should take this record with you to every clinic visit.

How will I know if my transplant is working?

One to two months after your transplant, the islet cells should start to produce insulin, your blood glucose levels should improve and you should be able to reduce your insulin doses. Until this happens, it can be difficult to be sure that your transplant is working.

Your transplant coordinator will check your blood to find out how much insulin your transplant is producing. Only a small proportion of people find that their transplant does not work at all after three months. If this happens to you, your medical team will discuss with you whether or not you should continue taking your anti-rejection medication.

If it becomes clear that your transplant has failed, this may be because your body has rejected it. Fortunately, this does not happen very often, but you need to be aware that this can happen at any time, even if you take your anti-rejection medication regularly.



Will I need a second islet cell transplant?

The timing of a second islet cell transplant will vary quite a bit between individuals. Some people are offered a second transplant within three months of the first, while others may have to wait more than a year. This is because of the limited number of organs donated for transplant.

If your first transplant is very successful, you may be advised to delay having a second transplant until there are signs that this is required. These include whether you are able to control your blood glucose levels (and avoid lows), your insulin requirement and the results of your blood tests. A small number of transplant patients never need a second transplant.

How long will my transplants work?

Currently, at least half of islet cell transplants work for 6 years or longer. The long term results of islet cell transplantation continue to improve as anti-rejection medications and the ways that donated islets are prepared improve.

What happens if my transplant fails?

If your islet cell transplant does fail, your blood glucose levels and insulin requirements will return to pre-transplant levels, as will your risk of severe lows. Transplant loss will be confirmed by your medical team using blood testing. Unfortunately, it is not possible to work out in advance which transplant patients will gain long-term benefit from their transplant, and which will lose their transplant soon after it is given



Important Telephone Numbers

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

PROGRAF® (Tacrolimus immediate release)		
GENERIC NAME	BRAND NAME	REASON FOR USE
Tacrolimus immediate release Strengths: 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		
<p>1. INCREASED BLOOD PRESSURE Your blood pressure will be monitored. You may require treatment with blood pressure medications.</p> <p>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.</p> <p>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.</p> <p>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</p> <p>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.</p> <p>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 <i>immediately</i>.</p> <p>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.</p>		



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.



PREDNISONONE

GENERIC NAME	REASON FOR USE
Prednisone Strengths: 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.



CELLCEPT® (mycophenolate mofetil)

GENERIC NAMES	BRAND NAME	REASON FOR USE
Mycophenolate mofetil MMF Strengths: 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 Strengths: 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 Strength: 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
<p>Sulfamethoxazole/ Trimethoprim or Cotrimoxazole</p> <p>Strengths: Single strength tablet (400/80 mg) Double strength tablet (800/160 mg)</p>	<p>SEPTRA® (and generics)</p>	<p>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.</p>

SIDE EFFECTS

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

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

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

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

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



DAPSONE

GENERIC NAME

Dapsone **Strength:** 100 mg tablet

REASON FOR USE

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

SIDE EFFECTS

1. **SKIN RASH** This may be a sign of an allergic reaction. If this occurs, stop taking this medication and report this to your transplant team. A different drug may be prescribed.
2. **SENSITIVITY TO SUNLIGHT** Your skin may burn more easily if exposed to the sun. Avoid excessive exposure to sunlight and wear protective clothing or sunscreen products on all sun-exposed areas, even in the winter.
3. **YELLOW COLORATION OF SKIN, DARK URINE** These symptoms are rare but may be a sign of liver damage or a problem with your red blood cells. Report these symptoms to doctor or your transplant team as soon as possible.
4. **FEVER** A fever is a temperature above 37.5°C or 99.5°F. Fever should be reported to a doctor or your transplant team immediately. Fever may be a sign of infection, rejection or an allergic reaction to this medication. Acetaminophen (Tylenol®) may be used to control the fever.

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



NYSTATIN

GENERIC NAME	BRAND NAMES	REASON FOR USE
Nystatin Strength: 100,000 units per mL oral suspension	NILSTAT® MYCOSTATIN® (and generics)	This medication is an antifungal. It is used to prevent yeast infections in the mouth (also known as oral thrush), which appear as white spots or patches.

SIDE EFFECTS

- 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 Strengths: 450 mg tablets 50 mg/mL oral solution	VALCYTE®	This medication is an anti-viral. It is used to prevent infections caused by viruses such as herpes virus and cytomegalovirus (CMV). It may also be used to treat infections caused by CMV.
SIDE EFFECTS		
<p>1. DECREASED BLOOD CELL COUNT Your blood cell counts will be monitored. If this side effect occurs your transplant team may ask you to stop taking this medication until your blood counts recover. This should only be decided by your transplant team.</p> <p>2. GASTROINTESTINAL UPSET Diarrhea, nausea, vomiting, or stomach pain may occur. Taking the medication with food may prevent these side effects. If these symptoms are severe or last for more than one day, report this to your transplant team.</p> <p>3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM This can include headaches or trouble sleeping. Report these symptoms to your transplant team if they become troublesome. Medications may be prescribed to help manage this.</p>		
<p>HOW TO USE THIS DRUG ● If your doctor has prescribed a once daily dose of this medication it may be taken either in the morning OR the evening. Take the medication at the same time every day. ● If a twice daily dose of this medication has been prescribed, take it in the morning AND the evening, approximately 12 hours apart. ● Take this medication with food.</p>		
<p>Your transplant team will adjust the dose of this drug according to your level of kidney function.</p>		



PANTOPRAZOLE (Pantoloc®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Pantoprazole Strength: 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.
SIDE EFFECTS		
● 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.		
HOW TO USE THIS DRUG		
● 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. ● Doses may be taken without regard to meals.		
SPECIAL INSTRUCTIONS		
● Swallow tablets whole with a glass of fluid such as water or juice. ● Tablets must not be chewed or crushed.		



METHYLPREDNISOLONE (Solumedrol®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Methylprednisolone Sodium Succinate Strengths: 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 Strength: 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*.



ACYCLOVIR (Zovirax®)

GENERIC NAME	BRAND NAME	REASON FOR USE
Acyclovir Strengths: 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.



Special Thanks too...

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