

Post-Liver Transplant Manual

POST-LIVER TRANSPLANT MANUAL



Toronto
Liver Transplant
Program



University Health Network

Toronto General Hospital Toronto Western Hospital Princess Margaret Hospital

Dedication

This manual is dedicated to our living liver donors and to the families of deceased donors who make liver transplants at our center possible.

A liver 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 of 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 endeavour to provide you with the best possible transplant care based on current research and our clinical expertise.

Our Philosophy of 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 Multi Organ Transplant 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.

Table of Contents

Dedication	2
Our Philosophy of Care	3
While You Are in Hospital	7
Assessing and treating Complications	7
Protecting You and Your New Liver	10
Patient Education.....	11
Medications	11
Your Home Medications and Complete Medication History.....	11
The Self Medication Program	12
The Transplant Pharmacy Website	13
Transplant Medication Information Teaching Tool (TMITT)	14
Common Post-Transplant Medications	14
While Taking Immunosuppressive Drugs.....	15
Drug Interactions	16
Pain Medications.....	16
Self-care and Monitoring at Home	16
1. Monitoring for Rejection	17
2. Monitoring for Infection	17
3. Activity	18
4. Avoiding Skin Cancer.....	19
5. Nutrition.....	20
Planning For discharge.....	21
Rehabilitation.....	21
Communication after Discharge	21
Out of Town Patients	22
Home Care	22
Paying for Medications	23
Transportation	23
Clinic and Blood tests after Discharge	23
Post-Discharge “To-Do” List.....	24
Returning your pager	24
Complete your “Contacts” List.....	24
Complete Medic Alert Bracelet Form	24
Thanking Your Donor family	24
Monitoring and Care after Discharge	25
Clinic.....	25
Lab Tests.....	27
Routine blood work	27
Rejection:	27
Assess Drug Levels:	27
Drug side effects:	27
Blood work on Clinic day:.....	28

Blood work drawn at your local lab (Lifelabs):	28
Medical Imaging (Scans, x-rays etc)	28
Abdominal ultrasound:	29
Abdominal x-ray:	29
CAT (CT) Scans:	29
MRCP:	30
Liver Biopsies	30
Diagnostic liver biopsies:	30
Surveillance liver biopsies:	31
Care by Other Health Care Professionals	32
Family Physician or Primary Care Provider	32
Dentists	33
Local Liver Specialists	33
Other Specialists	33
Complications Encountered in the Early Post Transplant Period	34
Leg and abdominal Swelling	34
Wound Infection	34
Diabetes	35
Rejection Episodes	35
Long-Term Complications	36
Rejection Episodes	36
Cardiovascular Risk Complications	37
Diabetes	37
Hypertension (High Blood Pressure)	38
High Cholesterol	38
Kidney Dysfunction	38
Bile Duct complications	39
Hernias	40
Infection	40
Cytomegalovirus/CMV infection:	41
Infection prevention	41
Osteoporosis	42
Cancer	42
Disease Recurrence	42
Hepatitis B Virus (HBV)	43
Hepatitis C Virus (HCV)	43
Non-Alcoholic Fatty Liver Disease (NASH)	44
Autoimmune Hepatitis (AIH)	44
Primary Sclerosing Cholangitis (PSC)	44
Primary Biliary Cirrhosis (PBC)	45
Hepatocellular Carcinoma (HCC)	45
Information on Commonly Asked Questions	46
Symptoms to Report to the transplant office	46

Staple Removal	46
Driving	47
Wearing Seatbelts.....	47
Exercise and Lifting Restrictions	47
Swimming.....	48
Hot Tubs and Saunas.....	48
Diet.....	48
Avoiding Infections	48
Increased nasal secretions.....	49
Prescription renewals	49
Immunizations/Flu Shots/Pneumovax vaccine.....	50
Insurance Forms.....	50
Returning to Work	51
Pain Medications.....	51
Over the Counter and Herbal medications.....	52
Medications to avoid	52
Pets.....	53
Sexual Activity/Birth control	53
Pregnancy/Planned Parenthood.....	53
Travelling.....	54
Alcohol	55
Smoking.....	55
Gardening.....	56
Telehealth Ontario	56
Urgent Situations	56
Re-Transplant	57
We want to know what you think.....	58
Important Telephone Numbers	59
Appendix 1 - Returning the Pager.....	60
Appendix 2 - Saying Thank You.....	61
Appendix 3 - Letter for Dentists.....	62
Appendix 4 - Medication Reference for Other Providers.....	63
Appendix 5 - Vaccine Reference	64
Appendix 6 - Medication Profiles.....	65

While You Are in Hospital

Goals of Treatment

After your surgery we have a number of goals which guide our assessment and care for you while you are in hospital. These include:

1. Assessing for and Treating Complications
2. Protecting you and your new liver
3. Patient Education
4. Planning your discharge

The average hospital stay is 1 to 2 weeks but could be as short as 5 days or may be longer depending on factors such as your state of health before surgery and any complications you have in hospital. It is normal for you and your family to feel anxious about going home but we will give you all the information you need to care for yourself.

Assessing and treating Complications

Liver transplant surgery is complicated and involves both removing your old liver (and gallbladder if you have one) as well as implanting your new liver (the donor's gallbladder is removed). The attachment of the blood vessels and the bile ducts is complicated. As we discussed in the pre-transplant manual, complications related to the surgery that we may encounter include:

1. **Internal bleeding** – Most patients who need a liver transplant have bleeding tendencies which take a few days to correct and this along with the surgery may result in bleeding. This is detected by decreases in hemoglobin and may result in the need for blood transfusions and sometimes a return to the operating room to stop the bleeding. (Risk is less than 5%)

2. **Blood clots** – These may occur in the new veins or arteries and can be serious as they interfere with the circulation to your new liver. These are detected by scans done following your surgery. They are treated by giving you blood thinners and/or additional surgery to remove the clots. (Risk is 1 %)
3. **Bile leaks** – This may occur where the donor bile duct and your bile duct are surgically connected. It can also occur from the cut surface of the liver if you receive a living donor liver or a split deceased donor liver. It is detected by scans following your surgery and by an increase in the size of your abdomen. It is treated by inserting a drainage tube or by additional surgery to correct the problem. (Risk is 10-20 %)
4. **Bile duct strictures** – This is a narrowing of the bile duct – usually at the site of the connection between your bile duct and the new one. The ducts are very small and a narrowing can result in decreased flow of bile from your liver. Narrowing of the ducts is detected by blood tests and scans. It is treated by medication (Ursodiol) and either the placement of a tube in the duct or less frequently by further surgery. (Risk is 10-20 %)
5. **Acute Rejection episodes** – Your body's immune system recognizes that your new liver is foreign and tries to reject it. Anti-rejection medications are started immediately after your surgery but it is common to have a rejection episode especially during the early post-transplant period. This is diagnosed by blood tests and a liver biopsy. Rejection episodes are treated by adding additional medications or by adjusting the doses of the ones you are taking. (Risk is 15 %)

6. **Wound Infections** – The incision for this surgery is large and it is common to have some fluid leaking through the incision after this surgery. A wound infection is detected by redness spreading in the skin out from the incision line and by a thicker fluid coming from the incision line. Infection is treated by antibiotics and sometimes by opening the upper layer of the incision to allow it to drain. (Risk is less than 5 %)
7. **Confusion** – This is a common symptom seen prior to the transplant and some patients experience it early after transplant. The reasons for confusion are different after transplant and include a long operation with anesthetic, pain medications and the new medications especially prednisone. It does not last long and can be managed with medication. (Risk is 10-20%)
8. **Primary Non-function** – In rare cases, for unknown reasons, the liver may fail to function in spite of all the safeguards to assess it prior to surgery. This is detected by blood tests and possibly a biopsy. If this occurs, you may need to be re-listed urgently for another transplant. (Risk is less than 0.5 %)

Liver transplant surgery is considered major surgery and additional complications we can encounter include:

1. **Kidney dysfunction** – Some liver transplant recipients have this issue prior to the transplant and this makes this problem more likely to occur after transplant. In most cases, this improves as the new liver starts to function. Occasionally this is serious enough to require kidney dialysis temporarily.
2. **Heart problems** – This could include rhythm abnormalities or even a heart attack. These may result in the need for further assessment and medications.

3. **Neurological problems** – These can include confusion – often related to pain medications, or less commonly seizures or stroke.
4. **Chest complications** – These can include pneumonia – this can usually be avoided if you do your deep breathing and coughing exercises. The risk for pneumonia is reduced by getting you up and moving. Pneumonia is more common in those who smoke or who have smoked in the past. You could also develop a fluid collection around your lungs called a “pleural effusion”. This usually resolves on its own in time but occasionally needs to be drained by inserting a needle into the collection to drain it.
5. **Infections** - This includes urinary tract infections, bowel infections and infections in intravenous sites.

Protecting You and Your New Liver

Your progress and your physical and emotional status are evaluated constantly while you are in hospital by your nurses and doctors as well as by social workers, physiotherapists, occupational therapists and pharmacists. Making you comfortable and getting you active and mobile are 2 key areas of focus. Most people experience some discomfort after their surgery and we work with the pain service to make you as comfortable as we can. You will be encouraged to do deep breathing and coughing exercises as soon as you are awake. This helps avoid the risk of pneumonia, a common complication of any surgery. We also will get you out of bed and walking as soon as you are able, in order to begin rebuilding muscles that may have become weak while you were sick. Walking also helps avoid blood clots developing in your legs.

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.

Medications

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 and Complete Medication History

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. All of your home medications will be returned to you before you are discharged.

If you are re-admitted to the hospital for any reason after a transplant, it is still important that you bring in all of your 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 need to 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
2. Click on the “Focus on Care” link on the left side of the page
3. Click on the “Multi-Organ Transplant” link
4. Click on the “Transplant Pharmacy” link on the right side of the page

Or, you can type the address for the Transplant Pharmacy homepage directly into the address bar of your web browser:

http://www.uhn.ca/Focus_of_Care/MOT/Transplant_Pharmacy/index.asp

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

also watch a short video entitled *Your Transplant Pharmacist: Caring for Your Medication Needs During Your Hospital Stay*. This video will describe some of the services you can expect from your Transplant Pharmacist while you are in the hospital. In the *Patient Toolbox* area you can access information regarding prescription drug coverage and download log sheets to help you manage common medical conditions such as high blood pressure or high blood glucose.

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

The TMITT program can be launched through the Transplant Pharmacy website. To access this tool you may click on the link that is displayed on the right side of any page. You can also go directly to this program by visiting www.TMITT.ca.

Common Post-Transplant Medications

Information on common post-transplant medications can be found in **Appendix 6** 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, osteoporosis, and diabetes 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** talk 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.

If you would like to take a multi-vitamin or any herbal remedy (including herbal teas), 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). This includes ibuprofen (the active ingredient in Advil[®] and Motrin[®] products); naproxen, which is found in Aleve[®] and Naprosyn[®]; and also ASA or Aspirin[®]. If you are taking an 81mg ‘baby’ Aspirin[®] once daily to prevent heart attack and stroke, this is okay if it is on the advice of a doctor. 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

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 liver is destroyed. The liver is usually able to regenerate completely from the injury rejection causes. 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^o C or more (check your temperature twice a day for the first 3 months)
- fatigue
- dull ache in the area of your abdomen where the liver is
- sudden weight gain of a kilo or more in 24 hours (weigh yourself daily if you have scales)
- jaundice (yellow colour best seen in the white part of your eyes)

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^o C or more (check your temperature twice a day for the first 3 mo 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
- If you have a personal or family history of melanoma have regular skin check-ups by dermatology
- 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 or elevated blood sugars. Some people also find that they gain weight after their surgery especially when the prednisone doses are higher.
- 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.
- Patients who have diabetes will need to pay special attention to the amount of carbohydrates in their diet and may need to meet with the dietician.

If you need diet information, please contact:

Janet Madill, Transplant Dietician
Phone #: 416-340-4800 Ext 3447

Planning For discharge

Rehabilitation

Most patients are able to go directly home after they recover from surgery. Some patients, however, require additional physiotherapy and recovery time in order to be able to return home safely. As we discussed previously, if this is the decision of the team, then an application will be completed for rehabilitation. We will accept the first available bed for you in order to get you started with intensive rehabilitation with the goal of getting you home as soon as possible. We will monitor you with the team while you are in the rehabilitation facility. The length of time you need at the rehabilitation hospital varies but on average is 3-4 weeks.

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, 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 to 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 such as diabetes support, 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 cannot 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 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. Clinic is usually once weekly at first and blood tests, one of which is done in clinic, are twice a week. At each clinic visit you are given further instructions to guide you until the next clinic.

Post-Discharge “To-Do” List

Returning your pager

It is important that you return your pager as soon as possible after you go home (see **Appendix 1** for the address). You should return it by a method that gives you a receipt and confirmation that you sent it. The cost of the pager is covered by the pager company and only covers the period of time that you have the pager pre-transplant so you need to send it back as soon as possible.

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

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. (See Appendix 2 for additional information)

Monitoring and Care after Discharge

Clinic

Location : 12th Floor Clinical Services Building (West 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 medications or medication list with names, doses and pill size.
- 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 three 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. All medications except for cyclosporine can be obtained at your local pharmacy. Cyclosporine must be filled at the Toronto General outpatient pharmacy for it to be paid for by the special government program for this drug. 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. After the first month we will give prescriptions for the immunosuppressive medications only – you will need to see your family doctor for the other prescriptions.
- 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.

Lab Tests

Routine blood work

Blood tests are an essential tool to help us monitor your liver transplant and overall health. We are able to assess for the following by monitoring your blood work including:

Rejection:

Often an episode of rejection of a liver transplant is detected by blood work. A rejection episode may also be accompanied by other symptoms such as an increase in temperature, jaundice etc.; as mentioned in the previous section, but it is important to remember that sometimes, rejection can be present without any visible symptoms. Doing your blood work as advised by your liver 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 impaired kidney function, low white blood cell counts and increased potassium.

Blood work on Clinic day:

New transplant patients usually require blood work on the day of clinic. We have a blood technician in the clinic area on the 12th 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.

If you take ***Tacrolimus (Prograf)***, please bring your morning dose with you to take after the blood work has been drawn. (This applies to every set of blood work). The blood test should be drawn 11 to 13 hours after your previous dose.

If you take ***Cyclosporine (Neoral)***, please ensure you have taken this medication 2 hours prior to arriving for your appointment. (This applies to every set of blood work).

Blood work drawn at your 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. 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.

Medical Imaging (Scans, x-rays etc)

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 liver tests become elevated, this is often the first test which is ordered to further assess if there is any change within the liver. This test uses sound waves to detect any changes within the blood flow to the liver (doppler) or in the liver tissue. The ultrasound can also pick up obvious changes in the bile ducts.

Abdominal x-ray:

Sometimes a small stent is inserted into the main bile duct during the transplant surgery. The purpose of the stent is to prevent narrowing in the bile duct as it heals. In most cases it is excreted with a bowel movement. It is a very tiny tube and most patients are unaware that it has passed. We check to see if it is gone by doing an x-ray about 6 weeks after transplant. If the stent is still seen on the abdominal x-ray, a gastroscopy will be arranged to remove it. Note: not all patients have stents.

CAT (CT) Scans:

Patients who have a history of tumor in their original (native) liver will have abdominal and chest CTs to monitor for tumor recurrence at 6 months, 1 year and 2 years after transplant. CTs may also 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. If your kidney function is abnormal, you may need additional special preparation for the scans (fluids and medication)

MRCP:

This test is done in the MRI (Magnetic Resonance Imaging) machine but it specifically assesses the bile ducts within the liver. This test is arranged if changes are suspected in the bile ducts. As well, patients who receive a living donor or split graft liver transplant will have a routine MRCP booked 3 months after the transplant. This 3-month test is a baseline study and will only be repeated if the liver enzymes associated with bile duct irritation become elevated in the future.

Liver Biopsies

Diagnostic liver biopsies:

- If there is a rise in your liver tests, your blood work may be repeated earlier than scheduled. If they continue to rise an ultrasound is often done, and if this test does not show any obvious abnormality, then a liver biopsy is usually organized for further assessment.
- In most cases, we arrange the liver biopsies through the ultrasound department. You will be given some local freezing (similar to dental freezing) and a needle will be inserted, with the guide of the ultrasound machine, to obtain a small sample of liver cells. This sample is assessed by the pathologist to see if rejection is the cause of the rise in your liver tests as seen in your blood work. We usually have the results within 24-48 hours so that we can arrange treatment for rejection if this is the final diagnosis.

Surveillance liver biopsies:

- If your liver disease is hepatitis C, you will require regular biopsies to assess the effect the recurrent virus has on the liver transplant. These are scheduled at 6 months, 12 months, 18 months, 24 months then usually yearly.
- All hepatitis C positive patients have fluctuations in their liver enzymes as a result of the virus irritating their liver. These fluctuations do not give an accurate picture of the damage the virus has on the liver tissue. The virus can cause inflammation in the transplant liver tissue and this can lead to fibrosis or scarring in your liver. This can only be accurately monitored through liver biopsies. The results for these surveillance biopsies are usually reported 2-3 weeks after the biopsy.
- If fibrosis appears to be progressing, your transplant team will discuss options for treatment. If your liver enzymes change significantly between these scheduled biopsies, an additional diagnostic biopsy may be ordered.

Care by Other Health Care Professionals

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 liver transplant team very regularly but it is important to remember that we are your liver transplant specialists and our focus of care is on your liver transplant.

We recommend that you see your family doctor within a month after discharge especially if you have diabetes, hypertension or other underlying medical conditions requiring monitoring by your family doctor. We ask that the family doctor assess and manage other conditions such as diabetes and hypertension. Anti-rejection medications can cause an increase in blood sugar and blood pressure which is most pronounced early after transplant. These conditions require early assessment and possible medication adjustment by your family doctor.

Anti-rejection medications should only be adjusted by your liver transplant specialist. Family doctors may have questions about what medications are acceptable for you. We have included a medication reference sheet ([Appendix 4](#)) as well as a summary of information on vaccinations ([Appendix 5](#)) at the end of this manual. Please feel free to share these with your family doctor. If your family doctor has other questions about medications we encourage them to contact our office for additional information. We also ask that you update us with any new medications, prescribed by outside doctors. Please leave this information on easy call and we will update your medication list. It also allows us to check to ensure the medication is compatible with your other medications and condition. After clinic appointments, we will mail or fax a note to your family doctor. 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. When you are booking an appointment with your dentist, or if urgent care is required, please give them the standard letter for dentists located in [Appendix 3](#). If there additional questions, the dentist can contact us for additional information.

Local Liver Specialists

In some areas we are beginning to work with the specialists who referred you for transplant to organize your post-transplant care close to home. This can make your care and follow-up more convenient. The areas we currently are working with to develop local care are Kingston, Hamilton and Ottawa. If you would like to consider this option, feel free to discuss this with your team. If local care is organized for you then all of your care would be transferred and we would not be involved in day to day care – you would get medications, scans, biopsies and clinic visits with your specialist. Any questions which you have would be answered by the local doctors. We would of course be available if your local team needed to consult with us.

Other Specialists

You may have other conditions which require ongoing monitoring by other specialists. Common examples are endocrinologists (diabetic specialists), cardiologists (heart specialists), nephrologists (kidney specialists) etc. If you have been seeing a specialist prior to your transplant, it is important for you to let them know you have had a liver transplant and to ask them to copy future consult notes to your liver transplant doctor. If a new condition is identified by the transplant team, we do our best to refer you to a specialist close to your home if there is one available and appropriate for the specific issue. Otherwise it may be necessary for you to see a specialist in downtown Toronto.

Complications Encountered in the Early Post Transplant Period

(After discharge)

Leg and abdominal Swelling

You may have had this issue prior to your transplant as well - fluid retention is a common problem in patients with liver disease. This will eventually resolve in the majority of cases but depending on the degree of fluid retention you had before your surgery, the amount of fluid we give you during surgery and the course you experience in hospital post transplant, you may still have significant swelling in your legs and abdomen when you go home. Even patients who do not have leg and abdominal swelling pre-transplant, may have some swelling post transplant. Until the excess fluid is gone, you should follow a low salt diet and keep your legs elevated when you are sitting down. You should monitor your weight daily at home and report any weight gain over 1kg in a 24hour period especially if you are experiencing any shortness of breath with the weight gain. We sometimes use diuretics to help eliminate the fluid but you must not use these medications on your own.

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.

Diabetes

This is a common side effect of prednisone as well as some of the other commonly used medications to reduce the risk of rejection. Patients who controlled their diabetes before transplant with pills or by diet will often require insulin afterwards at least for a short time, while the prednisone dose is highest. If you had diabetes prior to transplant, your insulin dose will require adjustment or sometimes the type of insulin will need to be changed. Even individuals without a history of diabetes, can develop this complication after their liver transplant and require medication to maintain a normal blood sugar. As the prednisone and other medications are reduced, your blood sugars will be easier to control. If you have diabetes post transplant, it is very important to see your family doctor regularly, closely monitor your blood sugar, and have your insulin adjusted as necessary.

You will be taught to monitor your blood sugar at home using a glucometer. You will be given guidelines to follow if you do develop diabetes.

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 liver, 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 rare cases, admission to hospital is required to treat the rejection with more potent intravenous immunosuppressive drugs.

Long-Term Complications

Rejection Episodes

Although 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 may include: fever, jaundice, generalized itching, sudden weight gain or fluid retention, new aches or pain to the right side of your abdomen. However, it is possible to have rejection without symptoms and that is why it is vital that you continue monitoring liver tests- 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 liver function and stop the rejection process. It is important that you do blood level testing of immunosuppression medications accurately i.e. with Neoral (Cyclosporine) - 2 hours after taking AM dose give or take ½ hour, or with Prograf (Tacrolimus) approximately 12 hours after taking your PM dose but before you take your AM dose. 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 liver biopsy

Cardiovascular Risk Complications

These are conditions monitored through family doctors as well as by other specialists such as endocrinologists. You may be at higher risk for developing these conditions post transplant. Annual check-ups and follow-up is vitally important to assess and if necessary treat cardiovascular disease. These complications can impact your long term health. Obesity or weight gain beyond what is recommended is common post transplant and adds to the risk for these conditions. Following healthy diet guidelines, watching your weight and exercising regularly are helpful in avoiding cardiovascular complications. You may find speaking to a dietician helpful, and definitely discuss your risks for these complications with your family doctor.

All of these conditions, if not treated, can contribute to coronary artery disease. As well, stopping smoking is the single most important factor in reducing your risk for heart disease.

Diabetes

As previously discussed diabetes management can vary from diet control with exercise to oral medications, or insulin injections. Diabetes can lead to other health problems including blood vessel disease affecting heart, kidneys, vision and circulation to fingers and toes. Monitoring and control of blood sugars is required as well as follow-up through either your family doctor or an endocrinologist (diabetes and endocrine problems specialist) to prevent long term complications. There are diabetes education programs that can be arranged through your family doctor or endocrinologist. These will include consult with a dietician.

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. Keep all of your physicians including the transplant team informed of the medications you are taking to avoid drug interactions. The monitoring and treatment of high blood pressure will be done through your family doctor.

High Cholesterol

Many factors can contribute to high cholesterol such as can age, hereditary factors, diet/exercise and other medical conditions such as diabetes. Some of the anti-rejection medications may also affect your cholesterol levels. Cholesterol levels are routinely monitored by your family doctor – we do not monitor this. If you develop high cholesterol, talking to a dietician may be helpful in making adjustments your diet. 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. Please be sure to let your transplant team know if you are to starting cholesterol medication. Although many of the medications used can cause increased liver blood tests, they are usually tolerated well. You will require more frequent blood test monitoring for a short period after starting the medication to be sure it is not causing abnormal liver function tests.

Kidney Dysfunction

Kidney function abnormalities are a common post transplant problem. This is partially a result of the side effects of antirejection medications as well as other factors such as age, and other diseases especially diabetes. Some patients have abnormal kidney function before their transplant. Your transplant doctor may try adjusting the dose of immunosuppressive drugs you take to reduce the impact on your kidneys. This is done carefully as

there is a chance of causing rejection if the dose is reduced too much. If your medication is being adjusted, it is especially important that you do your blood tests according to the schedule you are given.

It is also important to assess and treat other disorders which can affect kidney function. Two of these disorders are diabetes and high blood pressure. Carefully controlling both will be helpful in reducing the risk to your kidneys. Avoiding medications that can damage kidney function is also recommended. One type of drug which can affect the kidneys is nonsteroidal anti-inflammatory drugs (NSAIDs). These include the over-the-counter medications Advil, ibuprofen and motrin as well as several prescription drugs in this same class. It is good practice to inform the transplant team (by leaving an easy call message) to let us know of any new medications you are prescribed before filling prescriptions.

Kidney dysfunction can also lead to elevated uric acid levels and this may result in gout. Symptoms include an episode of joint pain – often in toes, ankles or knees, with redness and inflammation in the affected joint. If this occurs seek medical attention. Treatment most often does not differ from the nontransplant population but it is advisable to inform your transplant coordinator through easy call if this is a problem for you. In rare cases, kidneys fail completely and dialysis and/or a kidney transplant is required.

Bile Duct complications

As mentioned previously, it is possible to develop narrowing in your bile ducts especially where your duct is connected to the bile duct of the new liver. The size of the ducts is very small and when healing occurs this may narrow the opening of the duct as it drains to the bowel. This can cause a reduced flow of bile from the liver into the bowel and may result in inflammation in the liver. We detect this problem by blood tests and scans. Medications to help bile flow more easily are usually prescribed. If the narrowing is very significant, it may be necessary to try to widen the opening of the duct. This may be done in some patients by placing a small stent in the bile duct. This is done through a special scope procedure called “ERCP”. It is similar to the gastroscopy done pre-transplant but the scope is passed further into the small bowel where the connection of the bile ducts is made. This procedure may need to be repeated every few months for as

long as a year until the duct is widened. Other patients may need to have a tube inserted through their abdomen into the duct to try to widen it above the duct connection. This is called a “PTC” tube. Less commonly, surgery to correct the narrowing may be necessary. If you develop a bile duct complication you will see your transplant surgeon and they will recommend a specific plan for treatment.

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.

Hernias can be quite uncomfortable. They can even become hard and bulge outward and cause pain. If this occurs; lie on your back and gently apply pressure with your hand to reduce the hernia. If it does not reduce and if you experience nausea and vomiting as well as ongoing pain, please go to your local emergency department.

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.

Infection

The antirejection or immunosuppression medications you are prescribed suppress your immune system making you a little more prone to acquiring infections and less able to fight them. You therefore need to be aware of signs of infection:

- Fever/chills
- Pain or burning on urination (a need to void frequently and /or urgently may indicate an infection or bacteria in the urine)
- Worsening cough with green or yellow sputum, new shortness of breath or pain with a deep breath may be due to an infection in the respiratory system like pneumonia, an infection in the lungs.
- Redness, swelling, or discharge from any open wounds.

- If you are in contact with chickenpox and have not had it before you should let us know.
- If you have had chicken pox in the past the virus can reactivate and present as 'shingles'. Symptoms would include pain or burning along the skin, developing into first redness, then a blistering rash.
- You should seek medical attention if you have these symptoms so that medication can be prescribed. Please keep us informed through easy call of infections and treatment. If you need advise leave an easy call message or contact telehealth.

Cytomegalovirus/CMV infection:

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 look out 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

(refer to previous 'monitoring for infection')

- 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. It is generally recommended to have repeat BMD 6months to 1 year after transplant. This can be arranged and monitored through your family doctor. If there is concern with your bone density your family doctor can elect to refer you to a local specialist.

Cancer

Liver 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. Patients transplanted for PSC are at increased risk for colon cancer and should have colonoscopy screening. This should be discussed with your physician and may vary according to findings and other risk factors. Refer to page 18 'avoiding skin cancer'.

Disease Recurrence

Some liver diseases that were present prior to transplant, and caused the need for transplant in the first place, may recur in your new liver, others will not. The following is a brief summary of some disease recurrence risks and the impact on the health of your new liver, as well as measures to prevent or treat it should this occur.

Hepatitis B Virus (HBV)

There are several medications that are well tolerated and effective in suppressing the virus preventing replication. These medications do not differ from those used pre transplant and need to be continued long term. Monthly intramuscular injections of antibodies to further suppress HBV are given once a month for the first year after transplant. This is usually arranged in the transplant day unit. For out of town patients, it may be possible to arrange it closer to home. Modern antiviral drugs are virtually always successful in protecting the graft from recurrent hepatitis B.

Hepatitis C Virus (HCV)

The Hepatitis C virus is present in all parts of the body and as a result it has the potential to affect the new liver after transplant. The virus may be present and have little effect on the liver. Often, at some point after transplant, it will cause inflammation and scarring called fibrosis. The effect of the virus is checked through blood tests and by regular biopsies which are done every 6 months for the first 2 years after transplant and then at least yearly. When the virus is causing significant damage, then we will recommend treatment with antiviral drugs to try to eliminate the virus. The most common time to need this treatment is 2 to 5 years after transplant. Less commonly it might be necessary within a few months of transplant surgery or many years after the transplant. Your biopsy results and any concerns we have about the effects of the virus on your liver will be reviewed with you on a regular basis. Approximately 2/3 of patients develop disease progression serious enough to require antiviral medications; successful treatment dramatically improves patient survival.

Non-Alcoholic Fatty Liver Disease (NASH)

The same factors which caused this type of liver disease can affect the new liver. These may include elevated lipids and blood sugars. After transplant, we recommend that you try to stay at a healthy weight, exercise and watch your diet as these are factors within your control. We will monitor your blood sugars and cholesterol values with your family doctor and ensure they are treated if necessary. The majority of patients transplanted for NASH will continue to struggle with weight and the other risk factors for fatty liver, and although recurrence does develop, it does not appear to have any shorter term impact on transplant outcomes.

Autoimmune Hepatitis (AIH)

This disease can flare and cause inflammation in the transplant liver. This is because it is a result of an imbalance in the immune system and this is not cured by having a liver transplant. A possible flare of this disease is recognized by blood tests and diagnosed by a liver biopsy. It is treated by adjusting medications and can usually be controlled. A flare can occur at any time after the transplant. Recurrent AIH develops in <20% of patients, but almost always responds to medical therapy and rarely necessitates consideration of retransplantation.

Primary Sclerosing Cholangitis (PSC)

This disease is also an autoimmune disease and it can also recur after transplant. It does not recur in everyone and there is no usual time that it recurs. Recurrence is recognized by abnormal blood tests and confirmed by MRIs and biopsies. These show strictures in the bile ducts. Medication to help bile flow may be given and it may take many years for it to cause serious damage to the liver. Recurrent PSC is diagnosed in up to 25 % of recipients and does, in perhaps 1/3 of those, result in progressive graft dysfunction and the need for retransplantation.

Primary Biliary Cirrhosis (PBC)

Also an autoimmune disease, this disease recurs less commonly after transplant. It also does not recur in everyone and there is no usual time that this can happen. Recurrence is recognized by abnormal blood tests and confirmed by biopsy. Medication to help bile flow may be given and it may take many years for it to cause serious damage to the liver. Recurrent PBC is described in up to 20 % of our recipients, but only occasionally (perhaps ¼ of those) progresses to graft failure prompting assessment for retransplantation.

Hepatocellular Carcinoma (HCC)

Patients who have this type of liver cancer before their transplant may develop tumour recurrence after transplant. Although the main tumour is removed at the time of transplant, cancer cells may have travelled outside the liver before the transplant takes place. These cells can grow and develop into a new tumour after surgery. All patients with HCC pre-transplant are monitored after transplant on a regular basis for new tumours by scans and blood tests. The most common sites for new tumours are the lungs and bones as well as in the new liver itself. If a new tumour is discovered, then we work with other specialists such as surgeons and oncologists to try to treat the tumour. The type of treatment will depend on the location and size of the tumour and could include surgery, radiation, chemotherapy and medication changes. Tumour recurrence is a serious complication post-transplant. Our overall recurrence rate for HCC over the past decade is approximately 15%; long term survival in patients who develop recurrent HCC is only about 30-40%, however.

Information on Commonly Asked Questions

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 2-3 weeks after surgery
- Removed by the nurse usually in 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 steristrips 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
- Normally able to drive 6-8 weeks after surgery
- If your driving license was suspended pre-transplant this needs to be reactivated when you are fit to drive post transplant and is dependant on the issue which resulted in the suspension. This process takes 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 NOT lift more than 10 pounds for the first 3 months after your surgery
- Lifting larger amounts may result in stress to your incision and can affect 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
- You can swim in lakes etc provided the water is clean

Hot Tubs and Saunas

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

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
- Be extra careful to wash hands in hospital or nursing homes where there may be people with infections

- 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 colds etc but 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 – at least 3 business days
- Check your bottles to see if there are repeats on the prescription before calling us for renewals
- After the first few months we will renew the immunosuppressive medications and antivirals but ask that you get the remainder of your medications through your family doctor or the specialist who prescribes them - for example insulin from your endocrinologist

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 3 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 6 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
- Once you have recovered from surgery and are fit to return to work, if there are still issues keeping you from work, then you need to have your family doctor complete the forms
- Some patients qualify for the income tax disability credit in the year they have their transplant but not usually in the years after that.

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 for the new liver 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 dependant 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 aspirin (ASA) for pain – this can make your blood difficult to clot and can irritate your stomach (Note: some patients are prescribed low dose aspirin for their hearts and this is acceptable)
- You must not take anti-inflammatory medications (“NSAIDs”) such Advil, Motrin, ibuprofen – these meds are not good for

your kidneys and can cause stomach irritation. If you uncertain if a medication you are considering is in this category ask the pharmacist. Some drugs in this class are given by prescription and should be avoided as well

- If you have pain sufficient to need regular pain medication you should discuss the cause with your family doctor

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 which protect your liver
- These medications vary in the amount of active ingredients they contain and this adds more uncertainty to their effect on your body
- Gravol for nausea is safe – use according to package instructions
- 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 us before you use them

Medications to avoid

- Avoid ASA and anti-inflammatory drugs as previously discussed
- 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 – remember to wash your hands after handling them
- It is safest not to kiss your pets
- If someone else is available to clean the litter box is better to avoid this 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 bacteria 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 etc) 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
- After the first year, it may be possible to consider oral birth control methods or intrauterine devices (IUDs) but this must be discussed with your transplant doctors first

Pregnancy/Planned Parenthood

- It is possible to father a child or become pregnant after a liver transplant
- In female patients we strongly recommend that all pregnancies be planned pregnancies
- For female patients, if we know you are considering having a child we think it is helpful to have a consultation with the high

risk pregnancy clinic to assess your specific situation and risks before you become pregnant.

- 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,- 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 book your own appointment and this is not covered by OHIP (the approximate cost is \$40.00). If you have access to a computer you can search for a clinic in your area (google search “travel clinic in _____”) or check the yellow pages
- 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. We need 2 weeks warning to prepare and mail this to you

- 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

Alcohol

- The policy of the program is that you should not drink alcohol after your transplant
- This recommendation applies to all liver transplant patients especially in those whose liver disease was related to alcohol and in those who have Hepatitis C
- Alcohol is detoxified in the liver thus creating additional work for your new organ
- Alcohol may interact with other medications and affect the way they work
- Additional calories without nutritional benefit are another negative impact of alcohol
- Low alcohol beverages still contain alcohol

Smoking

- We strongly recommend that if you smoke, that you must stop
- Lung cancer in those who smoke is a risk for everyone but in transplant patients on immunosuppression this risk is increased. The complication of lung cancer usually results in death
- Other 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 a significant risk in secondhand smoke
- These cautions re smoking also apply to marijuana

Gardening

- The soil may contain many fungus and bacteria that can cause infection
- If you working with soil, then you should wear gloves and wash your hands when you are finished
- If you are working with yard waste and there is airborne dust, then you should wear a mask and goggles

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 – this may be because of disease recurrence of some diseases or if there was a circulation problem with the first graft
- In rare cases, the first graft does not function and the patient is re-listed urgently
- Patients who develop recurrent Hepatitis C are not considered for re-transplant because the success rate and thus the benefit is poor
- 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

We want to know what you think

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

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

Appendix 1 - Returning the Pager

PAGER

***** IMPORTANT REMINDER *****

Now that you have been transplanted, it is your responsibility to make sure that your pager is returned to **Bell Mobility in a bubble envelope via registered mail to:**

200 Bouchard Blvd.

Dorval, Quebec

H9S 5X5

Please remember to do this as soon as possible as further charges will no longer be covered by our program.

Thank you for your cooperation.

Multi Organ Transplant Unit
Ambulatory Transplant Program
Toronto General Hospital
University Health Network

Appendix 2 - Saying Thank You

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 3 - Letter for Dentists

May 2011

Dear Dentists and Oral Surgeons,

This letter is to alert you to the recommendations of The Liver Transplant Program, Toronto General Hospital, regarding the dental management of our liver transplant patients.

Most liver transplant patients have normal liver function and coagulation once they are six months following their liver transplant. We will attach the most current biochemistry and coagulation results.

As you know, viral Hepatitis B and C are indications for liver transplantation. There are most certainly other hepatitis viruses that have not been “discovered” that are the cause of the end-stage liver disease in our patients. We therefore advise that you take hepatitis precautions in patients who have a history of hepatitis B or C. You should consider that this virus persists in these patients after their liver transplant.

We do not recognize that our patients have an increased risk of infectious complications following routine dental procedures over that of the normal population. While our patients are on long-term immunosuppression the doses that are used in our patients have not predisposed them to bacterial complications related to dental procedures.

We do not recommend the routine use of prophylactic antibiotics for liver transplant patients. We would however, leave at your discretion, the appropriate decision as to whether prophylactic antibiotics are required on an individual basis. Certainly the standard indications for prophylaxis should be follows as per the CDA guidelines.

In patients who require antibiotic prophylaxis, we recommend the use of Ampicillin, Amoxicillin, Gentamicin, Clindamycin or Vancomycin. It is important to avoid the use of Erythromycin or other macrolide antibiotics, as they interfere with the metabolism of Cyclosporine or Tacrolimus which may result in increased levels and increased toxicity.

Many of our patients have considerable gingival hyperplasia second to the Cyclosporine. In patients for whom this is problematic a resection of this hypertrophic tissue may be appropriate.

If you have any questions or concerns regarding our mutual patient please contact the primary liver transplant coordinator for your patient.

Note: Fax # (416) 340-4340

Leave messages for specific nurse @ 416-340-4113

Sincerely,

Brenda McQuarrie, RN (EC) BScN

Irene Worms, RN, BScN

Jill Quance, RN (EC), BScN

Marie-Claire Ghattas, RN, BScN

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"> All NSAIDs – worsening of (subclinical) Cyclosporin/Tacrolimus-induced renal dysfunction and G.I. irritation Macrolide antibiotics (e.g. Erythromycin) inhibition of drug metabolizing enzymes in the liver with significant increases in the cyclosporine/tacrolimus levels. Azithromycin seems to be an exception and has minimal impact on the levels and thus is acceptable
Vaccines	<ul style="list-style-type: none"> NOT to receive vaccines with live virus or bacteria thus no herpes zoster vaccine, MMR etc Annual flu shot is recommended preferably after the first 3 months post-transplant to improve benefit Pneumovax recommended q 5 years for all patients rather than single dose in lifetime
Antibiotics	<ul style="list-style-type: none"> No contraindications except macrolides (see above) and rifampin. Rifampin induces the drug metabolizing enzymes in the liver and therefore causes a marked decrease in Cyclosporin/Tacrolimus levels. If it is used close monitoring of the Cyclosporin/Tacrolimus levels and respective dose adjustment is necessary
Cholesterol Rx	<ul style="list-style-type: none"> Lipid lowering meds well tolerated Agent we have most experience with is atorvastatin – start at lowest possible dose due to potentiation effect with immunosuppressives, -increase dose gradually if necessary LFTs monitored q 2 weeks x 3 Limited experience with rosuvastatin (Crestor), but has been used, again starting with the lowest possible dose
HTN	<ul style="list-style-type: none"> Follow usual guidelines with some caution related to diuretics, ACE inhibitors and ARBs due to commonly encountered baseline renal dysfunction and risk for hyperkalemia
Gout	<ul style="list-style-type: none"> Colchicine in small doses the usual choice since no NSAIDs allowed: Brief course of prednisone acceptable unless patient has Hep. C. If recurrent acute attack: Allopurinol acceptable provided patient not on azathioprine (Imuran).
Seizures	<ul style="list-style-type: none"> Many antiepileptics such as phenytoin and carbamazepine induce the drug metabolizing enzymes in the liver and therefore cause a marked decrease in Cyclosporin/Tacrolimus levels. If these drugs have to be used, close monitoring of the levels is advised and respective dose adjustment if necessary
Erectile Dysfunction	<ul style="list-style-type: none"> No specific transplant concerns, use usual risk assessment

Appendix 5 - Vaccine Reference

Vaccines in Adult Solid Organ Transplant Recipients

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

* In new patients we recommend that the flu shot be delayed until 3 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

Appendix 6 - Medication Profiles

CYCLOSPORINE (Neoral[®])

GENERIC NAME	BRAND NAME	REASON FOR USE
Cyclosporine Strengths: 10, 25, 50 and 100 mg capsules 100 mg/ mL oral solution	NEORAL [®]	Cyclosporine 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

1. INCREASED BLOOD PRESSURE

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

2. HARMFUL EFFECTS ON THE KIDNEY

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

3. TREMBLING OF THE HANDS

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

4. SWELLING OF THE GUMS

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

5. GASTROINTESTINAL UPSET

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

6. DIABETES (Increased blood sugar)

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

7. INCREASED HAIR GROWTH

Report this to the transplant team if it becomes bothersome.

8. INCREASED SUSCEPTIBILITY TO INFECTION

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

9. INCREASED RISK OF DEVELOPING CANCER

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

CYCLOSPORINE (Neoral®)

DOSAGE ADJUSTMENTS

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

STORAGE

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

INTERACTIONS WITH OTHER MEDICATIONS

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

REMEMBER

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

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

CYCLOSPORINE PRODUCT INFORMATION

CAPSULES: Neoral®	ORAL SOLUTION: Neoral®
<ul style="list-style-type: none">• Usually supplied as 25mg and 100mg capsules (10 and 50mg also available)• Dose may be any combination of these strengths – check strengths carefully• Take with fluids e.g. water, juice, milk• Avoid grapefruit as this can increase your blood levels of cyclosporine• Capsules have an unpleasant skunk-like odour• Remove capsules from the foil package only when ready to take	<ul style="list-style-type: none">• Supplied in a bottle with syringe• Place syringe in bottle, draw up correct amount as indicated on scale: 100mg = 1 mL, 275mg = 2.75 mL, etc.• Mix dose with ½ glass of milk or juice (use same type of fluid every time)• Use only a glass, ceramic or china container (no styrofoam, plastic or paper cups) and only a metal spoon to mix (no plastic spoon or straws)• Once opened use within 2 months

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

1. INCREASED BLOOD PRESSURE

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

2. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

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

3. HARMFUL EFFECTS ON THE KIDNEY

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

4. GASTROINTESTINAL UPSET

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

5. DIABETES (Increased blood sugar)

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

6. INCREASED SUSCEPTIBILITY TO INFECTION

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

7. INCREASED RISK OF DEVELOPING CANCER

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

PROGRAF® (tacrolimus immediate release)

DOSAGE ADJUSTMENTS

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

STORAGE

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

INTERACTIONS WITH OTHER MEDICATIONS

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

REMEMBER

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

TAKING YOUR MEDICATION

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

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.

SIROLIMUS (Rapamune®)

TAKING YOUR MEDICATION

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

STORAGE

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

INTERACTIONS WITH OTHER MEDICATIONS

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

REMEMBER

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

INSTRUCTIONS FOR SIROLIMUS ORAL SOLUTION

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

PREDNISONE

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.

PREDNISONE

TAKING YOUR MEDICATION

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

Examples: 20 mg = 4 of the 5 mg tablets

15 mg = 3 of the 5 mg tablets

12.5 mg = 2½ of the 5 mg tablets

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

Examples: 75 mg = 1½ of the 50 mg tablets

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

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

REMEMBER

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

**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.

CELLCEPT® (mycophenolate mofetil)

TAKING YOUR MEDICATION

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

INTERACTIONS WITH OTHER MEDICATIONS

Cellcept® may interact with other medications including:

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

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

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

REMEMBER

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

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.

MYFORTIC[®] (enteric coated mycophenolate sodium)

TAKING YOUR MEDICATION

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

INTERACTIONS WITH OTHER MEDICATIONS

Myfortic[®] may interact with other medications including:

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

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

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

REMEMBER

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

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.

AZATHIOPRINE

TAKING YOUR MEDICATION

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

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

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

INTERACTIONS WITH OTHER MEDICATIONS

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

REMEMBER

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

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 style="text-align: center;">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	REASON FOR USE
Dapsone Strength: 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 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

1. DECREASED BLOOD CELL COUNT

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

2. GASTROINTESTINAL UPSET

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

3. EFFECTS ON THE CENTRAL NERVOUS SYSTEM

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

HOW TO USE THIS DRUG

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

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

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		
<ul style="list-style-type: none"> • 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		
<ul style="list-style-type: none"> • 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		
<ul style="list-style-type: none"> • Swallow tablets whole with a glass of fluid such as water or juice. • Tablets must not be chewed or crushed. 		

**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.

SIDE EFFECTS

- Side effects may include headache, dizziness, constipation, nausea and abdominal pain.
- 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 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.
- If it is to be taken twice daily, take it in the morning and at night.
- Doses may be taken without regard to meals.

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***.

**BASILIXIMAB
(Simulect®)**

GENERIC NAME	BRAND NAME	REASON FOR USE
Basiliximab Strength: 20mg/5mL injection	SIMULECT®	This is an anti-rejection medication. It is given intravenously in two doses following a transplant to prevent rejection of your transplanted organ.

SIDE EFFECTS

- This medication is very well tolerated and has minimal side effects
- Allergic reactions are very rare but if they occur the drug will be stopped and antihistamines and steroids may be given.

**GANCICLOVIR
(Cytovene®)**

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

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 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.