

# Solid Organ Transplant Program

## Patient Discharge Information

Please complete this form as soon as you receive this booklet so that we may better help you prepare for hospital discharge. Keep the completed form in this book as a worksheet for you and your transplant team. You may be scheduled for discharge any time during the day or evening. Please make your driver aware of this.

Patient Name \_\_\_\_\_

1. Where do you plan on staying after discharge?

\_\_\_\_\_

2. Who will drive you home from the hospital?

\_\_\_\_\_

3. Phone number (home and cell) of that person \_\_\_\_\_

4. How much notice will your driver need?

\_\_\_\_\_

5. You will be getting your discharge prescriptions at Strong Memorial Hospital outpatient pharmacy if your insurance allows it. Who will pick them up for you?

\_\_\_\_\_

6. Do you know what your prescription coverage is and your co-pay for medications?

\_\_\_\_\_

7. Who will fill your medicine box? If someone other than you is helping to fill the medication box, it is recommended that they attend the discharge teaching class and they participate filling the medication box with the nurse before discharge.

\_\_\_\_\_

8. Do you have any other areas of concern regarding your discharge?

\_\_\_\_\_

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## **Your Transplant Team at Strong Memorial Hospital**

<u>Interim Director, Solid Organ Transplant Division</u> <u>Transplant Surgeons</u>	Dr. Mark Orloff Dr. Mark Orloff, Dr. Randeep Kashyap
<u>Nurse Manager on 8-3600 (SICU)</u>	Joan Romano
<u>Nurse Practitioners on 8-3600 (SICU)</u>	Cheryl Hokula, Jennifer Mercandetti, Kathy Singer
<u>Nurse Manager on 6-1600</u>	Joan Cahill
<u>Nurse Practitioners on 6-1600</u>	Jen Boehly, Christine Shade
<u>Physicians' Assistant (PA)</u>	Sarah Marquette
<u>Transplant Discharge Care Coordinator</u>	Kate Norway (Interim)
<u>Transplant Pharmacist</u>	Jennifer Cooley, PharmD
<u>Clinical Nurse Specialist</u>	Linda Plano
<u>Transplant Offices Nurse Manager</u>	Pat Milot
<u>Post-Transplant Coordinators</u>	Pam Batzold, Leah Bryan
<u>Post-Transplant Secretary</u>	Lisa Walravens
<u>Transplant Inpatient Social Worker</u>	Kristin Hoogland
<u>Transplant Outpatient Social Worker</u>	Megan McKee
<u>Transplant Psychiatrist</u>	Dr. Mark Nickels
<u>Transplant Nutritionist</u>	Gwen Kendall
<u>Transplant Financial Coordinator</u>	Meredith Gray

## Introduction

This booklet has been prepared to provide you with information you need to know after receiving your transplant. Information regarding the types of medications you are taking, diet, activity levels, lab work, and follow-up care are discussed.

Two charts are provided for you on pages 29 and 30. This is your record of the medications you take each day. The chart will help you remember when to take your medication and the dosage. Before you are discharged from the hospital, your nurse will review your medication uses and doses, complete your medication schedule, and will show you how to record each medication correctly. It is recommended that you always use a pencil as changes will occur frequently. This information is very important to you and you will be required to pass a written test before you are discharged from the hospital.

We invite you to share the information in this booklet with your family. Your nurses and transplant coordinators are available to answer questions about every aspect of this booklet.

*You must have a primary care physician (PCP) to help manage your day-to-day problems.* If you do not have a PCP you will need to find one as soon as possible. Upon discharge from the hospital, please make an appointment with your primary care physician to acquaint them with your current medical condition and transplant plan.

Office number to call with any problems/questions: 585-275-5875

Transplant Office Hours:  
Monday through Friday, 8:00 am-4:30 pm

**For life-threatening emergencies call 911 first. CALLS AFTER OFFICE HOURS ARE FOR URGENT CONCERNS ONLY. The answering service will take your information and forward it to the Transplant Coordinator on-call. Your call will be returned promptly. PLEASE CALL DURING OFFICE HOURS FOR ALL NON-URGENT ISSUES.**

## Lab Work

Your transplant team will order your laboratory work. The frequency of these tests will depend on your individual progress. The Lab and Outpatient Services (Room # 1-1350) is located on the first floor past the Main Lobby on the left at Strong Memorial Hospital. You will have your labs drawn at SMH before each clinic visit until you are advised otherwise. Your transplant coordinator will help you make these arrangements.

Before you are discharged from the hospital, be sure you are given your lab slip. You need to bring this with you each time you come to the lab for blood work. You do not need to fast before your lab work is done. **DO NOT take your medications until after your blood work is drawn.**

The ideal time to have your labs drawn on the day of your clinic visit is **before 8 am.** This will ensure that your results are available to the transplant physician before you go home from your clinic visit.

**Strong Memorial Hospital Outpatient Lab hours:**

Monday – Friday      6:30 am – 6:00 pm  
 Saturday              9:00 am – 1:00 pm  
 Sunday                 Closed

**Laboratory Values:**

<b>Test</b>	<b>Result</b>	<b>Normal Range</b>
Total Bilirubin	↑ Bile duct obstruction ↑ May be a sign of rejection or infection	0.3-1.5
Alk. Phos.	↑ Bile duct obstruction ↓ Malnutrition ↑ Bone disease	45-129
AST	↑ Liver injury, rejection	0-34
ALT	↑ Liver injury, rejection	10-44
GGT	↑ Liver injury, rejection ↑ Bile duct obstruction	0-38

(These references are specifically at Strong Memorial Hospital-other labs may vary slightly).

**On lab work days, if you routinely take Insulin, please follow this routine:**

**Get up > Check your blood sugar > Take your Insulin > Eat your usual breakfast > Bring the rest of your medications with you to the outpatient lab > Have your blood work drawn > Then take the rest of your medications.**

**Transplant Clinic Location and Routine**

Please park in the ramp garage. We do not provide parking passes. If you require assistance, you may contact the Transplant Social Worker. Upon entering the hospital you will find the Silver Elevators on your left. The Transplant Clinic is located on the second floor (AC-2) of the Ambulatory Surgical Center.

Appointments for Transplant Clinic are scheduled for Mondays, Tuesdays, and Thursdays. Please plan to spend the morning in clinic. Do not make additional appointments on the day you come into clinic.

Items you will need to bring to your clinic appointments include:

1. This booklet
2. Your pill box
3. All pill bottles for the first clinic visit; you will be informed if you need to bring them to future appointments
4. Your Discharge Instructions (SMH 1089 form)
5. An overnight bag (leave in trunk of car)
6. Your lab requisition

**Your Liver Transplant Support Team**

**As you have progressed through the transplant process, you have become acquainted with many members of the transplant team. After transplantation, it is important that you maintain regular contact with this team. You will be followed by the transplant team at Strong Memorial Hospital for the rest of your life. This team will provide advice and support for you and your loved ones.**

Your transplant team consists of many members. The **Transplant Surgeons** are medical doctors that specialize in liver surgery and transplantation. They will be involved in your care and medical management as you recover from your transplant. The **Hepatologist** is a medical doctor who specializes in diseases of the liver. He will continue to monitor your progress following liver transplantation. **Transplant Nurse Practitioners** have an advanced practice degree and are directly involved in your inpatient care. They write orders, monitor your condition, educate you and update your plan of care on a daily basis. After you are discharged from the hospital, the **Post-Transplant Nurse Coordinators** are your link to other members of the transplant team. They monitor your progress, medication levels and blood work, help you problem solve, and assist you with any concerns or issues that might arise.

The **Transplant Nutritionist** will help you manage your diet after your liver transplant. You may require assistance with special dietary instructions or restrictions. The nutritionist may provide you with educational materials to help you understand your dietary requirements. Your **Transplant Social Worker** specializes in helping patients and their loved ones cope with the stresses and challenges of their lives after transplantation. Your social worker may assist you in providing emotional support, identifying community supports, helping with financial difficulties, and by offering information and referrals for counseling. The **Transplant Financial Coordinator** assists patients with insurance questions and problems. The **Transplant Psychiatrist** provides

assessment, evaluation and a plan of treatment for transplant patients who are depressed, stressed, or anxious.

**Remember, the most important member of the transplant team is YOU!  
The team's best efforts can only succeed with your active participation.  
You are the new lifetime caretaker of your transplanted liver.**

## **The First 3 Months Post Liver Transplant:**

### **Bile Tube Care**

Your gallbladder was removed during your transplant. Its function was to store the bile from the liver and release it into the small intestine as needed. Some patients have a bile tube after liver transplantation. The bile tube is a flexible rubber tube placed in the bile duct (the duct that carries bile from your liver to your intestine) at the time of surgery.

Prior to discharge the bile tube may be capped or left attached to a drainage bag. If it is attached to a drainage bag, empty and measure the fluid every day. Please document the amount (for example 1 bag full or 1 cup full) on the flow sheet in the back of this booklet. Ask your nurse for a clean measuring (specimen) cup before you are discharged from the hospital. Your bile tube will remain in place for approximately 3-4 months from the date of your surgery. It will be removed in the outpatient transplant clinic by your transplant physician.

It is important that you check the bile tube insertion site every day for any signs of infection, such as redness or drainage. Keep the clear dressing over the tube to prevent it from being pulled out. The transplant team or public health nurse will change this dressing if needed. If it becomes loose, reinforce over the existing dressing with tape. You may shower daily with the bile tube in place. **Absolutely DO NOT** take tub baths or go swimming until all tubes are removed in clinic. *If the bile tube becomes dislodged or comes out, notify your transplant coordinator immediately.* You may be instructed to see the transplant team; SAVE the bile tube and bring it with you.

The bile tube may be used for access to inject dye into your bile ducts. This test is called a cholangiogram and is commonly used in the early postoperative period to evaluate the status of your bile ducts. It is a simple procedure and rarely causes any significant discomfort. After your discharge from the hospital this procedure may be done as an outpatient.

## Infection

Since you will be taking drugs to suppress your immune system, you will be more susceptible to infections. You should avoid contact with persons who have obvious infections such as the flu, colds or childhood diseases. Remember that good hand washing techniques help prevent transmission and spread of disease.

The medications that you take to prevent rejection increase the risk of infections. You are on medications to prevent infections, but they may still occur. Signs of infection are important to know. Early detection and treatment may reduce your risk of complications or major illness. Notify your Transplant Coordinator for signs of infections.

Common signs and symptoms of infection include:

- Fever (greater than 100.5 degrees F. or 38 degrees C.)
- Chills, shaking chills
- Swelling, drainage or redness of any area
- Diarrhea lasting more than 24 hours
- Persistent vomiting more than 12 hours

Other signs and symptoms of infection to follow up with your Primary Care Physician include: Persistent cough, sputum production that is green or yellow and foul smelling, sore throat, white patches on your mouth or tongue, flu-like symptoms, earache, burning with urination, and skin blisters or sores that do not heal.

### Fevers:

Keep a thermometer in your home and know how to read it. For the first month, take and record your temperature daily on the flow sheet in the back of this booklet (first thing in the morning).

### Avoiding Infection

Because immunosuppressive medications interfere with your natural immune system, you need to consciously protect yourself from infections after your transplant by taking the following precautions:

- Wash your hands often
- Stay away from people with colds or other infections
- Ask friends to visit only when they are well

- If you have a wound and must change your own dressing, wash your hands before and after the dressing change
- Wash your hands after coughing or sneezing, and throw used tissues into the trash immediately
- If someone in the your family becomes ill with a cold or flu, have that individual follow normal precautions (use separate drinking glasses and eating utensils, covering their mouths when coughing)
- Avoid working in the soil for 6 months after your transplant. Thereafter, wear gloves and wash your hands thoroughly when you are finished. **Please inform your family and friends not to send flowers while you are in the hospital.** The standing water is a potential source for bacterial growth and therefore not permitted for transplant patients. Silk floral arrangements are acceptable.
- Avoid handling animal waste. If your pet has an accident, have someone else clean it up. If you must clean up after your pet, wear gloves and wash your hands thoroughly. Do not clean birdcages, fish or turtle tanks or change cat litter. Avoid contact with stray, exotic or sick animals. Be sure your pet is healthy, has regular check-ups, and has received its required immunizations. If you are bitten by any animal, call your primary care physician immediately.

#### **About vaccinations**

- Now that your immune system is suppressed, you must never receive these vaccines that contain live viruses: Oral Typhoid (live typhoid vaccine), MMR (measles, mumps, rubella), Varivax (chickenpox or varicella vaccine), Yellow Fever, or Zostavax (shingles vaccine). A live virus vaccine may cause serious health issues as you may develop the virus you are being immunized against.
- The yearly "flu" vaccine is an inactivated vaccine used to provide protection from influenza. Transplant recipients and their close contacts are encouraged to get this vaccine every year. You may receive this vaccine if it has been at least 3 months since you had your liver transplant. Pneumovax (a vaccine that protects you from a common type of pneumonia) is recommended every 5 years.
- The general public is advised to get a tetanus booster every 10 years. If you get a dirty injury or cut, or are scratched or bitten by an animal, you should get this vaccine.

#### **SPECIAL WARNING TO PARENTS OF CHILDREN WHO HAVE HAD TRANSPLANTS**

*Ask the school nurse to notify you immediately of any communicable diseases (for example, measles, chicken pox) that may be circulating in your child's school.*

## Rejection

Your body recognizes your transplanted organ as a foreign object and tries to destroy it through a process known as rejection. Patients may experience one or more episodes of rejection during their recovery period. This commonly occurs within the first 3 months following surgery. The chances of rejection diminish with time, but rejection can occur at any time following transplantation. It is important that you be aware of signs or symptoms of rejection. Notify your Transplant Coordinator if these occur.

Common signs and symptoms of rejection include:

- Fever (over 100.5 degrees F)
- Eye whites (sclera) and skin turning yellow (jaundiced)
- Dark-colored urine (tea or coca-cola colored)
- Light-colored stools
- Elevation in liver function tests
- Confusion
- Abdominal pain/tenderness
- Abdominal swelling (ascites)

If you develop any of these signs or symptoms of rejection, call your Transplant Coordinator. Rejection may be mild to severe. In most cases, rejection can be controlled successfully if treated promptly. Rejection is most commonly determined by performing a liver biopsy. A biopsy may be done as an inpatient or an outpatient by your transplant physician.

Medications used for treating rejection may include:

- Intravenous steroids
- Increased oral prednisone
- Adjustments in immunosuppressive drugs

**The onset of rejection does not mean you will lose your transplanted organ, but more intensive treatment is usually necessary. This may require admission to the hospital.**

## Other Considerations

### Weight

Weigh yourself each day for the first three months after your transplant. Then you may weigh yourself weekly at approximately the same time (preferably in the morning before breakfast). Always record your weight on the flow sheet in the back of this booklet.

### Bathing and Wound Care

Shower at least once a day even with your staples and bile tube in place. This helps keep the incision clean. Wash your incision with antibacterial soap and pat dry. **Absolutely no tub baths** or swimming until after all your tubes are removed in clinic.

### **Walking**

Once you are discharged, you are encouraged to return to your normal activities. Moderation is the key. You may take walks or walk up and down stairs. Start to walk for a minimum of 15 minutes 3-4 times each day. Gradually increase your walking time. This prevents blood clots from forming in your legs. It builds your strength and endurance.

### **Exercise**

You should maintain a regular exercise program. Physical exercise is necessary to maintain a normal body weight, minimize the destructive effects of Prednisone on muscles and bones, improve cardiovascular health, increase endurance, and reduce stress. If you are wondering about whether or not you should participate in a specific exercise, please discuss this with your transplant physician or Transplant Coordinator.

### **Swimming**

You may swim in chlorinated pools after the drainage tubes have been removed and all your wounds and incisions have healed. You may swim in the ocean/large lakes if the water has been tested to be safe by the local health department. Avoid public hot tubs.

### **Lifting**

You may not lift anything that weights more than 10 pounds (for example, an average bag of groceries weighs 8 pounds) for twelve weeks after your surgery. Do not move furniture or lift appliances. After this time, you may gradually resume normal lifting if you do not have incisional pain.

### **School and Work**

Following your transplant you should be able to return to your normal lifestyle. Most people are able to return to school or work. You may consider returning to work on a part-time basis and increase your hours as your endurance and energy levels improve. Please discuss your plans with your transplant physician or Transplant Coordinator.

### **Sun Exposure**

The immunosuppressive medications you take to prevent rejection increase your risk for all types of cancer; especially skin cancer. These are usually treatable if recognized early. The best option is prevention. **ALWAYS wear sunscreen** (SPF of at least 30) and protective clothing. Limit exposure to the sun, especially when the sun is the highest in the sky, from 10:00 AM to 2:00 PM. Avoid tanning beds and ultra violet sunlamps even if you were never prone to sunburn. You should report all new skin growths that are raised, bleed or change in size or color to your primary care physician.

## **Driving**

Generally, we recommend no driving for 6 weeks following your transplant. Before you resume driving ask yourself the following questions:

- Are you well enough to drive today?
- Are you experiencing side effects from your medications that would interfere with your manual dexterity such as severe tremors, blurry vision, or lightheadedness?
- Are you experiencing significant incisional discomfort?
- If you were suddenly thrown into the steering wheel, would it cause more pain than if the incision were well-healed?
- Are you still taking narcotics (pain killers)?

Caution and restraint in this early post-operative period will help assure your personal safety and the safety of others. *Seat belt use is mandatory!!* Padding your abdomen with a towel or soft pillow will help cushion your abdomen from the seat belt while providing a safe restraint in case of an accident.

## **Sexual Activity**

Sexual activity is an important part of adult life. As you recover from your surgery, you may discover that your desire for sexual activity is returning. You may resume your normal sexual activity when you feel comfortable.

## **Birth Control**

The choice to have children is an important decision that is influenced by a number of factors that should be discussed with your spouse, transplant physician, local doctor, and obstetrician/gynecologist.

Women generally resume their menstrual cycle after transplantation. High dose prednisone may stop the menstrual flow, but ovulation (the time that you are fertile) will continue. You may become pregnant even though you are not yet having normal periods. The most acceptable methods of birth control are: foam with a condom or a diaphragm with spermicidal gel. IUD's (intrauterine contraceptive devices) are avoided because of the risk of infection. The use of birth control pills should be discussed with the transplant team. If you are thinking of becoming pregnant, please discuss this with the transplant team.

**The possibility of potential birth defects exists for women who are on Rapamune (Rapa). Sexually active women of child-bearing age must be on birth control while taking Rapamune and up to 12 weeks after discontinuing this drug. CellCept may**

cause fetal harm when given to pregnant women. Birth control must be used by sexually active women of child-bearing age while taking CellCept.

## NUTRITION FOLLOWING LIVER TRANSPLANT

Good nutrition is essential for your well-being. A transplant nutritionist who specializes in the dietary needs of the transplant patient will be available to you both in and out of the hospital.

The role of the transplant nutritionist is to:

1. Help you improve your nutritional state based on your needs.
2. Educate you on specific diets and nutrients.
3. Make adjustments in your diet as needed.
4. Serve as a resource for your nutrition questions and issues.

### Nutrition Related Issues After Liver Transplant

- **PROTEIN:** During the first few weeks after surgery, your body requires more protein. Steroids increase your protein needs. Protein will help your body heal and fight infection. Include a variety of the following high protein foods daily in your diet such as beef, lamb, veal, pork, fish, poultry without skin, cheese, milk, yogurt, eggs, peas, beans, and peanut butter.
- **APPETITE:** Even if you experience taste changes or a poor appetite after your transplant, it is important to eat. Your body requires extra calories for strength and recovery during the first few months after surgery. Here are some tips to increase calories. Try 5-6 small meals or snacks throughout the day. Choose high calorie, high protein drinks such as milk, milkshakes or Carnation Instant Breakfast. Ask your nutritionist about other liquid supplements. You may add cream soups, sauces, gravies, butter, margarine and peanut butter to your diet for a few weeks after transplantation.
- **RETAINING FLUIDS:** Swelling of your hands and ankles may be caused by fluid retention. Your weight may increase. If this occurs, limit your table salt and high salt foods such as: garlic salt, celery salt, onion salt, monosodium glutamate (MSG), pastrami, ham, salami, bologna, hot dogs, bacon, sausage, canned soups, salted nuts, snack chips, pretzels, pickles, TV dinners and many processed foods. Report swelling of your hands or ankles to your Transplant Coordinator. Do not use a salt substitute without consulting your Transplant Coordinator. Some salt substitutes are high in potassium.

- **HIGH BLOOD SUGAR:** If you are diabetic or have high blood sugar, you will need to avoid high sugar foods (concentrated sweets). These foods include: candy, table sugar, honey, syrup, jelly, jam, Jell-o, popsicles, cake, pie, cookies, pastries, ice cream, sherbet, soda, sweetened beverages, Gatorade and molasses.
- About half your diet should be carbohydrates. Carbohydrate foods include: breads, pastas, grains, potatoes, corn, peas, beans, cereals, fruits and vegetables. Consult your transplant nutritionist for an individualized plan.
- **ELECTROLYTES:** Your medications may affect the levels of potassium and magnesium in your body. You may need to either increase or decrease your intake of these electrolytes to keep them in a desirable range. Remember, your nutritionist or Transplant Coordinator can help you with this. Foods high in potassium include: bananas, oranges, orange juice, potatoes, sweet potatoes, tomatoes, tomato sauce, cantaloupe, some salt substitutes. Foods high in magnesium include: dark leafy greens, nuts, seeds, peas, beans, tofu and shrimp.
- **BONE DISEASE:** Transplant patients are at greater risk for bone disease. This is due to poor nutrition before surgery, chronic liver disease, or the long-term use of prednisone. You may need to increase your dietary intake of calcium. Consult your Transplant Coordinator before starting any calcium supplement. Good sources of calcium include: yogurt, low fat milk, low fat cheeses, sardines, salmon, dark green leafy vegetables and calcium fortified orange juice.
- **FOOD SAFETY:** Food can carry bacteria, viruses, fungi and parasites. People on immunosuppressants are at a higher risk for infections from foods that are improperly stored or prepared. Here are some suggestions for safe food handling:
  - ✓ **Wash your hands thoroughly before and after handling food.**
  - ✓ **Dairy-** Only use pasteurized milk and milk products
  - ✓ Do not drink unsterilized lake or river water. Several types of parasites live in these waters can cause serious infections in transplanted patients.
  - ✓ **Eggs-** Yolks and whites should be cooked thoroughly
  - ✓ Avoid raw meats, fish, sushi- Many types of parasites can cause serious infections from these raw foods. Cook all shellfish thoroughly prior to eating. Juices from meats should not be pink-tinged or red.
  - ✓ **Fruits and Vegetables-** Wash fruits and vegetables using a scrub brush and chlorinated water. Only drink pasteurized apple cider.
  - ✓ **Avoid cross-contamination-** Thoroughly clean counter tops and dishcloths.
- **NEVER EAT GRAPEFRUIT OR DRINK GRAPEFRUIT JUICE.** These foods should not be eaten if you take Cyclosporine or Tacro (Prograf). There is a

- **SUPPLEMENTAL VITAMINS.** If you eat a well balanced diet, supplemental vitamins are probably not necessary. If you would like to take a vitamin, you may choose an over the counter regular vitamin preparation such as One-A-Day or Centrum. Remember, vitamins are not a substitute for healthy eating.
  
- **DO NOT USE HERBAL REMEDIES OR ALTERNATIVE THERAPIES.** Although there has been some research done on herbal remedies, it is too soon to be sure they are safe for the transplant patient. We do not always know how they interact with other medications or what side effects they may cause. The purity, potency and actual content of these products is largely unknown and not regulated by the FDA. Herbal remedies are potentially dangerous for the transplant patient. Your nutritionist has more information on this for you.
  
- **FUTURE HEALTH AND WELL-BEING:** Here are some dietary suggestions to consider after your first three months following transplant:
  1. 5 vegetables and fruits per day.
  2. Whole grain breads and cereals.
  3. Low fat or non-fat milk and dairy products.
  4. Lean meats, fish, and poultry. Limit fried foods. Bake, broil, and grill. Trim fat and skin from meats before cooking.
  5. Limit egg yolks to 3 per week.
  6. Limit sweets.
  7. Drink 1.5-2 liters of fluids a day. Try to make water most of the content.
  8. Limit high fat and high sugar foods.
  9. Avoid gravies and sauces made with meat drippings, oil, cheese, cream, butter and whole milk.
  10. Limit processed and convenience foods.
  11. Use salt free seasonings such as garlic, onion, peppers, vinegar, and lemon in your cooking.

**CONTACT YOUR TRANSPLANT NUTRITIONIST FOR MORE  
INFORMATION ON THE BEST DIET FOR YOU.**

### **LIFE AFTER TRANSPLANT**

Clinic visits, lab tests and hospital stays will decrease in frequency. It's time to think about what you want to do with your new life.

**Employment:** The transplant physicians anticipate you may be able to return to work 3-4 months after your surgery. Ask a member of the transplant team about any precautions you should take.

**Social Security Disability:** Having a transplant does not automatically make you eligible for Social Security Disability. Social Security may review your case after transplant. Your disability coverage will continue only if you have other disabling medical problems.

**Job Retraining:** If you have not worked for a while, you may want to consider education or job retraining. You may be eligible for services from VESID (Vocational and Educational Services for Individuals with Disabilities) to assist you in returning to the job force. Ask your transplant social worker for more information.

**Changing Family Roles:** Remember the changes that occurred when you first became ill? It was a time of adjustment. Perhaps you were able to do less. Other family members may have taken new responsibilities. Some changes may have been stressful. Now you are entering another phase of adjustment. As you begin to feel better, you will be able to do more and take on more responsibilities. Sometimes family members have difficulty changing their patterns and expectations. The transplant social worker is skilled in helping family members make these adjustments. The social worker can meet with your family and help all of you have a smooth transition into your new life.

**Anxiety and Depression:** Transplant recipients often describe the first year after transplant as a roller coaster ride. You are feeling fine and then blood tests indicate an issue with your new transplant. Suddenly you are back in the hospital. Anxieties about keeping the transplant may occur. Medications may cause mood swings, irritability and changes in your appearance.

With all that happens to you after a transplant, it is normal to experience ups and downs. A serious operation such as the one you had can put a lot of stress on you and your family. It is common for transplant patients to have anxiety and perhaps depression after their surgery, during their stay in the hospital, and/or upon return home. If these feelings are interfering with your life, you can meet with your transplant social worker. You may receive counseling to assist you with the following concerns:

- Feelings of depression or anxiety
- Concern about losing the transplant or dying
- How your illness affects your children
- Marital and family stress related to your illness
- Sexual dysfunction
- Anger about your illness; wanting to be “normal” again
- How to share your experience with others, how to deal with their reaction to you

**Other Health Issues:** Smoking is a risk to everyone's health. Smoking is known to cause cancer. The immunosuppressed transplanted patient that smokes is at additional risk for prolonged lung infections that are hard to treat. Your transplant social worker can assist you in finding local support groups to help you stop smoking. Please refer to the web sites listed under support groups for additional support and information.

Alcohol is metabolized, or broken down, in the liver. Drinking any type of alcoholic beverage can harm your new liver. Many of your medications are metabolized by the liver and the additional stress of breaking down alcohol may destroy liver cells and tissue. If you had a problem with alcohol in the past, you may have already attended a rehabilitation program before you received your liver transplant. It is important that you continue counseling as you recover from transplantation to avoid any injury to your healthy liver through alcohol abuse. Please contact your Transplant Coordinator or your transplant social worker for any assistance with this concern. Illegal drugs such as marijuana, cocaine, LSD, and Ecstasy are filled with toxic chemicals that are harmful to your liver. These drugs interfere with the metabolism of your transplant medications. If you had problems with illegal drugs in the past or are concerned you may want to use them again, please discuss this issue with your Transplant Coordinator or Transplant Social Worker so that they can assist you through counseling and support groups.

**Vacations and Travel:** Permission to travel is determined on an individual basis. You may need to have your lab work drawn before vacation to assure all levels are within normal ranges. If you are traveling to a different time zone, you may wish to discuss how to adjust your medications with your transplant coordinator. *Know where the nearest hospital and/or transplant center is located in case of emergency.* Plan ahead for your medication supply so that you do not run out. If flying, pack your medication in a carry-on bag. Travel to third world countries is generally discouraged for immunosuppressed patients since the risk of acquiring infections in these areas is high and health care may not be available. If you plan to travel in this type of area or need vaccines, please discuss your plans with your transplant physician and Transplant Coordinator.

## Follow Up Medical Care

**Ophthalmologist** Routine eye examination will be very important because Prednisone may cause a change in your eyesight or blurry vision. You should alert your eye doctor to all of your medications, especially your Prednisone. These visual changes may be related to the dosage of Prednisone prescribed. Refer to your ophthalmologist for guidance when deciding the appropriate time to change your corrective eyewear. Cataracts and glaucoma are eye problems that may develop as a result of your steroid doses. Since routine screening for these problems may not be part of your routine eye examinations, you may have to specifically request that these examinations be performed.

**Gynecologist** Routine visits to your gynecologist are suggested particularly for those patients who are of child-bearing age. Your menstrual cycle should resume within several weeks to several months after your transplanted organ is functioning. Birth control will be necessary. See the recommendations in the previous section on birth control regarding acceptable methods. IUD's (intrauterine device), birth control pills and/or the rhythm method each have risks and are **NOT** routinely advised for transplant patients. The frequency of routine PAP smears and exams should be outlined by your gynecologist but usually are performed at least once per year.

**Dentist** Routine dental care should be maintained. It is recommended that you wait 3 months after transplant before initiating routine dental care. If you have your teeth cleaned or filled or require dental surgery, such as a tooth extraction or a root canal, you will need to pre-medicate with antibiotics to prevent infection. The usual prescription for antibiotic is Amoxicillin 2 gm, 1 hour before the procedure. If you have a Penicillin allergy, another antibiotic will be substituted. Inform your dentist that you are a transplant patient and are on immunosuppression medication, particularly of your Cyclosporine (Neoral) regimen. Cyclosporine (Neoral) may cause an overgrowth of your gums. This will decrease when your dosage is reduced. This overgrowth is a side effect of the

medication and can generally be alleviated without surgical (periodontal) intervention. However, if your gums become swollen and painful, your dentist may suggest oral hygiene measures that may relieve this temporary discomfort. Many home remedies such as gargling with warm salt water or using Chloroseptic spray may be effective.

**Endocrinologist** If you have diabetes or are having trouble controlling your blood sugar we may have you evaluated by an Endocrinologist.

**Medic Alert Tag** Mistakes can be made during emergency medical treatment unless those who are giving you care know about your transplant. You are dependent on medications and must continue to receive them at all times. If you cannot speak for yourself because of unconsciousness, shock, delirium, hysteria or loss of speech, the Medic Alert emblem speaks for you. The Medic Alert emblem is recognized all over the world. On the back of the emblem is engraved the medical condition and the file number of the wearer, as well as the telephone number of the Medic Alert's Central File. Doctors, police, or anyone giving aid can immediately get vital information such as the phone number of your personal physician. Since you have received an organ transplant and you are dependent on daily drugs (Cyclosporine, Tacro or Prednisone), it is recommended that you obtain a Medic Alert Tag. In addition to noting your transplant, any special medical problems should be listed, for example: diabetes or allergies. Your nurse can give you a pamphlet for this tag. Your Medic Alert Tag should read: **LIVER TRANSPLANT ON CYCLOSPORINE (Neoral) OR TACRO (Prograf) plus ANY SPECIAL MEDICAL PROBLEMS.**  
**On-line address: [www.medicalert.org](http://www.medicalert.org).**

### **About your Donor Family**

Although the decision to write your donor family is very personal, many transplant recipients want to know about the person who donated the organ they received. If you wish to write to your donor family, please visit the website below. It includes guidelines as to how the process works, what information to include and not include in a letter, and questions surrounding confidentiality.

<http://www.transplantliving.org/afterthetransplant/contactdonorfamily.aspx>

## Paying for Prescriptions after a Liver Transplant

Medications can be the most expensive part of your care after your transplant. Consult with your social worker about the following options:

1. Prescription plans may be offered through your employer's insurance. Your insurance company can give you specific information about your coverage. Most prescription plans include immunosuppressants as maintenance drugs.
2. There are Medicare changes which took effect 1/1/2006 that created the need for new types of policies to complement traditional Medicare. The changes created a new Medicare Part D that may pay for part of your outpatient medication costs. There are several versions of these plans and they all have some limitations. One good resource for finding a new plan to go along with Medicare is the [Medicare.gov](http://www.Medicare.gov) website. These plans all have some restrictions in terms of the medications they cover. Immunosuppressants often require prior authorization. Your Transplant Coordinator will help you obtain authorization for your medications.
3. New York State Medicaid is available to people who meet income criteria, however, this is adjusted annually. For example, the maximum income allowed in 2008 is \$700/month for a single person and \$900/month for a couple. Contact your local county Medicaid office for specific figures for the current year.
4. Some pharmaceutical companies have programs to assist patients who are unable to pay for medications. See your social worker for details.
5. EPIC (Elderly Pharmaceutical Insurance Coverage) is a prescription plan available to NYS residents age 65 or older whose income falls within specific guidelines. Information is available through your Transplant Social Worker.

We will make arrangements with you to have your first month's supply of medications available to you through the Strong Memorial Hospital Outpatient Pharmacy prior to discharge. Bring your insurance cards to the hospital so that the pharmacy can bill you correctly. Your discharge prescriptions are not included in your hospital charges. **You**

**will be responsible for costs not covered by insurance at the time you pick up the medications.**

If your insurance company does not cover prescriptions at the Strong Memorial Hospital Outpatient Pharmacy, prior arrangements must be made by you and your family to ensure that the medications are obtained and brought to the hospital prior to your discharge.

Consider the following questions when selecting a pharmacy:

- Does my insurance plan limit my choices?
- Must I use one designated pharmacy for 90 day maintenance medications? (New Medicare part D plans often use *Preferred Pharmacies*)
- Does my insurance cover a prescription mail order option?

### **Strong Memorial Hospital Outpatient Pharmacy Hours:**

Monday – Friday      8:30 AM – 7:00 PM

Saturday              9:00 AM – 3:00 PM

Sunday                 9:00 AM – 1:00 PM

Outpatient Pharmacy Phone Number: 585-275-4931

Medications can initially run as high as \$4500 per month without health insurance. You **MUST** think about how you are going to pay for this. If you need help figuring out what plan is best for your needs, you may contact the Transplant Social Worker at 585-275-9826 or the Transplant Financial Coordinator at 585-275-6018 for assistance.

## **Commonly Prescribed Medications Following Liver Transplantation**

### **IMMUNOSUPPRESSION**

Now that you have had your surgery, recovery and improving function of your newly transplanted liver depend on the careful balance of your medications.

Your body protects itself by rejecting anything foreign, such as a new organ, through its immune system. After a transplant, the immune system must be held at a low level or must be suppressed to prevent rejection of the new organ. Taking medications known as immunosuppressants will accomplish this.

Immunosuppressants are medications that you **MUST** take daily for the rest of your life. They are powerful medications with many side effects, but they must be taken **EXACTLY** as prescribed to maintain a delicate balance. Taking too little medication will allow your immune system to destroy the organ. Taking too much medication will alter your ability to fight off infection and will increase the likelihood of side effects.

*Never stop taking your medications or change the dosage of your medication without the advice of your transplant physician!*

If you missed a dose, immediately take the dose and then take your next dose on schedule. You may take a dose up to 6 hours after it has been missed. **DO NOT** take both doses at the same time! Please call your Transplant Coordinator if you are unsure what to do.

Some of these immunosuppressive drugs include: Prednisone, Tacro (Prograf), Cyclosporine (Neoral) and CellCept. The next several pages will briefly describe these medications, how they should be taken, and some of their side effects.

## **PREDNISONE**

Prednisone is a steroid hormone similar to a natural hormone which your body normally produces. It is given with other drugs to help prevent rejection. Your prescription will be written in 5 mg tablets to easily make changes to the dosage.

Common side effects include:

- **Stomach irritation:** This may occasionally lead to bleeding ulcers. Always take Prednisone in the morning. Never take Prednisone on an empty stomach. You will also be taking medication to decrease the amount of acid in your stomach.
- **Swelling:** Hands, face, and ankles may swell if you retain fluid.
- **Weight gain:** You may experience an increase in your appetite. Weigh yourself each day to monitor for weight gain caused by overeating.
- **High blood sugar (diabetes):** This may occur with high doses of Prednisone therapy. This is called “steroid induced” diabetes. If you are already a diabetic, you may require additional insulin to maintain a normal blood sugar.
- **Skin Changes:** Slower healing, fragile skin, acne, rash, bruising, and stretch marks may occur. Prednisone may also cause loss of muscle tissue making you feel weak. Regular exercise is encouraged.
- **Mood Changes:** Emotions may swing from feeling up to feeling irritated or depressed. These mood changes usually improve as your dose is lowered. Difficulty sleeping may occur with high doses.
- **Osteoporosis:** Long term Prednisone may cause weakening of bones. Consult your transplant coordinator before taking any calcium supplements.

## **Tacro (Prograf or Tacrolimus)**

Tacro (Prograf) is a potent immunosuppressive drug that helps prevent your body from rejecting your new organ.

Common side effects include: tremors (shaky hands), increase in creatinine levels in the blood (decreased kidney function), headache, nausea, vomiting, burning or tingling of the hands or feet and around the mouth or face, difficulty sleeping (insomnia) or strange dreams, increase in potassium levels in the blood, increase in blood glucose levels (blood sugar) which may lead to diabetes, rash, high blood pressure, or low magnesium levels in the blood.

### **Taking your Tacro (Prograf):**

- Tacro (Prograf) is given in two divided doses; 12 hours apart ( 8 AM and 8 PM)
- On lab days, **DO NOT** take Tacro (Prograf) until after your blood work is drawn. Bring all your medicines with you and take them after your blood has been drawn.
- *Do not take Tacro (Prograf) with grapefruit juice or grapefruit.* It may dangerously increase your Tacro (Prograf) level.
- *Other drug interactions: Tacro (Prograf) can alter breakdown (metabolism) of other medications. Please contact your Transplant Coordinator if you are to be started on any over the counter or prescription medications.*
- Prolonged diarrhea, in some circumstances, may cause your Tacro (Prograf) blood level to fall to a level low enough to put you at risk for rejection. If you have persistent diarrhea lasting more than 24 hours, please contact your transplant coordinator.

### **CYCLOSPORINE (Neoral)**

Cyclosporine is a potent immunosuppressive drug that helps to prevent your body from rejecting your new liver.

Common side effects include: sweating or hot flashes, numbness or tingling in the hands or feet and around the mouth or face, shaking or trembling of hands and feet, hair growth most commonly noticed on the face, arms and legs, overgrowth or puffiness of gums, increase in creatinine levels in the blood (decreased kidney function), increased liver function tests, high blood pressure, increase in blood glucose (blood sugar) levels that may lead to diabetes, and an increase in potassium levels.

Prolonged diarrhea, in some circumstances, may cause your Cyclosporine (Neoral) blood level to fall to a level low enough to put you at risk for rejection. If you have persistent diarrhea lasting more than 24 hours, please contact your transplant coordinator.

### **Taking your Cyclosporine (Neoral):**

- Cyclosporine is given in two divided doses; 12 hours apart (8AM and 8 PM)

- On lab days, **DO NOT** take your Cyclosporine until after your blood is drawn. Bring all your medications with you and take them after your blood has been drawn.
- Cyclosporine capsules are individually packaged. Never open more than 2 days worth of Cyclosporine to avoid deterioration of the medication.
- Store at room temperature. Avoid extreme temperatures and direct sun light.
- *Do not take your Cyclosporine with grapefruit juice or grapefruit.*

*If you are taking Cyclosporine and Rapamune, you must take Rapamune 4 hours after your Cyclosporine (take Cyclosporine at 8 AM and Rapamune at NOON).*

### **RAPAMUNE (Rapa or Sirolimus)**

Rapamune (Rapa) is another immunosuppressant medication used to prevent rejection. It is used in combination with other anti-rejection medications.

Common side effects include: delayed wound healing, high cholesterol/high triglycerides, rash, acne, anemia, low platelets, joint pain, diarrhea or a lowered potassium level.

- On lab days, **DO NOT** take Rapamune until after your blood work is drawn. Bring all your medications with you and take them after your blood has been drawn.
- Rapamune is taken at NOON each day.

*If you are taking Rapamune with Cyclosporine, you must take Rapamune 4 hours after your Cyclosporine (take Cyclosporine at 8 AM and Rapamune at NOON).*

### **CELLCEPT (Mycophenolate)**

CellCept is a potent immunosuppressive medication used in combination with other drugs. It should be taken twice a day at 8 AM and 8 PM. CellCept is stored at room temperature.

Common side effects include: nausea, diarrhea, vomiting, abdominal pain, decreased white blood cells (WBC).

### **VALCYTE (Valgancyclovir)**

Valcyte is used to prevent viral infections. It is taken daily for 3-6 months after transplant to prevent CMV in patients who are at risk for the virus.

Common side effects include: nausea, vomiting, headaches, confusion, and possibly seizures.

## OTHER MEDICATIONS

In addition to your immunosuppressant medications you may be prescribed some of the following:

1. Bactrim (Co-trimoxazole, Sulfamethoxazole/Trimethoprim, Septra): One single strength tablet Monday, Wednesday, and Friday. This helps prevent bacterial infections in your lungs.
1. Magnesium Oxide: Replaces magnesium in your blood.
2. Pepcid (Famotadine), Zantac (Ranitidine), Nexium (Esomeprazole), Prilosec (Omeprazole), Prevacid (Lansoprazol), or Protonix (Pantoprazol): One of these medications may be prescribed to prevent ulcer formation by lessening the production of acid in your stomach.
3. Mycostatin (Nystatin) “swish & swallow”: 1 tsp four times a day. Do not eat or drink anything for 20 minutes after taking this medicine. This helps prevent fungal infections in the mouth and throat.
4. Diflucan (Fluconazole): Prevents fungal infections.
5. Colace (Docusate Sodium) 100 mg: 2 times a day as needed to prevent constipation.
6. Lasix (Furosemide): diuretic that treats fluid retention (water pill).
7. Cipro (Ciprofloxacin): antibiotic used to treat bacterial infections in the body.
8. Actigall (Urosdiol): gastrointestinal agent that thins bile drainage causing it to flow more easily.

**Ibuprofen**            Do not take any medication that contains ibuprofen or naprosyn unless you have permission from the transplant team. These medicines may cause kidney damage and stomach ulcers.

**Aspirin**            Unless specifically ordered by the transplant team, **AVOID** taking Aspirin as it may cause stomach irritation compounding the irritating effects of Prednisone.

**Dilaudid**            Dilaudid is used for pain control in the immediate post-operative period after your transplant. For chronic pain issues contact your Primary Care Physician for a referral for chronic pain management.

**OTC Medication**    Tylenol, Afrin nasal spray, plain Robitussin, Benadryl and Pseudofed may be taken per package directions. DO NOT take Tylenol or

Acetaminophen with other prescription pain medications as they often have Tylenol/Acetaminophen as an ingredient.

## ABOUT YOUR PRESCRIPTIONS

Your prescriptions may be filled at the Strong Memorial Hospital Outpatient Pharmacy before you are discharged. *If you must have your prescriptions filled somewhere else because of your insurance, tell your nurse and your Transplant Social Worker will be notified.*

If you need to order your medications at a pharmacy closer to your home after you are discharged from the hospital, please contact your Transplant Coordinator. Allow 1-2 weeks for the transition period from one pharmacy to another. Many pharmacies do not routinely stock transplant medications. It can take 2 or more days to receive them.

**DO NOT WAIT UNTIL YOUR MEDICATIONS ARE DOWN TO YOUR LAST PILL.**

*It is VERY important to plan ahead and know that you have enough medications for weekends and holidays. Omitted or missed medicine may result in the rejection of your new organ.*

**Never follow the instructions printed on your pill bottles!!!!** Follow only the written medication instructions in the back of this booklet and the instructions given to you after clinic or any subsequent hospitalizations. Your dosages may change frequently.

### **In conclusion...**

The purpose of this booklet was to provide you with general information about your care after transplantation.

We, the transplant team, hope to have answered many of your questions. If you have questions during your hospitalization or prior to discharge, please do not hesitate to ask to speak with a member of our team. Your nurse can contact us by pager within the hospital.

## CONGRATULATIONS, and

**Good Luck! We will see you at clinic!**

Updated and revised 5/2006

By Linda Plano, RN, MSN, CCRN, CNS with Patricia Milot, RN, BSN Nurse Manager

Reviewed 5/23/06 jb/lb/pm/lp/jr

Revised 12/06 lp/pm; 8/7/06 lp/pb

## **Transplant Educational Resources, Support Groups, and Organizations**

SMH is not responsible for any information located as a result of visiting these websites. These sites are provided as a network resource. Information from the internet in regard to your transplant should always be discussed with your transplant team.

**American Association for the Study of Liver Diseases**

<http://www.hepar-sfgh.ucsf.edu>

**American Diabetes Association**

<http://www.diabetes.org/>

**American Organ Transplant Association (AOTA)**

<http://www.a-o-t-a.org/>

**American Liver Foundation**

<http://www.liverfoundation.org/>

**Children's Liver Alliance**

<http://www.liverkids.tk>

**Children's Liver Association for Support Services**

<http://www.classkids.org>

**Children's Organ Transplant Association (COTA)**

<http://www.cota.org>

**Coalition on Donation**

<http://www.shareyourlife.org>

**Elderly Pharmaceutical Insurance Coverage (EPIC)**

[http://www.health.state.ny.us/health\\_care/epic/](http://www.health.state.ny.us/health_care/epic/)

**International Transplant Nurses Society (ITNS)**

**National Council on Patient Information and Education**

<http://www.talkabouttrx.org>

**National Foundation for Transplant**

<http://www.transplants.org>

**National Transplant Assistance Fund**

<http://www.transplantfund.org>

**Rochester AA**

<http://www.rochester-ny-aa.org/>

**Sangstat**

<http://www.Sangstat.com>

**Surviving Transplantation**

<http://www.stjosephs.london.on.ca/sjhc/about/programs/mental/survive/>

**Transplant Awareness Organization (TAO)**

<http://www.donorrecovery.org>

**Transplant Health**

<http://www.transplanthealth.org>

**Transplant Patient Partnering Program**

<http://www.rocheusa.com>

**Transplant Speakers International**

<http://www.transplant-speakers.org>

**Transweb**

<http://www.transweb.org>

<http://www.unos.org>

**United Network for Organ Sharing (UNOS)**

<http://www.unos.org>

**Medicare**

<http://www.medicare.gov>

**Vocational and Educational Services for Individuals with Disabilities (VESID)**

<http://www.vesid.nysed.gov/>

**Minority Organ Tissue Transplant Education Program**

<http://www.mottep.org>

**You Can Stop Smoking**

<http://www.surgeongeneral.gov/tobacco/conquit.htm>

## **Transplant Support Groups in Upstate NY**

### **Rochester, NY area**

Transplant Awareness Organization -- TAO-Rochester

Contact Dave Johnson at 585-889-1346 or Email: [membership@tao-rochester.org](mailto:membership@tao-rochester.org)

Website: <http://www.TAO-Rochester.org> No meetings July or August.

Meets the third Wednesday of the month at 7 PM; Al Sigl Center, Winton Rd Annex, 3399 Winton Road S.

### **Syracuse, NY area**

Central New York Transplant Awareness Group - T.A.G.

PO Box 2126, Syracuse, NY 13220 - 315-422-6781 or Email: [Mei5123@aol.com](mailto:Mei5123@aol.com)

Website: <http://www.tagcny.org> No meetings September or December

Meets the first Tuesday of the month at 7 PM in the Log Cabin Building on the NYS Fairgrounds

### **Buffalo, NY area**

Transplant Support Group of WNY, Inc.

5605 Genesee Street, Lancaster, NY 14086 - 716-685-4799

Website: <http://www.tsgwny.org> or Email: [mmar1@juno.com](mailto:mmar1@juno.com)

Meets the third Tuesday of the month at 7 PM at the Cleveland Heights Christian Church, 4775 Union Road, Cheektowaga

### **Elmira/Horseheads, NY area**

Elmira Area Organ Transplant Support Group

Contact Bonnie Patten at 607-732-2119 or Email: [bpatten2@stny.rr.com](mailto:bpatten2@stny.rr.com)

Meets the third Thursday of the month at 7 PM at Our Savior's Lutheran Church, 2872 Westinghouse Road, Horseheads

### **Chenango County, NY area**

Chenango County Organ and Donor Awareness Support Group

Contact Charles McMullen at 607-843-7215 or Email: [Crmmcmull@ascent.net](mailto:Crmmcmull@ascent.net)

Meets the third Wednesday of the month at 6 PM in the basement of the Chenango County Hospital in Norwich

### **Utica/Rome, NY area**

The Mohawk Valley Network - Organ Donor Awareness and Transplant Support Group

Contact John Weakley at 315-866-1995 or Email: [jweakley@twcny.rr.com](mailto:jweakley@twcny.rr.com)

Meets at various locations in the Utica/Rome/Mohawk Valley area. Contact John

### **Binghamton, NY area**

The Organ Transplant Support Group

Contact Liz DeVivo at 607-786-0097 or Email: [ldevivo@stny.rr.com](mailto:ldevivo@stny.rr.com)

Meets the third Wednesday of the month at 7 PM in the East/West Dining Room at Lourdes Hospital, Box 722, Westview Station, Binghamton

**St. Lawrence County area**

St. Lawrence Organ Donor Awareness Council

Contact Gayle Hammers at 315-379-9431 or Email: [Ghammers@gisco.net](mailto:Ghammers@gisco.net)

Meets the first Sunday of the month at 3 PM in the EJ Noble Building, 80 East Main St, Canton

**Watertown, NY area**

Contact Dawn Dame at 315-646-3440 or Email: [Fdame@northnet.org](mailto:Fdame@northnet.org)



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University of Rochester Medical Center  
Strong Memorial Hospital

Liver Transplant Test on Transplant Teaching Booklet

For the following questions, circle the best answer:

1. The purpose of immunosuppressive medications is to:
  - a. Control blood pressure
  - b. Prevent infection
  - c. Prevent rejection
  
2. The following are immunosuppressive medications that you will need to take for the rest of your transplant:
  - a. Cyclosporine
  - b. Tacro (Prograf)
  - c. Cotrimoxazole (Bactrim)
  - d. Rantidine (Zantac)
  - e. Prednisone
  - f. Cellcept
  
3. In order to obtain an accurate Tacro (Prograf) or Cyclosporine level you should take your medication:
  - a. **Before** your blood work
  - b. **After** your blood work
  
4. If you miss a dose of Tacro (Prograf) or Cyclosporine you will:
  - a. Take the dose **immediately** (as long as your next scheduled dose is at least 6 hours away)
  - b. Double up on your next dose
  
5. If you stop taking your immunosuppressive medications:
  - a. Your body will reject your liver
  - b. As long as you feel fine, you will be all right
  
6. If your temperature is 100.5 degrees, you:
  - a. Wait and take it again in 2 hours
  - b. Call your Transplant Coordinator immediately
  
7. If you have any signs of infection, you:

- a. Wait a few days to see if the infection improves
- b. Call your Transplant Coordinator immediately

8. Circle the symptoms you might have if you had an incisional infection:

- a. Pus-like drainage from the incision
- b. Tenderness over the incision
- c. Redness on the incision line
- d. Increased appetite
- e. Fever
- f. Swelling at the incision site

9. You should resume dental visits 3 months after your transplant, but before you go to the dentist for cleaning, you should:

- a. Call your Transplant Coordinator/dentist for a prescription for antibiotics
- b. Know that antibiotics are only necessary for fillings, root canals, and crowns.

10. If you visit your local physician for a health related problem, you always make sure:

- a. Your physician checks with the Transplant Office if he needs to prescribe any medication
- b. To follow his advice; there is no need to consult with the Transplant Office

11. Signs and symptoms of rejection include:

- a. Fever
- b. Dark colored urine (tea or coca cola colored)
- c. Eye whites (sclera) are yellow or skin is yellow (jaundiced)
- d. Confusion
- e. Light colored stools
- f. All of the above

12. Changes in physical appearance such as rounded cheeks and weight gain can mostly be attributed to which drug(s)?

- a. Cyclosporine
- b. Prednisone
- c. Tacro (Prograf)

13. Side effects of Prednisone may include:

- a. Weight loss
- b. Mood changes (feeling up and down)
- c. Vision changes
- d. Increased blood sugar
- e. Fluid retention

14. Match each medication with its action:

- |                       |                                |
|-----------------------|--------------------------------|
| a. Diflucan           | Bacterial infection prevention |
| b. Valcyte            | Ulcer prevention               |
| c. Bactrim            | Viral infection prevention     |
| d. Protonix or Zantac | Fungal infection prevention    |

15. Your daily responsibilities include: (Circle as many as are applicable to you)

- Weighing yourself
- Taking your temperature
- Blood sugar monitoring if blood sugars are elevated
- Daily blood pressures if your pressures have been elevated
- Measuring drain contents for amount, color, and consistency
- Taking your medications

16. If your bile tube becomes loose or falls out, you

- Tell your transplant physician at your next clinic visit
- Call your Transplant Coordinator immediately

17. You may take a tub bath when:

- You feel like it
- When all the tubes are out and everything is healed

The following questions are True or False. Place a T (true) or F (false) in the blank before each question.

18. \_\_\_\_ A Transplant Coordinator is available 24 hours a day for urgent calls at 585-275-5875.

19. \_\_\_\_ Side effects of Tacro (Prograf) may include high blood sugars, tremors of the hands, headaches, and insomnia.

20. \_\_\_\_ You are at little risk for developing skin cancer and do not need sunscreen.

21. \_\_\_\_ You may not take over the counter drugs and herbs without talking to your Transplant Coordinator.

22. \_\_\_\_ Grapefruits and grapefruit juice will increase your Tacro (Prograf) or Cyclosporine levels and are to be avoided.

23. \_\_\_\_ Bring your Teaching Booklet, pill box, and hospital discharge instructions with you to clinic.

24. \_\_\_\_ Rejection episodes are often seen in the first 3 months after liver transplantation.

25. \_\_\_\_ After discharge from the hospital you will be seen in clinic in AC-2.

**BONUS:** \_\_\_\_\_ You may take Motrin, Aspirin and Milk Thistle as you need to because they are good for you.

Liver Transplant Test Revised and Updated 5/5/2006  
Linda Plano, RN, MSN, CCRN, CNS  
5/17/2006 lp/pm reviewed with db/lb/pb/jr/lr

## **Flow Sheet**

