After Your Liver Transplant: What You Should Know
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CHAPTER 1

Introduction

Congratulations on receiving your liver transplant. Taking care of yourself and your transplant requires a lifetime commitment from you. This booklet is designed to help you with that commitment.

The transplant team includes nurses, doctors, a dietitian, a pharmacist, financial coordinators and a social worker. You are also expected to be an active part of the transplant team. As part of the transplant team, you will need to:

• talk to your transplant team regularly
• take your medications as prescribed
• keep to your schedule of clinic visits and lab tests
• check your weight, temperature and blood pressure as ordered
• maintain a healthy lifestyle (for example: a healthy diet, no drinking alcohol and no smoking)

We expect that you will have many questions after your transplant. Your transplant nurse will be your main contact with the transplant team. Our registered nurses specialize in transplantation. They will be able to answer most of your questions. When necessary, your transplant nurse will talk with other team members to get your questions answered.
Beaumont Transplant: Your Physicians

Surgeons
Alan Koffron, M.D.
Steven Cohn, M.D.
Vandad Raofi, M.D.
Daman Bedi, M.D.

Hepatologists
Mary Ann Huang, M.D.
M. Rasm AlSibae, M.D.

Nephrologist
Dilip Samarapungavan, M.D.

Beaumont Transplant Clinic Telephone List – Liver Transplant

Medical Office Building
3535 West 13 Mile Road
Suite 644, Royal Oak, MI 48073
Office: Monday through Friday,
8 a.m. to 4:30 p.m.
248-551-1010

Support Staff
Sandra LaDuke
Ann Stemas
Erica Threadgill
248-551-1010, or toll-free
800-253-5592
Refill line: 248-551-3434

Post-Transplant Nurse Coordinators
Patrice Garland, RN, BS, CCTC
Kelly Hendrix, RN, BSN, CNN
Beverlee Schoenherr, RN, BSN, CCTC
M. Irene Uly, RN, BSN, CNN
Danielle Lodato, RN, BSN
248-551-1010

Pre-Transplant Liver Nurse Coordinators
Stephanie Serra, RN, BSN
Lisa Zagata, RN, BSN
248-551-1033

Liver Transplant Social Worker
Sophia Awan, LMSW
248-551-1201

Transplant Pharmacist
Maxine Ng, Pharm. D.
248-898-2661

Transplant Financial Coordinators
Angelia Harris 248-551-0771
Terri Trepanier 248-551-0077

Transplant Dietitian
Jill Jensen, RD 248-898-6978

Transplant Unit
5 Central East nursing station
248-898-5790

Problems and concerns
After 4:30 p.m. Monday-Friday, weekends and holidays, please call 248-898-5000. Ask the operator to page your transplant doctor.
CHAPTER 2

Medications

You will be on many different medications after your transplant. These include anti-rejection medications (or immunosuppressants), antibiotics, antivirals and antifungals. You may also need to take other medications based on your individual case. For example, you may need medication to lower your blood pressure or blood sugar.

It is critical to take these medications as prescribed. Even little changes from what the doctor prescribed can harm you and your liver.

This chapter will list some of the medications you will be taking and their side effects. Talk to your transplant doctor, nurse or pharmacist if you have questions about:

• when and how to take your medications
• what to do if you forget a dose
• where to get your medication
• how to get medications if you don’t have enough money to afford them

It is very important to take all medications exactly as directed. Sudden changes in dosages may lead to serious complications. You must follow the directions for your medications and write down changes that are made by the physician. This is vital to the success of your liver transplant.

It is important to learn about your medications including:

• the name
• the purpose of the medication
• the dose/strength
• when to take each one
• possible side effects

It is also helpful to always carry a list of all your current medications.
Continue to follow these rules after your liver transplant:

1. Keep a record of all the medications you take (including the dose and how frequently you take it).

2. Take all your medications exactly as directed.

3. Report any side effects to your transplant nurse, doctor or pharmacist.

4. Do not take any over-the-counter medications, vitamins or herbal remedies without talking with your doctor first.

5. Some medications interact with immunosuppressants and could harm your transplanted liver. If you are prescribed a medication by a doctor other than your transplant doctor, check with your transplant team to make sure that it is okay to take.

6. Call your pharmacist for refills at least one week before you are due to run out of your medication. Also make sure you will have enough medication with you if you will be away from home.

7. Store your medications in a cool, dry place away from direct sunlight.

8. Notify your transplant team immediately if you are unable to take your medications by mouth because you are sick or have nausea or vomiting.

9. Ask for prescriptions for medication refills at your clinic visits.

10. If you miss a dose of your medication, call your transplant nurse coordinator or physician for advice. Do not double the dose of your medication.

The most important thing to remember is to take the right dose of your medication at the right time.
Immunosuppressants

The following is a list of anti-rejection (immunosuppressant) medications that you may be taking. You will take these medications for as long as your liver transplant is working. These medications help to prevent rejection.

The most common medications that liver transplant patients receive are Prograf (tacrolimus) and Deltasone (prednisone). However, based on your individual case, you may be on a combination of one, two or three different immunosuppressant medications.

<table>
<thead>
<tr>
<th>Brand name</th>
<th>Generic name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deltasone</td>
<td>prednisone</td>
</tr>
<tr>
<td>Prograf</td>
<td>tacrolimus</td>
</tr>
<tr>
<td>CellCept</td>
<td>mycophenolate mofetil</td>
</tr>
<tr>
<td>Myfortic</td>
<td>mycophenolic acid</td>
</tr>
</tbody>
</table>

Do not change the dose or stop taking these medications until you have talked to your transplant doctor or nurse.
Your medication schedule

Before you go home, the nurse will give you a medication chart that will help you keep track of your medications. Always keep this sheet with your records and bring it with you to all of your Transplant Clinic visits.

During the first few months after transplant, there will be frequent medication changes. Please update your medication sheet using a pencil so changes can be made easily.

More information about your medications and possible side effects are on the following pages. You will also meet with a pharmacist for more detailed information about your medications before you are discharged from the hospital.

Remember, while we list many possible side effects of your medications, you may experience only a few of them or you may not have any. If you do notice any side effects, tell your transplant nurse or doctor during your clinic visit. If any side effect becomes worse for you and you believe that you cannot wait for your next appointment to tell the transplant team, please call your transplant nurse.

Do not change the dose or stop taking this medication unless you have talked to your transplant doctor or nurse.
<table>
<thead>
<tr>
<th>Tacrolimus (Prograf)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Purpose</strong></td>
</tr>
<tr>
<td>Tacrolimus helps prevent transplant rejection by reducing the number of blood cells that are part of the rejection process. You will take this medication for the rest of your life. In some cases, because of side effects, patients must take an alternative medication, such as cyclosporine or sirolimus. If this is the case, you will be educated about this new medication.</td>
</tr>
<tr>
<td><strong>Dosing</strong></td>
</tr>
<tr>
<td>The capsules come in the following sizes: 0.5 mg, 1 mg and 5 mg. The medication is taken twice a day, 12 hours apart, in order to keep the medication at an even level in your blood.</td>
</tr>
<tr>
<td><strong>Monitoring</strong></td>
</tr>
<tr>
<td>Your dose of tacrolimus will be based on your weight, the level of medication in your blood, and any side effects that you may have. Therefore, on the day of your scheduled lab draw or clinic visit, <strong>do not take your morning dose of tacrolimus until your labs have been drawn</strong>. Bring your dose of medication to clinic with you to take as soon as your blood has been drawn. Your blood should be drawn about 12 hours from your last evening dose.</td>
</tr>
<tr>
<td><strong>Precautions</strong></td>
</tr>
<tr>
<td>Tacrolimus may interact with some commonly used prescription medications (such as certain antibiotics), over the counter medications and herbal products. Always check with your transplant physician or nurse coordinator before starting a new medication. Do not use any pain medication besides Tylenol unless instructed by your physician. You may take up to 2 grams (2000 mg) of Tylenol in a day. Medications like Motrin, Advil and Naprosyn should be avoided as they may put stress on your kidneys when taken in combination with tacrolimus.</td>
</tr>
</tbody>
</table>
### Tacrolimus (Prograf) (cont.)

#### Precautions (cont)

Some fruits may alter the way that your body absorbs tacrolimus. These include grapefruit and pomegranate in any form (fresh or canned fruit and any juices made with pomegranate or grapefruit). Some examples of juices that include grapefruit are Squirt, Fresca, Sunny Delight, Sundrop and Five Alive.

Any immunosuppressant medication will lower your body's defenses against cancer. Skin cancer is the most common cancer seen. Tacrolimus may increase your risk for developing certain cancers that affect the lymph nodes. See the section of this booklet titled “Cancer Precautions” for more information.

Missing a dose of tacrolimus may allow your body to recognize the new organ and cause a rejection episode. Call your transplant doctor or nurse coordinator for further direction if you miss a dose or if you take too much tacrolimus.

#### Common Side Effects

- lowered resistance to infection
- tingling, numbness or tremor in your hands or feet
- high blood sugar
- high blood pressure
- high cholesterol
- high potassium levels
- changes in kidney function
- headache
- hair thinning or hair loss (usually temporary)
- nausea, vomiting or diarrhea (if you are unable to keep fluids and/or your medication down, go to the Emergency Center at Beaumont for treatment)

Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.
**Prednisone (Deltasone)**

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Prednisone helps prevent rejection by reducing inflammation and antibody production.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dosing</td>
<td>You will be prescribed 5 mg tablets. Right after transplant, you will be taking several prednisone pills together once a day in the morning. You will be given a schedule which decreases the dose to 5 mg over several months. The majority of patients will be off of prednisone completely at the end of three months. However, patients with certain diagnoses may have to take prednisone for the rest of their lives.</td>
</tr>
</tbody>
</table>
| Precautions | Do not stop taking prednisone abruptly. It must be gradually decreased.  
Do not take prednisone on an empty stomach as it may cause stomach irritation and/or ulcers. Report bright red or black stools or vomiting blood.  
At higher doses, prednisone may increase your appetite. To help prevent weight gain, follow the instructions that the dietitian gave you.  
Prednisone is a steroid and can cause water retention (swelling in the legs, feet or abdomen). Follow a low-salt diet, as instructed by the dietitian. Tell your transplant physician or nurse coordinator if you gain 2 pounds overnight or five pounds in a week.  
Prednisone can cause high blood sugar. If you are already diabetic, your insulin dose may have to be adjusted. Monitor your blood sugar four times a day.  
If you are not a known diabetic, watch for signs of high blood sugar:  
• increased thirst  
• increased urine output  
• headache or blurred vision  
• feeling more tired than usual  
Mood swings are common with prednisone. You may feel angry, sad, irritable, anxious or energetic. This effect usually improves as the prednisone dose decreases. |
Prednisone (Deltasone) (cont.)

Common Side Effects
- lowered resistance to infection
- increased blood pressure
- high cholesterol
- acne
- insomnia/sleep disruption
- "moon face" (fatty deposits in the face)
- blurred vision
- cataracts or glaucoma
- brittle bones
- joint pain
- muscle weakness
- increased risk of skin cancer

Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.

Mycophenolate mofetil (CellCept) or Mycophenolic acid (Myfortic)

Purpose
This medication (you will be given one or the other) works by reducing the number of blood cells that are part of the rejection process. Mycophenolic acid is enteric coated.

Dosing
The medication is taken twice a day, 12 hours apart, in order to keep the medication at an even level in your blood.

Cellcept comes in 250 mg capsules and 500 mg tablets
Myfortic comes in 180 mg and 360 mg tablets.
You will likely be on this medication for the rest of your life.

Monitoring
Your blood work will be monitored for side effects such as low white blood cell counts, red cell counts and/or platelet counts (which may increase the potential for infection or bleeding).
**Mycophenolate mofetil (CellCept) or Mycophenolic acid (Myfortic) (cont.)**

<table>
<thead>
<tr>
<th>Precautions</th>
<th>Do not open or crush the capsules/tablets. If your skin comes in contact with contents from a capsule/tablet, wash the area with soap and water immediately. You should not take CellCept and Myfortic at the same time. They are not interchangeable. Mycophenolate mofetil may decrease the effectiveness of birth control pills. Mycophenolate mofetil has the potential to harm a developing fetus. This medication must be stopped (by a physician) before attempting to become pregnant. If you are planning to conceive a child, discuss this with your transplant doctor first.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Common Side Effects</td>
<td>• lowered resistance to infection • nausea, vomiting • diarrhea (if you are unable to keep fluids and/or your medication down, go to the Emergency Center at Beaumont for treatment); notify your transplant physician or nurse coordinator if you are having four or more watery stools in a day • slow wound healing Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</td>
</tr>
</tbody>
</table>
**Other Medications**

Right after your transplant, you will take several more medications. Bactrim SS, Valcyte and Nystatin are used to help protect your body from infection. Prilosec is used to prevent stomach upset and ulcers.

### Sulfamethoxazole/trimethoprim or SMX/TMP (Bactrim single strength)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>SMX/TMP is an antibiotic. It is used to prevent a specific type of upper respiratory infection (pneumocystis carinii).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dosing</td>
<td>Take this medication at night with at least 8 ounces of water. SMX/TMP may cause crystals to form in your urine. Water will help to prevent them from forming. You will take this medication for three to six months after your transplant.</td>
</tr>
<tr>
<td>Monitoring</td>
<td>Your labs will be monitored to look for certain possible serious side effects, such as decreased white blood cell count and platelets or kidney dysfunction.</td>
</tr>
<tr>
<td>Precautions</td>
<td><strong>Do not take this medication if you are allergic to sulfa medications.</strong> SMX/TMP may cause an allergic reaction. Stop the medication and seek help immediately if you experience a severe skin reaction (rash with hives or severe itching) or other signs of an allergic reaction such as difficulty breathing or swelling in your mouth or throat.</td>
</tr>
</tbody>
</table>
| Common Side Effects | • sensitivity to sunlight  
• nausea, vomiting and/or diarrhea  
The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator. |
## Valganciclovir (Valcyte)

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Valganciclovir is an anti-viral medication that is used to prevent CMV (cytomegalovirus).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dosing</td>
<td>This medication is usually taken twice a day. You will take this medication for three to six months after your transplant.</td>
</tr>
<tr>
<td>Monitoring</td>
<td>Your blood work will be monitored as valganciclovir may cause a decrease in your red or white blood cell counts and/or platelets (which may increase the potential for infection or bleeding).</td>
</tr>
<tr>
<td>Precautions</td>
<td>Do not break or crush the tablets. If your skin comes in contact with contents from a tablet, wash the area with soap and water immediately.</td>
</tr>
</tbody>
</table>
| Common Side Effects | • nausea, vomiting or diarrhea  
• headache  
• change in kidney function  
Some of these side effects may go away with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator. |
### Nystatin (Mycostatin)

| Purpose | Nystatin is an anti-fungal medication used to prevent fungal infections in the mouth. This infection, called thrush, may happen because the immunosuppressants decrease the “normal” bacteria in the mouth that keep the fungus from overgrowing. Thrush is identified by a white coating on the tongue and inner cheeks. |
| Dosing | Nystatin comes as a liquid. Swish the prescribed amount around your mouth for 30 seconds and then swallow it. It is taken four times a day (after meals and at bedtime). |
| Notes | Do not eat or drink anything for 30 minutes after taking a dose of nystatin. It works by coating the inside of the mouth and throat. This medication is taken for three months after transplant. |
| Common Side Effects | Side effects are rare with nystatin but may include mild nausea and/or stomach pain. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator. |

### Omeprazole (Prilosec)

| Purpose | Prednisone may cause stomach irritation. Omeprazole helps to prevent stomach and duodenal ulcers by reducing the amount of acid in your stomach. |
| Dosing | Take one pill daily. You will take this medication for three to six months after your transplant. |
| Common Side Effects | Side effects are rare but may include abdominal pain, constipation or diarrhea. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator. |
Chapter 3

Caring for yourself after surgery

Incision care:
Clean your incision by showering daily. You may not take a bath or swim until your incision is completely healed. This is usually about six weeks after your surgery. Call your doctor if you notice redness, swelling or drainage from your incision.

Your staples/sutures will be removed in the transplant clinic about three weeks after your surgery.

Driving:
You may usually begin driving four weeks after your transplant. Seat belts are recommended.

Exercise:
As you move around more, your strength and endurance should improve. Each person’s recovery is different.

For the first month, avoid bending, stretching or lifting more than 10 pounds. Exercise will increase your strength, and it is important because prednisone can lead to muscle weakness, especially in the legs. Walking, bike riding and swimming are excellent choices to improve leg muscle strength.

Other benefits of exercise include:
- weight control  •  increased energy
- reduced stress  •  improved sleep
- better digestion  •  better glucose (blood sugar) control

Exercising with weights, jogging and racquetball should only be started after first talking with your surgeon.

Avoid:
- contact sports  •  horseback riding
- motorcycling  •  snowmobiling
- any sport in which you may receive blows or strains to the liver or abdomen
**Sexual activity:**
After one month, you may resume sexual activities at your own discretion. Noticing changes in your sexual response is common among transplant patients. Changes may be due to the surgical procedure or the disease process which originally caused your liver failure. Changes in your medication may also affect your sexual response. Discuss questions or concerns with your doctor. Women of child bearing age should discuss birth control with their doctor and/or gynecologist. If you are a female who has been prescribed CellCept, it must be stopped before you attempt to conceive a child. Speak with your physician about this if you are planning to start a family in the future.

**Pregnancy:**
We recommend that you wait one year after your transplant before attempting to become pregnant. During your pregnancy you will be monitored closely by your doctor and an obstetrician who specializes in high-risk pregnancy.

**Return to work/school:**
Returning to work and/or school is encouraged. Talk to your doctor about resuming these activities.

**Smoking:**
Smoking is a major risk factor for heart disease and certain types of cancer. Therefore, you should not smoke after receiving your transplant. If you need help quitting, consult your transplant nurse or doctor.

**Alcohol:**
Alcohol is harmful to the liver and may interact with your medications. Caring for your new liver includes avoiding anything that may damage it, *so you should avoid alcohol consumption entirely.*
**Traveling:**

We recommend that you do not travel for the first three months after your transplant while your body heals and adjusts to the new medications.

Before traveling abroad, consult your doctor about vaccinations or preventive medications needed. Beaumont also has the Interhealth Clinic (248-551-0495) which specializes in medical needs for travelers.

**If you travel:**

- Be sure to drink only spring or distilled bottled water without ice when traveling outside the United States.

- Remember to bring extra medications with you, in case your trip is extended for any reason. When traveling by plane, store your medications in your carry-on luggage. **Do not put your medications in bags to be checked onto the plane.** Also, protect your medication from extreme temperatures.

- Consider purchasing supplemental health insurance when traveling outside the United States. If there is a change in your liver function, you may need treatment right away. Think about buying cancellation insurance when ordering airline tickets or making other travel plans.
Diet

Your post-transplant diet should be low in sodium (salt) and saturated fats (low cholesterol). Before discharge, a dietitian will meet with you to discuss your individual diet needs.

Weight gain is common after a liver transplant. This may be due to several factors. First, food may taste better now that you are feeling better. Second, prednisone may increase your appetite. In order to keep your weight in control, it is important to follow the guidelines given to you by your dietitian and to follow an exercise program.

People who have had a liver transplant are at a greater risk of developing injury to their kidneys. This is because of several factors. Before transplant, when your liver was failing, the blood flow to your kidneys was decreased. In addition, Prograf can cause harm to your kidneys over the long term. Dehydration can also contribute to kidney dysfunction. Drinking at least two quarts of fluid per day will help you avoid dehydration. Water is the best fluid for you to drink.

Some signs of dehydration are:

- decreased weight
- increased pulse
- low blood pressure
- decreased urine output
- dizziness when standing
- thirst

Some causes of dehydration are:

- not drinking enough fluids
- vomiting
- diarrhea
- fever
- diuretics (water pills)
- sweating

Your medications may cause changes in your calcium, phosphorus, potassium or magnesium levels. Your doctor will monitor your blood levels and let you know if any changes in your diet are necessary.
CHAPTER 5

Monitoring yourself at home

When you are discharged from the hospital, it is your responsibility to update your transplant record book every day. Bring this record and your medication list to each clinic visit. Forms are in the back of this booklet.

**Things to do each day and record in your transplant record:**

- Take your temperature each morning and evening.
- Weigh yourself each morning before breakfast.
- Take your blood pressure morning and evening.
- If you are diabetic, do finger-stick blood sugar (glucose) levels four times a day. Enter the levels into a log.
- Take your medications as ordered by your doctor.
- Note any changes, problems or questions to discuss with the transplant doctor, nurse or pharmacist at your next clinic visit.

**When to call the Transplant Clinic**

- If you notice edema (swelling of the ankles, legs or hands).
- If you feel tenderness or soreness over the incision.
- If your temperature is 100.5 degrees or greater.
- If you notice a change in your general sense of well being (i.e., increased fatigue or decreased energy level).
- If you are diabetic: If your blood sugar levels are consistently above or below the recommended range made by your doctor.

*Do not hesitate to call the Transplant Clinic during office hours if you have any symptoms of rejection or infection. Prompt treatment is essential. Call the doctor after hours only if you need to receive immediate attention.*
Chapter 6

Rejection episode

A rejection episode is the body’s normal response to a new liver. The body doesn’t recognize it as its own tissue and it tries to destroy the liver. However, a rejection episode doesn’t necessarily mean that you will lose your transplant. You will be given antirejection medications (immunosuppressants) to lower the possibility of rejection.

Acute rejection usually occurs within the first six months after a transplant. It is not unusual to have an episode of acute rejection. Acute rejection usually can be reversed with prompt treatment.

Chronic rejection can occur after many months. It is different from an acute rejection. It is not reversible by treatment, but the process may be slowed down.

Signs and symptoms of a rejection episode:

- fever of 100.5 degrees or higher
- tenderness or swelling in the abdomen
- flu-like symptoms (muscle aches, nausea, vomiting, fatigue)
- increased blood pressure
- jaundice (yellow eyes or skin)
- dark colored urine
- light colored stools
- elevated bilirubin and other liver function tests

You may have some, all or none of these symptoms if you experience rejection. It can be difficult to decide whether a patient is actually having a rejection episode. An ultrasound of your liver transplant may be done to rule out other causes of increased liver blood tests, such as obstruction. In most cases when rejection is suspected, a biopsy of the transplant is done to be sure that the correct treatment is started. See the pamphlet, “Liver Biopsy – Transplant Patients” for more information.
When a rejection episode occurs, it is usually first treated with Solu-Medrol, a form of intravenous prednisone. Treatment is once a day for three days. It is given as an outpatient in the medical short stay unit.

**Treating rejection:**

After finishing the SoluMedrol treatments, you will be required to start on prednisone. The prednisone dose will slowly be reduced over several weeks. Your labs will be monitored more frequently during a rejection episode.

In the rare case that the rejection episode continues, you may be treated with Thymoglobulin, CellCept or Prograf based on your individual circumstance. Treatment with Thymoglobulin requires being in the hospital for several days.
Chapter 7

Recurrence of disease

Diseases such as hepatitis B, hepatitis C, autoimmune hepatitis, hepatocellular carcinoma, primary biliary cirrhosis and primary sclerosing cholangitis may recur in your transplanted liver.

You will be monitored closely for signs of recurrence. There are strategies to help prevent this from happening; for example, medication to help prevent hepatitis B from damaging your new liver.

Evaluation for a second liver transplant may be an option for you if your liver becomes damaged by recurrent disease.
Chapter 8

Avoiding infection

The medications you are taking to help your body maintain liver function and prevent rejection episodes will also lower your resistance to infections.

Some things you can do to protect yourself from infection include:

- For the first month after surgery, avoid crowded areas such as churches, shopping malls, etc. Wear a mask to the transplant clinic for the first four weeks after surgery.
- Avoid contact with people who are obviously sick.
- Use good personal hygiene: Wash your hands frequently and shower daily (you may take tub baths after your incision has healed completely).
- Immediately wash cuts and scratches with soap and water and apply antiseptic ointment (such as Neosporin or Bacitracin).
- Have dental check-ups every six months. Before treatment always inform the dentist about your transplant. Antibiotics will be prescribed before dental work is done (this includes having your teeth cleaned).
- Women should have yearly gynecological examinations.
- Avoid undercooked meats or seafood. Your transplant dietitian will give you more information about how to avoid food borne illness.
- Avoid cleaning litter boxes, bird cages or reptile cages.
- Flu shots are recommended each year.
- Pneumovax shots are recommended every five to seven years.

The following are some signs and symptoms of infection:

- temperature of 101 degrees or higher
- chills
- joint pain
- increased pulse rate (greater than 100 beats per minute)
• swelling
• decreased appetite
• fatigue (lasting for more than one or two days)
• headache
• stiff neck
• swelling or drainage anywhere the skin is broken
• burning sensation when urinating
• sore throat and/or cough
• nausea, vomiting and diarrhea
• cloudy urine
• a rash or other skin change

Should one or more signs or symptoms occur, notify your doctor or nurse immediately.

Treatment:
Many infections can be treated and cured at home with prompt and proper use of antibiotics. Severe infections may require hospitalization.

It is important to know that antibiotics do not work against viral infections, such as colds. If you have cold symptoms, ask your doctor or nurse for a list of over-the-counter symptom relief medications that you may take safely.

Cytomegalovirus (CMV)
Cytomegalovirus infects most of us at some time in our lives. Because it has some of the same symptoms as a flu virus, most people do not even realize that they have been infected. However, in immunosuppressed patients, CMV can be a serious complication. You will be given Valcyte (mentioned in the medication section) to help prevent CMV. You will also be monitored for this at your clinic visits.

Symptoms to watch for:
• fever
• fatigue
• cough
• muscle aches
• stomach pain
• night sweats
• loss of appetite
• generally feeling like you have “the flu”
CHAPTER 9

Cancer precautions

You will be taking immunosuppressants to prevent rejection.

In the long run this suppression of the immune system may increase your chances of developing some forms of cancer.

We try to use the least amount of anti-rejection medication to best suit your individual needs to avoid some of these potential problems. Close monitoring of the dosages of anti-rejection medications is important.

Skin cancer

The most common cancer seen in patients after transplant is skin cancer. Skin cancer is caused by being in the sun for too long or over too many years. More than 90 percent of all skin cancers are on parts of the body exposed to the sun. The face, neck, ears, forearms and hands are the most common locations of skin cancers.

When diagnosed and treated promptly, skin cancer has a high cure rate. If untreated, skin cancers enlarge, but and in rare cases may lead to severe illness or death. Your hepatologist may refer you to a dermatologist to look for early cancers or to treat warts.

Look for these signs of skin cancer:

- Any new, small, shiny or fleshy nodules on exposed skin. They could be an early warning of a basal cell skin cancer.
- A red, scaly, flat patch or a nodule, which could be a sign of squamous cell carcinoma.
- Any sore that bleeds or doesn’t heal rapidly should be brought to your doctor’s attention.

Take precautions to decrease the risk of skin cancers:

- When outside, always apply sunscreen to all exposed body areas one hour before sun exposure. Reapply the sunscreen generously every two hours while in the sun. Sunscreens labeled with an SPF (sun protection factor) of 30 or greater provide the best protection.
• Limit outdoor activities between 10 a.m. and 2 p.m. in the summer months (11 a.m. and 3 p.m. daylight savings time). Play golf, tennis or swim in early morning or late afternoon.

• Wear light protective clothing to add protection to the back, shoulders, arms, chest and legs. Wear a wide brimmed hat to protect the face.

• Stay in the shade as much as possible.

• Avoid overexposure to the harmful rays of the sun on cloudy days. You still may become sunburned when the sky is full of clouds.

• Some drugs and cosmetics may increase the possibility of sunburn. Your doctor or pharmacist can advise you about medications that can cause problems in the sun.

• Avoid tanning booths. Tanning booths add more damage to what is received from natural sunlight. Tanning booth bulbs give off ultraviolet light and can cause sunburn, skin cancer and premature skin aging. A tan can give some protection against sunburn, but skin damage continues even with a tan.

**Other cancers**

People with transplants may develop other types of cancers at a slightly higher rate than the general population. Promptly report any unusual bumps or lumps on your body to make an early diagnosis of a tumor.

All female transplant patients should keep regular appointments (every year) with their gynecologist. They also should perform a monthly self-breast exam to monitor for lumps. Ask your nurse if you are unsure how to perform a self-breast exam.

Your doctor also may recommend other cancer screening tests such as a colonoscopy or prostate exam (for men over 50) or a mammogram (for women over 40). This will be determined by your age and risk factors.
Chapter 10

Immunizations/vaccinations

An important thing to remember is that transplant patients should never receive a “live” vaccine.

Examples of “live” vaccines include:

• Oral polio vaccine
  Avoid contact with anyone who has received the oral polio vaccine for six weeks following the vaccination. It is possible to develop polio if exposed to any body fluids of the vaccinated person. The injectable form of the vaccine is not a “live” vaccine, and is safe for transplant patients.

• MMR (measles, mumps, rubella)
  Transplant patients should not receive this vaccination, but there is no apparent risk if family members receive the vaccine.

• Chickenpox/shingles
  Transplant patients should not receive these vaccines, but there is no apparent risk if family members receive the vaccine. Notify your doctor immediately if you have been exposed to chickenpox or shingles.

Vaccinations safe for transplant patients:

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<tr>
<th>Vaccine</th>
<th>Recommendation</th>
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<tr>
<td>Influenza</td>
<td>Recommended yearly in the fall.</td>
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<tr>
<td>Pneumovax</td>
<td>Usually given every five to seven years at the discretion of your doctor.</td>
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<tr>
<td>Tetanus &amp; diphtheria</td>
<td>Booster shots are recommended every 10 years. If you are injured with a dirty object, a booster is recommended after five years.</td>
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</table>
A new liver can be the start of a new life. Significant improvement in health and quality of life often follow a transplant. However, the traumatic effects of anesthesia, surgery and steroid treatment may result in a variety of responses. They can include anxiety, confusion and irritability (particularly when steroids are at their highest level). These emotional responses vary in how often they occur, how intense they are and how long they last.

A transplant social worker is available and encourages all transplant patients and family members to discuss:

- emotional responses to the transplant
- adapting to changes in your body
- psychological acceptance of a body part from another individual
- coping with the uncertainties of the transplant experience
- developing strategies and resources for re-entry into roles within and outside the family
- vocational rehabilitation
- networking with other transplant patients and families
- anonymous correspondence with the donor family
Organizations: Information and Support

American Liver Foundation
1-800-GO-LIVER
liverfoundation.org/chapters/michigan
liverfoundation.org
Provides patient newsletters, educational materials and assistance in obtaining medications.

Michigan Rehabilitation Services
PO. Box 30010
Lansing, MI 48909
517-373-3390
Can assist with job training and job placement.

Transplant Recipients International Organization (TRIO)
1000 16th St., NW Suite 602
Washington, DC 20036-5705
202-293-0980

Donate Life Coalition of Michigan
3861 Research Park Drive
Ann Arbor, MI 48108
800-482-4881 or 734-973-1577
Sponsors programs to increase donor awareness.

Second Chance at Life, Inc.
32591 Judy Drive
Westland, MI 48185
734-748-9690
Provides financial support to patients before and after transplant. Active in promoting organ donation.
CHAPTER 12

Post transplant financial concerns

Having a transplant is a life long commitment: Expect to take excellent care of your new organ for many years to come. This includes having a plan for your transplant related expenses. From the time you are listed for your transplant you need to have a long term financial plan. That long term plan should include your employment opportunities, insurance coverage and fundraising.

• If physically possible, your goal post transplant is to return to work with a job that provides insurance coverage. Begin planning for this while waiting for your transplant.

• Investigate options for additional coverage such as becoming a dependent on a spouse’s insurance policy. Even if your current coverage is excellent, you can choose to be a part of your spouse’s insurance as a way to maximize your coverage.

• Consider fundraising. Depending on the amount of your coverage, you might need to raise your own funds in order to have money available for follow-up care and medications.

Remember, it is possible that your current status may change. Whether you are no longer disabled, your company changes insurance plans, you change jobs (which in turn changes your insurance plan) or your benefits change as you retire, your coverage for transplant expenses may be altered. Stay knowledgeable about your current coverage and options in order to have the resources available to care for your new organ.

Work your plan. Please refer to “The Financial Handbook for Liver Transplant Patients” for more information. Don’t forget that your Transplant Financial Coordinator is available to assist and counsel you during this life changing experience.
Chapter 13

Clinic visits

Outpatient follow-up care:
You will be closely monitored by your transplant physicians and nurses for the first year after discharge.

At first, you will be scheduled for a physical exam and blood tests every week. The number of times you visit will decrease over three months. During this phase of your post-transplant care, your immunosuppressant (anti-rejection) medications will be adjusted and your liver function closely monitored. You may need to come to the clinic more or less often, depending on the results of your blood tests/condition.

Follow these steps when visiting the Transplant Clinic:
1. Register with the receptionist.
2. The office staff will let you know when and where to have your blood drawn. Routine blood tests include CBC, liver function tests, electrolytes, magnesium, glucose (sugar) and your anti-rejection medication levels.
3. A post-transplant nurse coordinator will assess you. You will be weighed and your vital signs will be checked. You will be asked for a list of your medications (include any vitamins or supplements that you are taking). The nurse clinician will review your records from home (blood pressure, weight, etc) answer many of your questions.
4. The transplant doctor will examine you and tell you about changes that need to be made in your medication or care. The doctor will answer any other questions you may have about your progress.

Remember:
Do not take your morning dose of tacrolimus (Prograf), cyclosporine (Neoral), or sirolimus (Rapamune) on the day of your appointment. Bring your tacrolimus (Prograf), cyclosporine (Neoral), or sirolimus (Rapamune) with you so you can take it after your blood is drawn.
5. After you see the doctor, check out at the front desk and make an appointment for your next visit.

After a year, you will see the transplant hepatologist in the Chronic Disease Management Clinic for continued medical follow-up of your transplant.

See a primary care physician (family doctor) for common problems such as colds or flu or sprains. Your primary care physician will also be responsible for prescribing and refilling any medications that are not related to your transplant.

**Long term follow-up for liver transplant patients includes:**

- Monthly lab work, including CBC, liver function tests, magnesium, BUN, Creatinine and Neoral or Prograf levels.

- Office visits every one to three months depending on the stability of your condition and the length of time since your transplant.
Right after your transplant surgery, you will have blood drawn twice a week. Eventually you will have your labs checked monthly for as long as your transplant is functioning. We will call you if any of your labs are of concern. If you wish to know your lab results, please call after 2 p.m. on the day after you have your labs drawn, or you may get a copy of your lab results at your next clinic visit.

**Some of the labs we monitor are the following:**
(These normal levels are only guidelines.)

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<thead>
<tr>
<th>LAB</th>
<th>NORMAL VALUE</th>
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<tr>
<td>AST (liver inflammation)</td>
<td>10-40</td>
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<tr>
<td>ALT (liver inflammation)</td>
<td>5-40</td>
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<tr>
<td>AP (liver bile duct inflammation)</td>
<td>30-120</td>
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<tr>
<td>Total bilirubin (ability for liver to drain bile)</td>
<td>0.2-1.4</td>
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<tr>
<td>Hematocrit</td>
<td>40.1-50.1</td>
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<td>White blood count</td>
<td>4.4-10.1</td>
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<td>Platelets</td>
<td>140-412</td>
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<tr>
<td>Neoral level</td>
<td>150-300</td>
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<tr>
<td>Prograf level</td>
<td>8-10</td>
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**Factors which may caused increased liver function tests:**
- dehydration
- rejection
- lab variance
- infection
- obstruction

*Your actual Neoral/Prograf levels may vary from our normal levels. Every case is monitored separately.*
Chapter 15

Definitions

Acute rejection
Acute rejection can happen at any time after a transplant. During an acute rejection episode, the liver function tests rise. This usually can be treated by taking higher doses of immunosuppressive (anti-rejection) medications until the lab tests return to a baseline.

Antibody
An antibody is part of the immune system that helps the body fight infections and foreign substances.

Antigen
An antigen is the “marker” that stimulates the body to produce antibodies.

Anti-rejection medication
This medication helps prevent your immune system from struggling against and rejecting the new liver. Also known as immunosuppressive medication.

Ascites
A buildup of fluid in the abdomen, usually associated with liver disease.

Bile
Thick alkaline fluid that is secreted by the liver and stored in the gallbladder.

Bile duct
Any of the ducts (tube) that transport bile from the liver.

Biliary atresia
A condition that results when the bile ducts inside or outside the liver don’t have normal openings. Bile becomes trapped in the liver, causing jaundice and cirrhosis. This condition is present from birth and without surgery may cause death.
**Bilirubin**
A breakdown product of hemoglobin from blood cells, the results of which are used in the MELD calculations as a measure of the severity of liver disease.

**Biopsy**
A diagnostic test in which a small needle is inserted into the liver and tissue is removed for analysis. The tissue can show rejection, disease or toxicity from medications.

**Blood typing**
A blood test that indicates blood group. You can be O, A, B or AB. The recipient’s blood type needs to be compatible with the donor’s blood type to receive the liver transplant.

**Chronic rejection**
Chronic rejection is a process that may happen after a transplant. It can develop over months or even years. During this process, the total bilirubin slowly rises. There is no medication to reverse chronic rejection.

**Chronic kidney disease**
Occurs when the overall function of the kidneys declines to less than 10 percent of normal. When this happens, treatment, such as dialysis or a transplant, is needed to replace lost kidney function and support life.

**Chronic renal failure**
Permanent damage to both kidneys that cannot be reversed, it is treated by dialysis or a transplant.

**Chronic liver disease**
Chronic liver failure is permanent damage to the liver that cannot be corrected. It is treated by a transplant.
Cirrhosis
A chronic liver condition caused by widespread scarring of the liver and damage to cells which replaces normal, healthy liver tissue. Cirrhosis makes it hard for the liver to remove poisons (toxins) like alcohol and drugs from the blood. These toxins build up in the blood and may affect the brain.

Creatinine
Creatinine is a product of muscle metabolism. Creatinine level serves as a good indicator of kidney function.

Cross matching
Cross matching is a test to find out if the blood of the liver donor and the person receiving the liver are compatible.

Deceased donor
A person who has donated their organs after dying from a severe brain injury or cardiac death that will not affect future liver function. The deceased or family has generously offered organs and/or tissues to be transplanted.

Dialysis
A process that cleans and balances the chemicals in the blood when a person’s kidneys have failed. Dialysis may refer to hemodialysis or peritoneal dialysis.

Diastolic
This is the bottom blood pressure number. It shows the force of the heart muscle at rest. This is when the heart expands and fills with blood.

Donor hepatectomy
Removal of a portion of liver for donation from a living person.

Encephalopathy
Serious brain function abnormalities experienced by some patients with advanced liver disease (and other diseases). Symptoms most commonly include confusion, disorientation, insomnia, and may progress to coma.
**End-stage liver disease (ESLD)**
Irreversible liver failure that requires transplantation as hepatic replacement therapy.

**Fatty liver**
A build-up of excess fat in liver cells.

**Fulminant**
A medical event that occurs very quickly with an acute onset, as in fulminant liver failure. Usually occurs over days and not weeks.

**Fulminant hepatic failure (FHF)**
Acute liver failure with no preexisting liver disease.

**Gallbladder**
Pear-shaped sac lying beneath the right lobe of the liver, in which bile is stored.

**Glucose**
Glucose is a type of sugar found in the blood.

**Graft**
Graft is your “new” liver.

**Helper T cell**
This is the specialized white blood cell that gives orders to other members of the immune system in combating infection or foreign invaders.

**Hepatic**
Having to do with, or referring to, the liver

**Hepatitis**
A viral infection or non-specific inflammation of the liver that can lead to liver failure.
**Hepatitis A**
An inflammation of the liver caused by the hepatitis A virus (HAV). Hepatitis A is transmitted when fecal matter from someone who has the disease is ingested, either directly or via food or water contaminated with the fecal matter.

**Hepatitis B**
An inflammation of the liver caused by the hepatitis B virus (HBV). Hepatitis B is transmitted through blood and infected bodily fluids. It is spread through unprotected sex; through sharing razors or toothbrushes with an infected person; through living in a household with an infected person; from an infected mother to her newborn child at birth; via unsterilized needles, including tattoo or piercing needles; through sharing IV drug needles; and through human bites.

**Hepatitis C**
An inflammation of the liver caused by the hepatitis C virus (HCV). HCV is transmitted primarily through direct exposure to infected blood through an opening in the skin or mucous membrane. The hepatitis C virus infects the liver, causing inflammation that results in damage to liver tissue. Hepatitis C is the leading cause of liver failure that leads to transplantation.

**Hepatologist**
A specialist who is an expert in the diagnosis and treatment of liver diseases.

**Hypertension**
Hypertension is another word for high blood pressure.

**Immunosuppressive medication**
This drug helps prevent the recipient’s immune system from struggling against and rejecting the new liver. Also known as anti-rejection medication.

**Intravenous (IV)**
Into or within a vein. It also refers to fluids and medications that are injected into a vein through a needle or catheter.
Jaundice
A symptom of many disorders. Jaundice causes the skin and the whites of the eyes to turn yellow.

Kidney
One of the two bean-shaped organs located beside the spine, just above the waist. They remove waste and balance fluids in the body by producing urine.

Liver
The largest organ in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. It also removes wastes from the blood. A living donor can give part of their liver, after which the liver will regenerate itself in both the donor and recipient.

Liver enzymes
Liver enzymes are substances produced by the liver. When the liver is injured, these enzyme levels can be higher than normal.

Model for end-stage liver disease (MELD)
The scoring system used to measure the illness severity in liver transplant candidates was implemented in February 2002. This system prioritizes the allocation of livers to adult patients waiting for a liver transplant. MELD is a numerical scale used for adult liver transplant candidates. The range is from 6 (less ill) to 40 (gravely ill). The individual score determines how urgently a patient needs a liver transplant within the next three months. The number is calculated using the most recent results of three laboratory tests:

- bilirubin, which measures how effectively the liver excretes bile
- INR, which measures the liver’s ability to make blood clotting factors
- creatinine, which measures kidney function – impaired kidney function is often associated with severe liver disease
**Rejection**
The way your body responds to a “foreign object,” such as a new liver, is rejection. Rejection can be acute or chronic (see definitions: acute rejection and chronic rejection).

**Split liver**
A split liver transplant occurs when the donor liver is divided into segments and then transplanted. These segments may be transplanted into more than one recipient, or a segment could be transplanted into a child for whom an entire adult liver would be too large.

**Systolic**
Systolic is the top blood pressure number. It measures the force of the heart muscle as blood is pumped out of the heart chambers (contractions).

**Tissue typing**
This is a blood test that evaluates if there is a tissue match between organ donor and recipient. It is done before a transplant.

**Transplant**
Transplantation is transferring organs or tissues from a donor to a recipient.
Patient Records
# Patient record

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Things to mention to my transplant team:

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**Patient record**

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Each person is an individual and responses may vary. If you have any questions, please talk to a member of your health care team.