You Need to Reconnect with Your Primary Care Physician

The goal is to help you stay healthy and productive following your liver transplant. To accomplish this, the transplant physicians partner with primary care physicians who provide the comprehensive care necessary to maintain your overall health. Every transplant patient is required to have a primary care physician (PCP).

The Inpatient Stay at the Hospital

Surgery

The length of time you will spend in the operating room varies, but generally is between four and 12 hours. Just prior to or during surgery your physician will place many tubes and equipment to assist in monitoring you. The following list includes the most frequently used.

- Central lines are inserted into the internal jugular vein in the neck or the sub-clavian vein in the upper chest.
- A catheter, inserted into a large blood vessel, is a special monitoring IV used to measure circulatory pressure and fluid volume.
- A catheter is placed in an artery at the wrist, elbow or groin area to constantly monitor blood pressure, and to act as a source for future blood draws.
- A ventilator or respirator is used to help you breathe. The breathing tube is inserted through the mouth into the lungs and is attached to a machine. This allows for optimal anesthesia, relaxation and sedation.
- A nasogastric tube (NGT) is placed through your nasal cavity into the stomach and is used to keep the stomach empty.
- A foley catheter is placed into your bladder to monitor urine output.
- A biliary drainage tube may be placed during the surgery into the common bile duct or the cystic duct. It is used to monitor the bile output and protect the connections made during surgery. The tube stays in place for six weeks to six months, depending upon the type of tube used.
- A JP drain may be placed during the surgery into the abdominal cavity to collect fluids.

The abdominal incision is quite extensive, often extending from one side of the upper abdomen to the other. The outer layer of skin is closed using staples, sutures or surgiglue which remain in place for approximately three weeks to give the incision time to heal. It is not uncommon to have drainage from the incision.
Following Surgery – Surgical Intensive Care Unit (SICU)

Following your liver transplant surgery you will be taken to the Surgical Intensive Care Unit (SICU) on the fifth level of University Hospital (5D SICU). You will not go to Recovery, but will be taken to the SICU instead.

The SICU team is a highly skilled team of registered nurses and physicians (called intensivists) that specialize in the care of complex and critically ill adults. The team is supported by a dedicated pharmacist (called a PharmD), a registered dietician, a physical therapist, a unit host and clerks and patient care techs (similar to nurse’s aide). During your stay in the SICU your transplant physicians will continue to see you and make recommendations but your immediate post-operative care will be managed by the intensivists in the SICU.

You may be in the SICU for several hours before your family will be able to visit you. Patients generally begin to “wake up” in one to two hours after arriving in the SICU and usually awaken with the ventilator in place. Because the ventilator tube goes through the vocal cords, you will not be able to talk. Until the ventilator tube is removed, usually within 24 hours, you will have to communicate by writing or non-verbal communications. Sometimes restraints are needed to remind the patient that they have tubes and lines in place.

While you are in the SICU you will remain connected to many lines, tubes and monitoring devices. Patients receive a large amount of IV fluids during surgery. Most patients will look swollen as they tend to retain these fluids. This “fluid weight” will gradually go away but it may take several weeks.

As you improve, equipment is removed and you will be encouraged to become more active. Patient activity and mobility is important to prevent pneumonia, reduce the potential for blood clots, and to increase strength and conditioning. The day after surgery you will be out of bed multiple times a day and sitting up in a chair. Increased mobility is dependent upon removal of lines and tubes. You will be encouraged to take deep breaths and use your incentive
spirometer 10 times an hour while you are awake. You will be provided with a pillow to “splint” your incision area to reduce the discomfort.

The SICU is supportive of your family members and/or your advocates to visit and participate in your plan of care. There are no posted visiting hours. Courtesy behavior and respect for the privacy of others is necessary when in the SICU.

Patient rounds occur every morning in the SICU. The entire team assembles in the patient’s room to review your status and to make goals for the day. An immediate family member or designed/advocate is invited and welcome to be present to answer any question the team may have or to voice input pertaining to the plan. Your bedside nurse can give you additional information about the time to be present for rounds.

Patients usually stay in the SICU for one to four days following liver transplantation and then are moved to the transplant general care floor, 5C.

The inpatient stay is designed to provide a significant educational opportunity for you to learn about maintaining your health following a transplant. You are expected to actively participate in your “care plan” as identified throughout the Patient Education Guide. Specifically, patients are expected to:

- Read the Patient Education Guide
- Learn about your medications and how to manage them
- Be out of bed multiple times each day, walking and/or sitting in a chair
- Participate in physical therapy
- Participate in prescribed diet regimens and blood draws

When you are medically ready, you will be discharged to your home. Occasionally, some patients require additional care and may be discharged to a rehabilitation center or extended care facility.

**Medications**

*What You Need to Know About Your Medications*

The success of the transplanted organ is dependent on the proper use of anti-rejection medications. For this reason you cannot be discharged from the hospital until you and your caregiver can demonstrate a basic understanding about medications. These are some of the things you need to know about your medications:
• Name of each medication
• When to take each medication
• How to take each medication
• Why each medication is needed
• What are the major side effects of each medication
• What food or drugs to avoid while taking each medication
• What actions to take if a dose is missed
• How and when to refill medications

_Anti-Rejection Medications_

You will take at least one anti-rejection medication for the rest of your life. Anti-rejection medications also are called immunosuppressive drugs. These drugs decrease the body’s ability to fight off what it sees as foreign. This can be an infection or the newly transplanted liver. The medical team uses immunosuppressive drugs to develop an appropriate balance to allow the body to fight infection without rejecting the transplanted organ.

Since the chance of rejection is highest immediately following the transplant surgery, patients receive the most drugs and in higher dosages shortly following surgery. As the patient moves farther from the date of surgery, it is likely the patient will take fewer drugs and in smaller doses. By the end of the first year, many patients remain on only one or two anti-rejection medications.

_Prescription coverage:_ Sustained and consistent use of the anti-rejection medications is essential to maintaining a healthy liver and is very costly. Therefore, you must maintain coverage for these medications at all times. If you have any questions, you are urged to contact the transplant financial coordinators at (734) 763-1528 or (734) 615-1833.

There are four groups of anti-rejection medications that are commonly used. Each group works differently in the body to prevent rejection. Patients often take a combination of drugs from the four groups, which are:

• Tacrolimus or Cyclosporine
• Mycophenolate Mofetil, Mycophenolate Sodium or Azathioprine
• Prednisone
• Sirolimus/Everolimus

_You Should Know_

You should take the dose you were instructed to take by the Transplant Clinic or Transplant Office.
Tacrolimus (Prograf®) or Cyclosporine (Neoral®, Gengraf®, other generics)

Tacrolimus and cyclosporine work the same way. You will take either tacrolimus or cyclosporine, but will never take both at the same time. Each drug is taken twice a day – **12 hours apart**.

It is important to maintain therapeutic blood levels. Blood concentrations are measured at their lowest level, which is referred to as a “trough level.” For example, if tacrolimus is taken at 9 p.m. on Monday night, you need to go to your lab on Tuesday at 9 a.m. to have your blood drawn before taking your morning dose of tacrolimus. Measuring trough levels reflects whether adequate blood levels are being maintained.

Frequently dosages are increased during the first month. These adjustments are made taking the following into consideration:

- Actual 12-hour trough level.
- Presence of any side effects.
- How recently the transplant was done.
- Whether the patient is on any other anti-rejection medications, such as prednisone or mycophenolate mofetil.
- Any previous episodes of rejection.
- Underlying liver disease, such as autoimmune disease. Some diseases require more immunosuppressive therapy than others.

If you miss a dose of tacrolimus or cyclosporine, and it is within four hours of your normally scheduled dose, go ahead and take the dose. If more than four hours has passed since the scheduled dose, call the Transplant Office. **DO NOT double the dose.**

When taking tacrolimus or cyclosporine you should not eat grapefruit, papaya, star fruit or drink grapefruit juice, since it increases the amount of the medication absorbed into the blood stream.

**Tacrolimus (Prograf®) generic available**

Dose Strengths:  
- 0.5mg capsule  
- 1mg capsule  
- 5mg capsule  

Frequency: Taken twice a day, 12 hours apart
Possible Side Effects:
- Kidney toxicity
- High blood pressure
- Diabetes or increased blood sugar
- Tremors, headache, tingling, confusion
- Nausea, vomiting, diarrhea
- High potassium
- Hair loss

Individual Dosing:
- Dose varies based on drug levels
  
  Higher doses are usually required shortly after transplant

  **DO NOT confuse 0.5 mg (1/2 mg) and 5 mg capsules!**

If cost is an issue and you have decided to use a generic brand, the following actions need to be taken:

- Notify the Transplant Office as to the change.
- Obtain drug levels within one month of beginning the new drug.
- Do not interchange different brands.

**Modified Cyclosporine (Neoral®, Gengraf®, other generics)**

Neoral® and Gengraf® are two brands of modified cyclosporine that are frequently used. There are several other generic brands that are available by manufacturers such as Pliva and IVAX.

Dose Strengths:
- 25mg capsules
- 100mg capsules
- 100mg/ml solution

Frequency:
- Taken twice a day, 12 hours apart

Possible Side Effects:
- Kidney toxicity
- High blood pressure
- High cholesterol
- Tremors, headache, tingling, confusion
- Overgrowth of gums
- Increased hair growth
- Nausea, vomiting, diarrhea
- High potassium
- Gout

Individual Dosing:
- Dose varies based on drug levels
  
  Higher doses are usually required shortly after transplant
Mycophenolate Mofetil (Cellcept®), Mycophenolate Sodium (Myfortic®) or Azathioprine (Imuran®)

These drugs work by inhibiting production of white blood cells. Many patients are weaned off mycophenolate by the end of one year. Azathioprine is not usually a first line drug, but may be used if you are unable to tolerate mycophenolate.

Mycophenolate Mofetil (Cellcept®) generic available

Dose Strengths: 250mg capsule
500mg tablet
200mg/ml suspension

Frequency: Taken twice a day

Possible Side Effects: Diarrhea, abdominal cramping
Nausea, bloating
Low white blood cell count and platelet count

Individual Dosing: Initial dose usually 1000 mg TWICE a day
Usually given with either tacrolimus or cyclosporine
Should not be crushed or cut

To Taper: Dose reduction is usually 500 mg twice a day, then 250 mg twice a day, then off completely. These medications are not scored so they cannot accurately be cut in half. A new prescription is needed when patients take 250 mg. Lowering the dose should only be done under the care of a physician.

Mycophenolate Sodium (Myfortic®)

Dose Strengths: 180mg tablet
360mg tablet

Frequency: Taken twice a day

Possible Side Effects: Diarrhea, abdominal cramping
Nausea, bloating
Low white blood cell count and platelet count

Individual Dosing: Initial dose is usually 720 mg TWICE a day
Usually given with either tacrolimus or cyclosporine
Cannot be crushed or cut
**Azathioprine (Imuran®)**

Dose Strength: 50mg tablet

Frequency: Usual dose taken once a day

Possible Side Effects: Low white blood cell count
Increased risk of pancreatitis
Increased rise of skin cancer
Diarrhea/nausea

Individual Dosing: Usual dose is 50-100 mg **ONCE** a day
Used with tacrolimus or cyclosporine
Cannot be taken with allopurinol

**Prednisone**

Prednisone is a generic name for steroid anti-inflammatory drugs.

Dose Strengths: 1mg tablet
2.5mg tablet
5mg tablet
10mg tablet
20mg tablet
50mg tablet

Frequency: Initially twice a day, then once a day; sometimes every other day

Possible Side Effects: Swelling of face (moon shape), hands and feet
Increased appetite and weight gain
Acne
Mood swings
Sodium and water retention
Stomach irritation
Muscle weakness
Bone loss
Diabetes, increased blood sugar
High blood pressure
Visual changes, cataracts
Poor wound healing
Insomnia
Increased cholesterol
Individual Dosing: Steroid may be administered as IV methylprednisolone immediately following surgery instead of oral prednisone. Initially, it is given every 12 hours. Prior to discharge, dosing will convert from IV to oral tablets. Approximately a week following surgery, a full dose is given once a day. Prednisone is the first drug decreased or tapered. Patients are generally discharged with a prescription for either 5 mg or 10 mg tablets, which can be cut in half. **DO NOT confuse prednisone and tacrolimus (Prograf)!**

To Taper Prednisone: Decreasing the dose should only be done under the care of a physician.

**Sirolimus (Rapamune®)**

Sirolimus can be given with tacrolimus, cyclosporine, or mycophenolate, or by itself. It is less harmful to the kidney than tacrolimus and cyclosporine. It is not used in the immediate post-operative period because of increased risk of forming a blood clot in hepatic artery.

- **Dose Strengths:** 1mg/ml solution, 1mg tablet, 2mg tablet
- **Frequency:** Taken once a day
- **Possible Side Effects:** Low red blood cell count, Low platelet count, Low white blood cell count, High cholesterol and triglyceride

Individual Dosing: Dose adjustment is made based on drug levels

**Everolimus (Zortress®)**

Everolimus is a newer anti-rejection medication that is similar to sirolimus. It can be given with reduced doses of cyclosporine or by itself. It is less harmful to the kidneys than cyclosporine and tacrolimus.

- **Dosing Strengths:** 0.25mg tablet, 0.5mg tablet, 0.75mg tablet
Frequency:  Taken twice daily

Possible side effects:  High cholesterol and triglyceride
Delay wound healing
Swelling of eyes, face, mouth, lips or tongue
Diabetes or increased blood glucose levels

Individual Dosing:  Dose adjustment is made based on drug levels

*Anti-Infection Medications*

After transplant, patients are at greater risk of infection. These infections can come from bacteria, fungus or viruses that are normally found in the environment. Since transplant patients take anti-rejection medications that lower their resistance to infection, they also are given several medications to help prevent infections.

*Anti-Bacterial*

Sulfamethoxazole/trimethoprim (brand names: Bactrim®, Septra®, Cotrimoxazole)
- Single-strength (80mg trimethoprim) 1 tablet daily for one month, taken with food
- You should be careful of sun exposure as this drug increases sensitivity to sun
- You should not take it if you have a sulfa allergy. If you have a sulfa allergy, you will be given pentamidine inhalation while in the hospital.

*Fungal*

Nystatin (Mycostatin®):  Swish & Swallow (S/S), 400,000 U (4 ml)
Use four times daily for one month
OR
Fluconazole (Diflucan®):  100mg once a day for one month

*Viral*

CMV (cytomegalovirus) is a common herpes virus most people have had as a child. Patients have often been exposed to CMV and have developed antibodies to it. **Prior to transplant patients have a blood test to identify the presence of this antibody.** The result of this test (and a similar test given to the organ donor) determines which anti-viral medications are prescribed to prevent CMV or other herpes infections.
Preventive medications prescribed may be:
Acyclovir (Zovirax®):  400mg twice a day for one month
Valganciclovir (Valcyte®):  450mg once a day for three months

Treatment medications prescribed for CMV infection:
Ganciclovir (Cytovene®) IV or higher dose of oral valganciclovir for three months. Dose reductions are sometimes necessary if the white blood cell count becomes too low.

Entecavir (Baraclude®)
Entecavir is used to prevent Hepatitis B after transplant. It is continued lifelong.

Dosing Strengths:  0.5mg tablet
                   1mg tablet
                   0.05mg/ml solution

Frequency:  Taken once daily

Possible Side Effects:  Nausea
                      Dizziness
                      Headache
                      Fatigue

Individual dosing:  Usual dose is 0.5mg once daily; however, it may need to be adjusted due to kidney problems

Lamivudine (Epivir-HBV®)
Lamivudine is used to prevent Hepatitis B after transplant. It is continued lifelong.

Dose Strengths:  100mg tablet
                 5mg/ml solution

Frequency:  Once daily

Possible Side Effects:  Nausea
                      Low red blood count
                      Low platelet count

Individual dosing:  Usual dose is 100mg once daily; however, it may need to be adjusted due to kidney problems
Other Medications

Most pre-existing medical conditions will continue after transplantation. Medications for pre-existing conditions, such as diabetes or high blood pressure, will be prescribed at the time of discharge. The medications prescribed may be different that those taken previously. You will be instructed to return to your primary care physician who will evaluate your response to the new medications and to have them continued or changed. All patients are asked to return to their primary care physicians as soon as possible following discharge for medical care for all conditions other than transplant-related issues.

Frequently, patients find they are taking medications that are new to them. Anti-rejection medications and the surgery itself can cause a patient to have high blood pressure, high blood sugars and stomach problems. These conditions can be temporary or permanent. The following are examples of medications that may become necessary:

Gastric Acid-Reducing Medications: These medications protect the digestive system and will be prescribed as long as you need them. Once some of the medications (prednisone or mycophenolate) are tapered, patients often no longer need anti-ulcer meds and will be asked to stop using them. Examples of these medications include Zantac®, Protonix®, Prevacid® and Nexium®.

Anti-Hypertensive: High blood pressure may be a result of the surgery and the anti-rejection medications. The high blood pressure may be a short-term or a long-term problem. Long-term hypertension will be managed by the patient’s primary care physician.

Diuretics: Many patients will go home while still using a water pill, such as furosemide (Lasix®). This drug will be decreased and stopped as swelling decreases. It can take several weeks to several months for the swelling to resolve. If you have other causes for swelling, such as kidney or heart problems, your local physician or specialist who cares for that problem will need to monitor the condition and order the medications for it.

Insulin: Tacrolimus and prednisone can cause blood sugar to increase. Elevated blood sugars can sometimes be managed using an oral medication such as glipizide, glyburide or several others. If oral medications do not manage the elevated blood sugar, insulin may be necessary. Elevated blood sugar may be a short-term or a long-term problem. Long-term management of diabetes is managed through the patient’s primary care physician.

As prednisone and tacrolimus are decreased, blood sugars may come down. Therefore, it is important for you to closely monitor your blood glucose levels. Monitoring blood sugar levels at home requires a machine (glucometer) which is prescribed at the time of discharge. You will be instructed on the proper use of the glucometer and how to record your glucose levels.
**Ursodiol (Actigall®)**
Ursodiol is used after transplant to help increase bile flow.

**Dose Strengths:**
- 300mg capsules
- 250mg tablet
- 500mg tablet

**Frequency:**
Two to three times daily

**Possible Side Effects:**
- Diarrhea
- Dizziness
- Nausea
- Backache

**Individual Dosing:**
Usual dose is 300mg twice daily

*You need to return to your primary care physician as soon as possible after discharge to receive proper monitoring and regulation of blood sugar levels.*

**Pain:** The transplant surgeons prescribe oral pain medications for patients at discharge. Surgical pain may last up to a month, depending on the presence of certain complications.

**Chronic Pain:** Chronic pain issues need to be addressed by your primary care physician, including conditions such as migraine headaches and chronic back pain.

*Antivirals for Hepatitis C Recurrence*

**Peginterferon Alfa-2a (Pegasys®)**
Treat Hepatitis C virus; usually given in combination with ribavirin.

**Dose Strengths:**
180mcg pre-filled syringes

**Frequency:**
Once weekly

**Possible Side Effects:**
- Low white blood cell count
- Low platelet count
- Depression and/or mood swings
- Changes in vision
- Fatigue
- Nausea/vomiting

**Individual Dosing:**
Dose adjustment is made based on side effects and response to the virus
**RibavirIn (Rebetol®, Copegus)**

Treat Hepatitis C virus; usually given in combination with peginterferon alfa-2a

**Dose Strengths:**
- 200mg capsule
- 40mg/ml solution

**Frequency:**
- Twice daily

**Possible Side Effects:**
- Low red blood count
- Low platelet count
- Dizziness, fatigue
- Depression
- Headache

**Individual Dosing:**
Dose adjustment is made based on side effects and response to the virus

**How Medications Should be Stored**

- Store them in the original container.
- Keep them tightly capped.
- Store them in a cool, dry place away from direct sunlight.
- Keep them away from children and pets/animals.
- Do not store them in an area that has a lot of moisture, such as the bathroom. Moisture can make them lose their strength.
- Don’t let liquid medications freeze.
- Do not store them in the refrigerator unless instructed by your pharmacist.
- Take your medications at the same time every day.
- Use a written schedule.
- Do not crush or cut tablets, capsules or caplets unless instructed to do so.

**You Should Know**

Refer to the Resources Section for detailed information on the levels of Acetaminophen in prescription narcotic analgesics.

**When to Call the Transplant Office About Medications**

You should call the Transplant Office about your medications if:

- You cannot take your medications by mouth for any reason.
- You have a fever, nausea, vomiting, diarrhea or any unusual symptoms.
- The medication looks different than what was taken before.
• You think you need an over-the-counter medication, such as pain relievers or cold medicines. Do not take aspirin or non-steroidal anti-inflammatory drugs.
• Your primary care physician prescribes or changes any of your medications.
• If you are not sure what dose to take. Remember: Doses are frequently changed and may not be the same as the directions printed on the bottle.
• If you have any doubts or questions.

**Prescriptions**

At the time of discharge, your prescriptions will be written for each medication to include several refills. It is important to verify with the local pharmacy that they have these drugs in stock at the time of discharge. You will be instructed on the proper use of medications, including the correct dose to take, how often to take the medication, and when to take the medication. Prior to discharge, you and your caregivers must demonstrate a basic understanding about medications and how they are administered.

You will be provided a schedule to assist you in managing your medications. You will be encouraged to make notes in pencil so changes can be made. This schedule, along with all medications, should be brought to each clinic visit.

**Refills**

What you need to know about prescription refills:

• **Do not run out of medication!** Plan ahead by always checking prescription bottles for available refills. If in doubt, ask the pharmacist.
• Call the pharmacy to request refills at least one week before the medications are gone. Allow more time if a mail order pharmacy is used or during a holiday season.
• You should always take medications with you when traveling, whether it is a short or a long trip.
• If you cannot afford your medications, you must call the Transplant Office.
• Prescriptions are good for one year. Expired prescriptions will need to be rewritten or called in to the pharmacy. When new prescriptions are needed, allow up to seven days for processing.
• When calling the Transplant Office for a prescription, please leave the following information in the message: patient name, name of drug, dose of drug, pharmacy name and pharmacy phone number.
• Prescriptions can be written for either a one-month or a three-month supply. The choice is determined by the patient’s insurance coverage.
• Mail order pharmacies provide a three-month supply – which requires you to pay one reduced copay for a three-month supply, reducing your out-of-pocket expense. Use of mail order pharmacies is dependent upon your insurance coverage.

• Mail order pharmacies require a written prescription which can either be mailed by you or faxed by the Transplant Office.

• If you use a mail order pharmacy, you also will need a local pharmacy for short-term medications.

You need to bring the following to your first clinic visit following transplant:

• Name and telephone number of your local pharmacy.

• Name and ID number of subscriber for a mail order pharmacy. The subscriber is often the spouse.

• Patients with Medicaid coverage need to bring their ID number, pharmacy and contact number.

The Transplant Office will write (or call in) prescriptions that are good for one year if the following criteria are met by the patient:

• Blood work is done on a routine basis

• Clinic appointments are kept

**Anticipated Cost of Medications – Per Month**

Proper use of prescribed medications is one of the most important ways for a patient to maintain a healthy liver. Unfortunately, these medications are very expensive – but necessary. Below are some estimates of the monthly costs for many of the medications used for liver

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>MONTHLY COST</th>
<th>MEDICATION</th>
<th>MONTHLY COST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclosporine</td>
<td>$200 - $1,000</td>
<td>Entecavir</td>
<td>$900</td>
</tr>
<tr>
<td>Tacrolimus</td>
<td>$1,000 - $2,500</td>
<td>Multivitamin</td>
<td>$18</td>
</tr>
<tr>
<td>Mycophenolate</td>
<td>$100 - $300</td>
<td>Colace</td>
<td>$3</td>
</tr>
<tr>
<td>Valganciclovir</td>
<td>$1,350 - $5,400</td>
<td>Gastric Acid Reducers</td>
<td>$22 - $155</td>
</tr>
<tr>
<td>Sirolimus</td>
<td>$1,350</td>
<td>Anti-hypertensives</td>
<td>$31 - $80</td>
</tr>
<tr>
<td>Prednisone</td>
<td>$20</td>
<td>Furosemide</td>
<td>$4.50 - $15.00</td>
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<td>Urosodial (Actigall)</td>
<td>$250</td>
<td>Anti-depressants</td>
<td>$62 - $100</td>
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<td>Bactrim SS</td>
<td>$35</td>
<td>Anti-osteoporosis</td>
<td>$80</td>
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<td>Fluconazole</td>
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<td>Antihistamines</td>
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<td>Nystatin Suspension</td>
<td>$108</td>
<td>Diabetic medications</td>
<td>$0 - $200</td>
</tr>
</tbody>
</table>
transplant patients. If you have concerns about your insurance coverage for prescriptions, you are asked to call the financial coordinators (734) 615-1833 or (734) 763-1528 who will assist you in developing a plan.

*Over-the-Counter (OTC) Medications*

There are many medications that do not require a prescription and can be purchased over the counter. These drugs are used to treat minor ailments and are generally safe to use. However, there are some OTC medications that may cause problems in a post-transplant patient.

Non-steroidal anti-inflammatory drugs (NSAIDs) are frequently taken for minor aches and pains.

In selecting OTC medications for these minor conditions it is important to avoid any medication that contains ibuprofen or naproxen because they can interact with anti-rejection medications and cause kidney failure. Examples that contain ibuprofen or naproxen and should be avoided include Advil®, Motrin®, Naprosyn® or Aleve®.

Aspirin-based drugs which contain salicylic acid, should also be avoided unless prescribed by a physician. Many times baby aspirin is prescribed to prevent heart attacks and is usually safe.

Acetominophen (Tylenol®) can be taken safely if the daily dose does not exceed 2 grams (2,000mg) in a 24-hour period. Again, it is important to read the labels on medications to know the content and dosage prior to taking the medication.

*Herbal Supplements*

We recommend that you DO NOT USE HERBAL SUPPLEMENTS. There are many herbal supplements available to the public – often promoted as cures for many illnesses. Herbal supplements are not regulated by the Federal Drug Administration (FDA) which means there are no standards for the ingredients used in each bottle of herbal supplements. There can be a wide variation in the contents from one bottle to another – even with the same brand. Some supplements are harmless, but others can be a serious health risk. This is especially true of St. John’s Wort. ALL TRANSPLANT PATIENTS SHOULD AVOID ST. JOHN’S WORT.
GOING HOME

When you are ready to go home, it is important you take very good care of your new liver. While the Transplant Team and patient’s family are available to help, it is your responsibility to know how to maintain a healthy lifestyle and to follow through with the activities to achieve a healthy lifestyle. Several important ways to maintain a healthy lifestyle and a healthy liver are covered here.

Discharge Education for Transplant Patients

You will receive several documents at the time of discharge that will assist you in managing your care as you transition from the hospital to your home.

- The Discharge Navigator provides discharge instructions.
- The nursing staff will review this document with you and your support person(s) prior to discharge.
- Instructions specific to you are provided to you in the following areas:
  - Plan for my Care, Treatment and Services
  - Tests and Procedures
  - Treatments
  - Medications (see My Daily Schedule, a daily medication schedule personalized for each patient)
  - Diet
  - Home Supplies/Equipment
  - Pain
  - Activity
  - Follow-up care
  - Contact information for Liver Transplant Team, holidays, evenings, weekends and emergencies
  - Community Resources
  - Basic Health Practices and Safety
  - Smoking Cessation
- A nurse from the Transplant Team on the inpatient floor will provide this packet to you prior to discharge and will review the information with you.
**My Daily Schedule** contains the following information:

- Each medication prescribed, dose prescribed, purpose of medication and time of day to take each medication.
- Special instructions are included for each medication indicating generic names, dosages, form (i.e., tablet, capsule), manufacturing company, and comments on how to take the medication (such as take with food).

**Transplant Home Monitoring Record** is available to record your daily readings of pertinent medical information, such as vital signs, weight and temperature, blood pressure and blood sugars if necessary.

**Transition of Care Following Discharge**

One of the first changes you will encounter after your liver transplant is that several of your health care providers will change.

- Immediately after surgery, your care will be directed by the transplant surgeons. This will continue until all surgical issues are resolved, usually for two to three months.
- In addition to the surgeons, you will be cared for by one or more surgical physician assistants or nurse practitioners.
- Your nurse for this period of time will be ____________________________.
- For any questions or problems, please call (800) 395-6431. This is the telephone number to the Liver Transplant Clinic Office. Contacting any other number will cause a delay in response time. Office hours are 8 a.m. to 4:30 p.m. Monday through Friday.
- To contact someone after regularly scheduled office hours, on weekends, or on holidays, please call the transplant resident-on-call at (734) 936-6267.
- At discharge, a clinic appointment will be made for you. If you do not receive an appointment, call the Liver Transplant Clinic to have them arrange it.

**Follow-Up Care for Patients Who Received a Liver from a CDC High-Risk Donor**

If you received a liver from a donor that the Centers for Disease Control (CDC) classified as a high-risk donor, you should have your blood checked intermittently for early signs of possible but unlikely infection. You will have blood tests at one month, three months, six months and one year after transplant. Since these donors are screened carefully prior to donation, it is likely you will not need any additional medications.
Follow-Up Care for Patients Who Received a Liver from a Donor with Prior Hepatitis B Infection
(also known as a Hepatitis B core positive donor)

If you receive a liver from a donor that had prior infection with hepatitis B, you will need to take a daily oral antiviral medication following the transplant to prevent the virus from reactivating. In addition, you will need to have your blood checked frequently for early signs of infection at one month, three months, six months and one year after transplant as well as twice yearly thereafter.

Your First Clinic Visit Following Discharge

Your first clinic appointment following discharge will be in the Post Transplant Clinic. Here’s what to expect:

• The clinic is located in Reception Area C on the second floor of the Taubman Center.
• The clinic hours are on Mondays and Fridays from 8 a.m. to noon.
• If you do not already have a lab slip, request one at the clinic check-in desk.
• Mark either tacrolimus, sirolimus, or cyclosporine or everolimus on the lab slip, according to which medication you are taking.
• Go to have your blood drawn at the blood drawing station on either the second or third floor of Taubman Center.
• The third floor blood drawing station hours are 7 a.m. to 6 p.m.
• The second floor blood drawing station hours are 8:30 a.m. to 3:30 p.m.
• After your blood draw, return to the waiting area in Reception Area C on the second floor of Taubman Center.
• You will be called and placed in an examination room.
• You will be seen by a physician’s assistant, nurse practitioner, a Nurse (RN) ____________________________________________, or a surgeon, ____________________________________________ and a pharmacist ____________________________________________.
• Together, the PA, nurse and pharmacist will review your medications and the results of your blood work and your physical examination.
• Your care will be discussed with the transplant surgeon, but you may not be seen by a surgeon during this visit.
Please bring the following contact information to your appointment:

- Your current home telephone number
- Your current cell telephone number
- The telephone number of any other location you may be staying
- The name, address, telephone number and fax number of the lab you plan to use
- The name, address and telephone number of the pharmacy you plan to use
- The name, address, telephone number and fax number of your primary care physician

Points to remember for this first clinic visit following your transplant:

- A detailed explanation of your post-transplant care will be provided during this visit.
- Your support person(s) should attend this visit with you.
- Do not take your tacrolimus (Prograf®) or cyclosporine (Neoral®, Gengraf®) before you have your blood drawn the morning of your visit. Bring it with you and take it after you have your blood drawn.
- Bring all your medications and medication containers each time you come to clinic – until instructed otherwise.
- Bring your medication record sheet to each clinic visit as changes made in clinic will be recorded at that time.
- This visit may take several hours as your lab tests need to be reviewed before you are discharged from the clinic.
- Bring your pain medications and a snack if you haven’t eaten.
- Bring any records such as your daily weights, temperatures, etc.
- If you do not have voicemail on your phone(s), please let us know as it is very important to reach you after each clinic visit and after you have had blood work done. Your voicemail should identify you by name and number.
- If you need any prescriptions renewed, please tell us at the beginning of the visit and do not leave without them. Some medications require a paper prescription to be filled at the pharmacy.
- If you have an insurance or disability form that needs to be completed please allow several days for them to be completed.
- If you have billing or insurance issues that need to be discussed, please ask to have the financial coordinator paged.
- Expect to have a clinic appointment once or twice a week for one to four weeks, then every two weeks, then monthly. The frequency will depend on your condition and recovery.
- Incisional staples/sutures are usually removed about the third week after surgery, if they have been placed.
Develop Plan for Outpatient Blood Work

Blood tests provide information about liver and kidney function. Since these tests are so important to the success of your transplant, you must develop a plan for getting routine blood work.

• **Frequency of tests** – Initially, you will need blood work twice a week. As time passes and you become stable, the frequency is reduced so blood tests are needed every month or every three months. Never go past three months without getting your blood work.

• **Reason for testing** – Transplant patients are always at risk for complications, such as rejection, problems with the bile duct or circulation to the liver. Abnormal blood results are one of the first indicators of problems. Identifying problems early may prevent permanent damage.

• **Find a blood drawing lab** – You must find a blood drawing lab near your home. It does not have to be a University of Michigan lab. However, the University of Michigan does have several satellite lab sites in lower Michigan.

• **Before going to the lab** - The Transplant Team will provide you with lab orders to take with you to the blood drawing lab. Tests to be done routinely will be marked on the lab order. Labels and mailing packets will be provided for patients to take to the lab, if you do not use a University of Michigan laboratory.
  - You are responsible for marking the box on the lab order indicating the drug you are taking; cyclosporine, tacrolimus, and/or sirolimus.
  - You are responsible to take the labels and mailers if you are going to a blood drawing lab outside the University of Michigan Health System.

  **REMEMBER – DO NOT TAKE SIROLIMUS, EVEROLIMUS, PROGRAF OR CYCLOSPORINE UNTIL AFTER BLOOD HAS BEEN DRAWN!**

• At the blood drawing lab, multiple tubes of blood will be drawn: two lavender-topped tubes and one red-topped tube. Sometimes coags are drawn to measure your clotting factors. This is a blue top tube. This test is ordered usually when you are followed by the surgeon.

• **University of Michigan Lab**
  - You must take your lab order which will become your “standing” order.
  - You must indicate on the lab order the drugs you are taking: tacrolimus, cyclosporine, sirolimus or everolimus.
  - Once the tests are completed the results will appear on your medical record and the Transplant Team can review them.
• *Local Lab (non-U of M)*
  - One lavender tube must include an identifying label. This lavender-topped tube will be placed in a cylinder, put in a mailer box and shipped to the University of Michigan. You should verify the identifying label that has been affixed to the tube. The results from this test will appear on your medical record approximately three days after the test for the Transplant Team to review.
  - The local lab will run all the other blood tests and will fax the results to the Transplant Team office. The Transplant Team office telephone and fax numbers appear on the lab order slip. When the results are received, they will be entered into your medical record, also known as the “lab flow sheet.” Local labs should complete and fax test results within 24 hours. At times, this is not automatically done. When this occurs the Transplant Team contacts the local lab to request the results, which is why it is important to have the name and telephone number of your local lab.

• Lab results - The Transplant Team will call you if your results indicate an abnormality and/or to make changes in medications. **Patients with normal blood results are not routinely called.**

• Timing lab work – You should plan to have your blood work done to allow the results to be available for review by the Transplant Team on the date of your clinic visits.
  - U-M lab – You can go to the clinic reception on the second floor of Taubman reception C, to obtain the appropriate lab slips. You will need to mark it for the correct drug test, then proceed to the lab draw station.
  - Local lab – You need to have your blood drawn at least three to four days prior to your clinic visit to allow the results to be available to the Transplant Team during your visit. **NOTE:** You can use your standing orders at any lab.

**Transition of Care to Post-Transplant Hepatology**

After all the surgical issues are resolved, your care will return to the hepatologist.

• Transplant nurses work as a team with specific physicians. Although you will be assigned a nurse who works with your physician team, you should feel free to speak with any of the nurses if you have a question or concern. To contact the Post Transplant Team:
  - Call *(734) 936-7670* or *(800) 395-6431* and leave a message. The message should include your name and telephone number.
  - The transplant office receives a high volume of calls daily therefore, provide a brief description of the problem or concern to allow accurate prioritization of the call.
Follow-Up Care for Patients with Cholangiocarcinoma

Patients who have had a liver transplant due to their cholangiocarcinoma have agreed to specific follow up procedures after transplant, which includes making and keeping their follow up appointments and completing the necessary blood work. Your follow up plan will include taking a baby aspirin daily and taking a medication to prevent heartburn. In addition, you will need to have frequent ultrasounds of your liver. An ultrasound examines the blood flow of your hepatic artery; the blood vessel that delivers blood to your liver. The ultrasounds will be performed on the first day after surgery, at one week after surgery, at three weeks after surgery, at four months after surgery, then every three months for the remainder of the first year. Other testing may be required based on liver cancer protocols.

Transplant Ambulatory Care Unit (TACU)

The TACU is an outpatient clinic located at University Hospital on 5C. The TACU offers expert care for transplant patients who would benefit from infusion therapy or special procedures in an outpatient setting. The clinical team of nurses and medical staff specially trained in transplantation, care for the special needs of transplant patients. Services you may receive through the TACU include:

- Infusions to treat rejection, dehydration and infections
- Transfusion of blood products
- Blood draws
- Physical examination
- Biliary tube or drain removal
- Education for patients and families
- Management of immunosuppression

The TACU has reclining chairs and a stretcher bay. It is open every day of the year, including holidays and weekends. The TACU has extended hours of operation Monday through Friday with shorter hours on weekends.

You must bring all your regular medications for the entire day when you are seen in the TACU. Many TACU appointments are quite lengthy and you are NOT allowed to leave the area during your stay. Beverages are available in the TACU, however, food service is not provided. It is suggested that you bring a lunch or plan to have a support person accompany you to obtain food from the cafeteria during your TACU stay. The TACU telephone number is (734) 647-5688.
Patients who experience problems after normal business hours should call Hospital Paging at (734) 936-6267 and ask for the transplant doctor on call. The operator will take the patient’s name and contact information and the physician-on-call will return the call.

**East Ann Arbor Infusion Clinic**

Another place you may be asked to go to for treatments is the East Ann Arbor (EAA) Infusion Clinic, an outpatient infusion clinic designed for adult non-oncology patients. It is specifically designed to administer infusions in a soothing and caring environment. The clinic staff consists of specially trained infusion nurses, medical assistants and pharmacists. It is located on the lower level, B1, of the East Ann Arbor Health and Geriatric Center at 4260 Plymouth Road, Ann Arbor, MI.

**Policy on Wearing Masks**

While in the hospital it is recommended you wear a mask to protect yourself from airborne contaminants.

We recommend you wear a surgical mask in waiting rooms and when you leave your hospital room during your inpatient or TACU stay. You will be provided with a supply of masks when you leave the hospital. In addition, you will be given information about where masks can be purchased and their approximate cost.

The transplant clinic in the Taubman Center will have masks available for patients while in the waiting rooms. The TACU has no waiting room; therefore, masks are not required.

Construction areas, especially when digging up soil, may have airborne particles that may cause a patient to become sick. We recommend patients wear surgical masks around construction sites.

Suggested suppliers for face masks (called Procedure Ear Loop Face Mask) include:

<table>
<thead>
<tr>
<th>Supplier</th>
<th>Phone Numbers</th>
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</thead>
<tbody>
<tr>
<td>Mitchell Home Medical</td>
<td>(734) 572-0203, (800) 420-0202 toll-free</td>
</tr>
<tr>
<td>Masters Medical Supply</td>
<td>(800) 286-9989 toll-free, $8.95 for box of 50</td>
</tr>
</tbody>
</table>

You Should Know

If you have a medical emergency, you should go to the nearest emergency room or call 911.
Special Care

Incision/Wound Care

Your incision may be closed with staples. The staples will be removed in the clinic about three weeks after your surgery. Alternatively your incision may be closed with sutures under the skin which will absorb over time.

Sometimes your health care provider will re-open part of, or the entire incision if it is red, draining, or the appearance is otherwise suspicious for an infection. The purpose of opening the incision is to allow for drainage of trapped fluid and/or to clean out any bad tissue so the healthy tissue can heal. Once the incision is opened it heals from the inside out. This may require doing dressing changes at home several times a day.

You and your family member will be taught how to change a dressing. A visiting nurse may be ordered to help you care for the wound at home. You will be able to take a shower and then re-dress the wound when dry.

You Should Monitor Your Own Health

Patients who become aware of their health and monitor changes in their body will be in a better position to respond quickly and appropriately to any issue that may arise. It is recommended that you follow these steps to routinely monitor your health.

• Check temperature twice each day – at the same time each morning and evening
• Check temperature any time when feeling ill
• Notify the Transplant Office when temperature is greater than 100.5°
• Check weight every morning – using the same scale every day.
• Notify the Transplant Office of a sudden weight gain. A sudden weight gain would be two to three pounds overnight or five pounds in a week.
• Check blood pressure twice daily.
• If you have diabetes, you should check your blood sugars as instructed – usually before meals and at night.
• Keep a record of temperature, blood pressure, weight, pulse and blood sugars. Bring this record to office visits.
You should call the Transplant Office if any of the following symptoms occur:

- Sores or rashes in the mouth or on the skin
- Redness, swelling or drainage from the incision
- Nausea, vomiting or diarrhea
- Burning or pain on urination
- Persistent headaches
- Sore throat
- New onset of pain
- Any feelings of being sick that you cannot explain
- Changes in vision – double vision, etc.
- Blood in urine or stools
- Shortness of breath
- Increased swelling of legs

### You Need to Reconnect with Your Primary Care Physician

You are encouraged to return to your primary care physician. If you do not have a primary care physician, you are encouraged to find one now. Medical care related to liver transplant will be handled by the Transplant Team, but all other issues need to be managed under the guidance of a primary care physician.

It is in your best interest for there to be coordination of care between the Transplant Team and the primary care physician. This is best achieved through good communication. For this purpose, you are asked to provide the name and telephone number of your primary care physicians and clinics where you are being seen. You are encouraged to provide the Transplant Office with updated information if you change physicians.

**IMPORTANT:** In the course of providing medical care, your primary care physicians are likely to prescribe medications for various illnesses. You should contact the Transplant Office prior to taking new medications. While most medications can be taken safely with anti-rejection medications, there are a few that can cause harmful side effects.

**AVOID:** Erthromycin, Biaxin, Ketoconazole, Cardizem, Verapamil, Diflucan.

If you need to take these medications, contact the Transplant Office so an adjustment can be made in the dosages of anti-rejection medications while on the medications listed above.
Over-the-counter medications also can have harmful effects.

**AVOID:** Non-steroidal anti-inflammatory drugs such as Motrin, Advil, Naproxen and Aleve. When in doubt, call the Transplant Office.

It is important to remember that following transplant the Transplant Team will only write prescriptions for immunosuppressive medications. Patients are often discharged on newly prescribed medications, such as insulin or anti-hypertensives for high blood pressure. You are responsible for contacting your **primary care physicians** to follow up on these conditions.

**Resuming Life After Transplantation**

The goal of the Transplant Team is to help you return to a “normal” life. We want you to be able to return to work or school, as well as be able to do activities that you had previously been able to do, such as hobbies or traveling.

**Lifting:** Do not lift, push or pull anything over 10 pounds for approximately six weeks after surgery and nothing greater than 25 pounds for at least 12 weeks.

**Physical Activity:** You may walk up and down stairs if you need to. If you need physical therapy, an exercise program will be prescribed. Regular exercise is encouraged as a lifelong habit, but should be resumed gradually. Examples of aerobic exercises are walking, running, bicycling and swimming.

**Driving/Travel:** You may resume driving after you are off all pain medication and have been cleared by the doctor. You do not have to stay home if you feel well enough to go out in public. It is advisable to avoid close contact with anyone who is sick with a cold, the flu or any other contagious illness. If you need to travel long distances by car, you need to clear this with your doctor and remember to get out of the car and stretch every two to three hours. You can travel by airplane once you have recovered from the surgery and do not have complications that require close monitoring. If you plan to travel outside the United States, you should discuss this with your physician. You may need to receive additional vaccinations. Like any traveler, you must be careful with food and water.

**Bathing:** You may shower every day, even if your incision is open. Tub baths are not recommended until after the incision is healed. Do not use spas or hot tubs. Do not swim in lakes or ponds. Chlorinated pools are acceptable after the incision is healed and you don’t have any external bile tubes or drains.
Dental Care: It is recommended you wait six months before having any dental work done. Good dental hygiene is important as infections can start in the mouth. Most patients DO NOT need antibiotics before a dental procedure. If your dentist thinks antibiotics are necessary from their point of view, please call the Post Transplant Office to make sure the antibiotic will not interfere with the medications you are taking.

Prevention: Since your immune system is suppressed, you need to avoid people (both adults and children) with colds, the flu, or other contagious illnesses. The best way to avoid transmission of illness is by frequent hand washing, using tissue when coughing or sneezing, and by refraining from touching your face with your hands.

Gardening: You may return to gardening, but should wear gloves and always wash your hands when finished. You should wear a mask when stirring up very dry and dusty soil.

Pets: Cats and dogs are generally considered acceptable pets. Birds, reptiles and rodents are not recommended. Make sure your pet receives routine veterinary care. DO NOT handle pet waste, such as feces, and DO NOT clean the cat’s litter box or fish aquarium.

Physical Appearance: Weight gain can be addressed through a good diet and exercise. Prednisone can make your face look very full and also distributes fat in the abdomen. When the dose of prednisone is lowered, this effect should decrease. Unwanted facial hair can be removed by use of wax, etc. Loss of hair may need to be addressed by a dermatologist.

Moods: Having a liver transplant does not change a person’s basic personality. However, drugs such as prednisone may cause fluctuations in moods. Emotional effects of these medications are reversible and are dose dependent.

Sexual Activity: You can resume sexual relations when you feel comfortable doing so.

Pregnancy: Pregnancy can increase the rate of rejection and the medications can be associated with fetal abnormalities. While pregnancy is not recommended, it is not always contraindicated. You are encouraged to discuss this with your physician as everyone needs to be evaluated on an individual basis.

Return to Work and Disability: Your disability status will change after you have had a liver transplant. The purpose of getting a transplant is to restore a patient to a healthier life. We will complete the necessary insurance and disability forms immediately after surgery. If you DO NOT have complications from the transplant and the liver is working, you WILL NOT be considered disabled from the liver disease or the transplant surgery. The Post Liver Transplant team will not provide statements verifying a disability if it is not liver related.
Indications
After transplant, you take immunosuppressant medications to prevent your body from rejecting your new liver. The suppression of the immune system makes it difficult to fight off infection. Your risk is highest one to six months after transplantation. Therefore, if you are taking a medication to prevent ulcers, you are at a higher risk for food borne illnesses because anti-ulcer medications reduces the normal acid in the stomach that usually kill bacteria. **Food can cause an infection** if proper food safety guidelines are not followed. This educational handout will be a reference to help keep you healthy and is not only for liver transplant patients, but, also relevant to the general population as well.

Safe Food at the Store
- Buy cans and jars that look perfect
- Dented or bulging cans, cracked jars, unsealed lids may mean food has germs that could make you sick
- Check for “use by” dates – **DO NOT USE IF BEYOND EXPIRATION DATE**
- Put refrigerated or frozen items in cart last and take home immediately
- Put raw meat and poultry into a plastic bag so meat juices won't drip on other foods such as lettuce or fruit that will be eaten raw
- Check eggs – open carton and do not buy if any are broken or cracked. Only buy refrigerated, pasteurized eggs
- **Use caution with deli foods as there is an increased danger of cross contamination due to frequent handling**
- Be sure food is being stored at safe temperatures – hot food is steaming and cold food is cold
- Make sure counter person washes hands and changes gloves

Quick Tips
- Wash hands frequently when working with food
- Avoid cross-contamination
- Cook all animal foods to appropriate temperatures
- Do not eat raw or undercooked meats
- Drink from safe water supplies
Safe Food at Home

Storing

- After shopping – go directly home and put food away immediately
- Water – well water should be tested periodically for contamination. Check with your local water treatment center on the proper protocol to collect water samples. Well water should be avoided unless it is tested frequently.

- Refrigerator
  - Use a thermometer to ensure food is being kept at 40° F or below
  - Make sure thawing juices from meat and poultry do not drip on other foods
  - Leave eggs in carton and do not store in door
  - Keep refrigerator clean
  - Store ground meat, poultry and fish up to 1-2 days; other red meats such as steak or roasts 3-5 days

- Freezer
  - Keeps food safe by preventing the growth of microorganisms that cause food to go bad and make you sick
  - Use a thermometer to ensure food is being kept at 0° F or below

- Pantry
  - Store canned foods and other shelf stable products in a cool, dry place.
  - Never put them above the stove, under the sink, in a damp garage or basement
  - High acid foods (tomatoes and fruit) – up to 18 months
  - Low acid foods (meat and vegetables) – 2 to 5 years

Cooking/Preparing Food Safely

- Make sure that you and your kitchen are clean
- Always wash your hands for at least 20 seconds before and after you touch food.
- Wash everything before and after it touches food
- Cutting boards
  - Use only plastic or glass for cutting raw meat and poultry or have a cutting board you use exclusively for meat and poultry
  - Sanitize with solution of 1 tsp. chlorine bleach per quart of water by flooding surface and allowing it to stand for several minutes, then rinse and dry
  - Commercial sanitizers are available – follow directions on product label
• **Fresh fruits and vegetables need to be clean.** Rinse them under warm running water to wash dirt away. Use a produce brush when appropriate.

• Keep raw meat, poultry, seafood and eggs and their juices away from other foods
  - Remember germs can be spread by a dish towel or wash cloth – when wiping up juices, wash towel before using it again or use paper towels and throw them away

<table>
<thead>
<tr>
<th>FOOD</th>
<th>TEMP</th>
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<tbody>
<tr>
<td>Ground Meat &amp; Meat Mixtures</td>
<td></td>
</tr>
<tr>
<td>Beef, Veal, Lamb and Pork</td>
<td>160° F</td>
</tr>
<tr>
<td>Turkey, Chicken</td>
<td>165° F</td>
</tr>
<tr>
<td>Fresh Beef, Veal, Lamb</td>
<td></td>
</tr>
<tr>
<td>Medium Rare</td>
<td>Not safe</td>
</tr>
<tr>
<td>Medium</td>
<td>160° F</td>
</tr>
<tr>
<td>Well Done</td>
<td>170° F</td>
</tr>
<tr>
<td>Poultry</td>
<td></td>
</tr>
<tr>
<td>Chicken and Turkey, whole</td>
<td>180° F</td>
</tr>
<tr>
<td>Poultry breasts, roast</td>
<td>170° F</td>
</tr>
<tr>
<td>Poultry thighs, wings</td>
<td>180° F</td>
</tr>
<tr>
<td>Duck and Goose</td>
<td>180° F</td>
</tr>
<tr>
<td>Stuffing (cooked alone or in bird)</td>
<td>165° F</td>
</tr>
<tr>
<td>Fresh Pork</td>
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<td>Medium</td>
<td>160° F</td>
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<tr>
<td>Well Done</td>
<td>170° F</td>
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<tr>
<td>Eggs &amp; Egg Dishes</td>
<td></td>
</tr>
<tr>
<td>Eggs</td>
<td>Cook until yolk and white are firm</td>
</tr>
<tr>
<td>Egg dishes</td>
<td>160° F</td>
</tr>
<tr>
<td>Fish</td>
<td>Should be opaque, firm and flake easily with fork</td>
</tr>
<tr>
<td>Leftovers &amp; Casseroles</td>
<td>165° F</td>
</tr>
</tbody>
</table>
• Meat, poultry and seafood need to stay cold while they thaw. Thaw them:
  • In the refrigerator – **1 to 2 days** before you will cook
  • In the microwave – use the defrost setting
• Cook food to safe temperatures
• Put leftovers in the refrigerator or freezer as soon as you finish eating. Put them in shallow dishes so they cool faster. Germs grow very fast at room temperature.
• Use refrigerated leftovers within **2 days**

**Eating Out Safely**

• Always order meat, poultry, and fish well done; if the food arrives undercooked, it should be sent back.
• Ask how sauces and dressing are prepared; if raw or undercooked eggs or insufficiently cooked meat drippings are used, do not order those dishes. If the server does not know how the food is prepared, ask him or her to check with the kitchen. If still doubtful, order something else
• Avoid salad bars – others may have left germs behind
• Avoid some buffets. If dirty plates are used for second helping, avoid. If holding temperatures are questionable, avoid (is the hot food hot?). Avoid high-risk foods from buffets (e.g., eggs, cream dishes, rare beef)
• At fast food restaurants, ask for food to be prepared freshly
• Do not eat raw seafood including oysters on the half shell, raw clams, sushi and sashimi; lightly steamed seafood, such as mussels and snails, should be avoided
• Caesar salad dressing should be avoided since it contains raw eggs

**Complications Post-Transplant**

Potential complications will be discussed with you during the education sessions and prior to surgery. As is the case with all major surgeries, you may experience problems with bleeding, your heart and/or kidneys. The complications noted in this section are more specific to liver transplantation.

**Complications Following Surgery**

Two of the most serious immediate complications following a liver transplant are primary non-function liver failure (PNF) and hepatic artery thrombosis (HAT). Primary non-function occurs when the newly transplanted liver simply fails to work. This is a rather rare complication, but
if it occurs, you will need another transplant. In hepatic artery thrombosis, the arterial blood supply to the liver is stopped. If this condition is not corrected immediately, the transplanted liver dies. Another transplant becomes necessary if the condition cannot be reversed.

If these complications occur, you will be immediately re-listed as a **Status 1**, which gives you a high priority for the next compatible organ.

**Infection**

Most of the infections seen in the post-operative period are related to immunosuppression drugs necessary after liver transplantation. You will receive higher doses of anti-rejection medication right after surgery and are at the highest risk in this immediate post-operative period.

Infections seen immediately are usually related to the surgical procedure. You could develop an abscess in the wound or anywhere in the body – even in the new liver. You also could develop pneumonia, a urinary tract infection or a blood infection.

During this period, bacterial or yeast infections are more common than viral infections. Viral infections are more likely in the period of one to six months following transplant. Viral infections include CMV, herpes simplex and herpes zoster. Shingles will be discussed later.

After six months, the rate of infections in liver transplant patients is similar to the general population with the exception of those individuals who still require high doses of anti-rejection medications.

**Acute Rejection**

Acute rejection is a natural response by the immune system when the body sees something it considers foreign. Up to 30% of liver transplant recipients have at least one episode of acute rejection in the first six months. This condition is reversible if treated early. Early treatment is dependent upon early diagnosis. Frequent and routine blood work is important to identify abnormal liver enzymes. Elevated liver enzymes are an early warning sign that something is wrong. A liver biopsy is ordered to make an accurate diagnosis of acute rejection.

**Acute rejection can happen at any time after the transplant, even years later.** One of the ways to stop this process once it has begun is to increase anti-rejection drugs. One common treatment is to give high doses of steroids.
For most episodes of acute rejection, a “steroid pulse” will be ordered. An IV dose of 250 mg of Solu Medrol is given once a day for three days, usually in the TACU. This is usually followed by oral prednisone at a high dose that is gradually tapered down. How quickly this will be done will be determined by blood work that measures the liver enzymes.

If the rejection, per a biopsy report, appears less severe, just an oral dose of prednisone may be ordered. This dose is higher than what you may have been taking and may be as high as 80 mg. The dose will be tapered down if acute rejection seems to be improving based on blood work.

**Chronic Rejection**

Chronic rejection is a slow process in which the bile ducts dissolve, also known as ductopenic rejection. Abnormal lab values indicate a problem exists and a liver biopsy is done to confirm the diagnosis. Tacrolimus (Prograf®) is the medication prescribed to slow this process. A person can live many years with chronic ductopenic rejection.

**Bile Duct Problems**

Bile duct problems are caused by either a leak or by a stricture – or narrowing of the bile duct. Bile ducts are the tubes through which bile moves from the liver into the small intestine (bowel). Bile is made continuously in the liver and flows through the small bile ducts to larger bile ducts and empties into the small bowel. Normally bile that is made in the liver is stored in the gall bladder. However, the gall bladder is removed during liver transplant. It is important that bile not remain in the liver and that it is transported to the small intestine.

**Bile leak** – A leak can develop where the two bile ducts are sutured together. At times, surgery may be able to repair a leak in the bile duct. However, treatment generally consists of placing a stent or a tube across this area until it heals. Stents are placed internally through a procedure performed in the Medical Procedure Unit called an Endoscopic Retrograde Cholangiopancreatography (ERCP). The stent remains in place until there is a confirmation the leak has sealed itself. Internal biliary stents need to be changed every four to eight weeks, but leaks usually heal without further treatment within a few weeks.

Some patients, who cannot have an internal stent, are treated with a Percutaneous Transhepatic Cholangiography (PTC) tube. The PTC tube is inserted through the skin by interventional radiology. It is considered an internal/external tube since part of it is inside the patient and part of it remains outside the abdomen. This tube needs to be changed every four to eight weeks.
**Biliary strictures** - Biliary strictures can develop for several reasons. Bile ducts need a constant blood supply from the hepatic artery. Any interruption of the blood flow will cause damage to the bile ducts. The most common problem in the bile ducts is that they become narrowed. This narrowing can occur where they are sewn together or it can occur within the smaller bile ducts within the liver. If the stricture is at the suture site (called the anastomosis), a stent is placed after it is ballooned open. Sometimes, this process is done several times. If it is unsuccessful, surgery may be able to correct the problem.

Strictures that are near the liver or within the liver (intrahepatic) are more of a problem, since they tend to be more permanent and are not usually corrected by surgery. Treatment is usually a percutaneous transhepatic cholangiopancreatography (PTC) tube as this type of tube can get into the liver and it forms a path from the liver to the bowel allowing the bile to flow out into the bowel.

If bile accumulates in the liver it can become thick like sludge and can form stones. This can cause a condition called cholangitis which can lead to a serious – perhaps life-threatening – infection. Inadequate bile flow can be identified through lab results. If this is suspected, you will be scheduled for an endoscopic retrograde cholangiopancreatography (ERCP) or a PTC tube. Liver transplant patients are asked to come to the University of Michigan to have these procedures performed by our physicians who have experience in performing them on liver transplant patients.

When lab work indicates the patient has a bile duct problem, it is likely the patient will be prescribed the medication Actigall or Ursodiol to help thin the bile.

**Treatment of Biliary Leaks and Strictures**

The goal for treating biliary problems is to provide a free flow of bile from the liver to the bowel. An endoscopic retrograde cholangiopancreatography (ERCP) is a test that combines the use of x-rays and a long flexible lighted tube to allow the physician to see inside your digestive tract. A process called 'ballooning' may be used to open the stricture, place a stent in the narrow portion and/or remove stones or sludge that has accumulated in the bile ducts. Stents inserted during an ERCP will always be internal and temporary.

If the ERCP indicates a Percutaneous Transhepatic Cholangiography (PTC) is necessary, an appointment will be made for you with Interventional Radiology. A PTC Radiologist specializes in using PTC to evaluate the bile duct system and place external PTC tubes if they are necessary. A PTC tube may require a longer treatment time and may, in rare situations,
become permanent. Your surgeon and your hepatologist will confer with the radiologist who performs the PTC procedure, and the placement and removal of PTC tubes. The initial PTC and tube placement will be done as an inpatient. An overnight admission is required to monitor for complications. With the exception of the initial placement, PTC tube changes are generally performed on an outpatient basis. You will be given conscious sedation or general anesthesia for these procedures. Nurse practitioners will provide information about PTC, will answer questions and will provide follow up care after the procedures.

**External Biliary Tube Care (PTC Tubes)**

If you have an external PTC tube placed, you will need to take the following steps to care for yourself:

A dressing will be placed over the insertion site. The dressing will need to be changed every one to two days for a period of two weeks or until the site is healed. To change the dressing:

- Wash your hands
- Remove the old dressing
- Clean around the tube site daily with a clean washcloth and a mild liquid soap
- Pat dry with a new clean washcloth
- You may apply over-the-counter antibiotic ointment, such as Neosporin® or Bacitracin
- Apply a clean new dressing being careful not to twist or kink the tube

Daily care of your PTC tube includes:

- Tubes are usually flushed twice each day.Flushes are done using a 10cc syringe with normal saline.
- Flush by connecting the syringe to the end of the tube and GENTLY pushing (not forcing) the saline solution into the tube as fast as possible without causing discomfort.
- Do not pull back on the syringe.

The Radiologist will give you a prescription for all the supplies you will need to care for your PTC tube. If pain medications are needed, a prescription will be provided for a short period of time after insertion.

Avoid activities such as bending forward or lifting heavy objects. Avoid any activity that causes a pulling sensation or pain around the tube.
For the first two weeks you may shower, however, you need to cover the dressing with a double layer of plastic wrap (like Saran Wrap) and tape the edges to your skin. After the site has healed plastic wrap is not necessary to take a shower.

Occasionally a tube may become blocked. The signs of a blocked tube include fever, chills, dark urine, light colored stools, yellow skin, leakage of bile around the tube that requires frequent dressing changes, difficulty flushing the tube, or leakage when the tube is flushed. If any of these occur, contact Interventional Radiology.

If the PTC tube falls out, it must be replaced within 24 hours. Cover the insertion site with a gauze pad and call Interventional Radiology at (734) 936-4536. On weekends, holidays or after hours call (734) 936-6267 and ask for the Interventional Radiologist on call.

PTC tubes are generally changed every four to six weeks, if they are needed. The goal of treating biliary leaks/strictures with a PTC tube is to correct the problem and remove this tube. Some patients may require several PTC appointments, but the radiologist will assess the improvements in your bile ducts and remove the tube once the problem is corrected.

**Blood Flow**

Patients may experience problems with blood flow to or from the liver. Since these blood vessels are sewn together problems can occur at or near the suture sites. Problems may be the result of a clot formation or a narrowing of the blood vessel. Treatment consists of opening the blood vessels either by removing a clot, ballooning open the vessel and/or inserting a stent. These procedures are performed by interventional radiography or surgery.

**Hypertension**

Hypertension is high blood pressure. Approximately 70% of liver transplant patients develop high blood pressure after a transplant. Hypertension may improve in liver transplant patients as the doses of anti-rejection medications are reduced. Hypertension is treated using anti-hypertensive medications.

**Diabetes**

Diabetes is an elevation of blood sugar which frequently occurs as a result of anti-rejection medications, especially prednisone and tacrolimus (Prograf). Approximately 20–30% of liver transplant patients have diabetes before transplant and 40% develop diabetes after transplant.
Renal Insufficiency

Renal insufficiency is defined as an increased serum creatinine level and can develop as a result of anti-rejection medications and can range in severity from very mild to the point of needing dialysis. The goal is to closely monitor blood work so anti-rejection medications are given at the lowest possible dose to prevent rejection and have the least harmful effect on kidneys. To minimize the risk of kidney failure it is important to maintain good blood pressure and good blood sugar controls.

High Cholesterol, High Lipids

Liver transplant patients should follow the guidelines for the general population and have their cholesterol/lipid profile done once a year. As many as 40% of liver transplant recipients will develop high cholesterol levels. Patients are encouraged to keep their cholesterol and lipids under control by:

- Controlling weight through a good diet and exercise program
- Use of anti-cholesterol and anti-lipid medications
- Smoking cessation

Osteoporosis

Previous liver disease and the use of medications, such as prednisone, make liver transplant patients very susceptible to thinning bones. Bone density tests, ordered by the patient’s primary care physician, are recommended at regular intervals. Over-the-counter medications that include calcium and vitamin D, as well as prescription drugs such as Fosamax® or Actonel®, are used to prevent and treat osteoporosis. Weight-bearing exercises also are very helpful.

Cancer

The risk of cancer is three to five times greater in the transplant patient than in the general population. The most common forms of cancers in the transplant patient are skin and lip cancers. Transplant patients need to:

- Avoid direct, prolonged sun exposure
- Use sunscreen, at least SPF 30 on exposed areas
- Wear hats and long sleeves if possible
- Wear sun glasses
- Avoid tanning salons
- Have annual examinations by a dermatologist
Other rare types of cancers include:

- Lymphomas – which make up 57% of all post-transplant tumors.
- Colon cancers – especially for patients with primary sclerosing cholangitis and ulcerative colitis.

Transplant patients need to follow the routine cancer screening recommendations for the general population, for:

- Mammogram
- Gynecology
- Colonoscopy
- Prostate

**Recurrent Disease**

*Autoimmune hepatitis* can return if steroids are withdrawn. Patients will need higher doses of anti-rejection medications for their lifetime.

*Primary sclerosing cholangitis* recurs in approximately 20% of liver transplant patients.

*Primary biliary cirrhosis* recurs in approximately 20% of patients within five years of the transplant, and in 45% of the patients within 15 years of the transplant.

*Hepatitis B virus* - Patients with recurrent Hepatitis B virus can expect the following treatment regimen following transplant. They will receive the first dose of Hepatitis B Immune Globulin (HBIG) during transplant surgery. They will continue to receive HBIG daily for post operative days one through six. Starting at post operative day 30, they will receive HBIG intravenously each month for one year, administered in the TACU. Usually they will also receive HBIG by intramuscular injections each month for one year. Patients will need to take anti-viral medications for life, most frequently Entecavir. Other medications may include Lamivudine, Adefovir, and Tenofir. Blood tests will be done monthly for the first two years, then every three months in years two through four, followed by testing every six months. Oral anti-viral medications will be required for life with blood testing of the virus every six months, in addition to the blood tests necessary to monitor the health of your new liver.

*Hepatitis C virus* - The treatment regimen will be different for recurrent Hepatitis than a patient may have experienced before transplant. Post transplant therapy may be as short as six months or as long as two years.
Two major drugs to treat Hepatitis C are peginterferon alfa-2a and ribavirin. The peginterferon is an injection taken once a week while the ribavirin is in pill form and taken twice a day. Many times additional medications are required due to the side effects of these drugs. Injections may be required to build up the red blood cells and also the white blood cells, which may be three injections per week. Blood tests can be as frequent as weekly since close monitoring is necessary. Patients are closely evaluated to their willingness to comply with the program and also for the necessary prescription coverage to cover the cost of the medications, which are quite expensive.

There is treatment available for recurrent Hepatitis C post liver transplant. The protocol will be different than what patients experienced pre-transplant. Patients are closely evaluated for their willingness to comply with the program and also for the necessary prescription coverage to cover the cost of the meds as these drugs are quite expensive. The peginterferon is an injection taken once a week while the ribavirin is in pill form and taken twice a day. Many times, additional medications are also required due to these drugs side effects. Injection may be required to build up the red blood cells and also the white blood cells. That can mean three shots per week. Blood tests can be as frequent as weekly since close monitoring is necessary.

Cancer of the liver rarely comes back. Patients are screened prior to surgery to be sure they have no other tumors prior to transplant. Patients will be screened using CT, bone scans and blood tests for recurrent cancer for three years following transplant. The testing will be most frequent the first year. A schedule will be provided to the patient at the first post-op visit. Patients are requested to have the scans performed at the University of Michigan to ensure the same technique is used in the event comparisons needed to be made.

A return to substance abuse will cause damage to the transplanted liver much quicker than what was experienced before transplant. Patients who return to substance abuse will not be a candidate for re-transplantation. Substance abuse is a clear example of non-compliance.

Fatty liver, BMI (Body Mass Index) is a calculation that is your weight from your height. It is used to define overweight and obesity. A BMI of 25 or greater is defined as overweight and a BMI of 30 or more is considered obese. Obesity is the leading cause of disease conditions, such as diabetes, kidney disease, heart disease and strokes. The buildup of fat effects not only your heart and blood vessels, but it also accumulates in the liver. A fatty liver is called steatosis. A more serious condition occurs when the fatty liver becomes inflamed, called steatohepatitis. Steatohepatitis can cause liver failure which can lead to liver transplantation. Steps to prevent a “fatty liver” include diet, exercise and control of your blood sugars and cholesterol and lipids.
**Re-Transplantation**

Certain liver diseases can re-occur in the liver and cause liver failure again. If this happens, another liver transplant may be considered. The process for re-transplantation is similar to the first transplant in that a patient will be evaluated by the Transplant Team after having all the same testing as before. Because re-transplantation is more difficult to do and has a higher mortality rate associated with it, several additional factors are looked at closely:

- How compliant has the patient been since their first surgery?
- How quickly and how severe the disease is that has returned after surgery?
- How sick the patient is presently – can the patient survive a second transplant surgery?

**Immunizations and Vaccines**

**Live vs. Dead Virus**

Immunizations or vaccines consist of viruses – either “live” or “dead.” Most vaccines are made from a “killed – or dead – virus” and are safe for patients to take themselves or to be around a recently immunized individual. Common examples of vaccines made from dead viruses include:

- Cervical Cancer vaccine
- DPT
- Hepatitis A
- Hepatitis B
- Influenza “flu” shot (but not Flumist nasal vaccine)
- Pneumococcal
- Polio
- H1N1 Vaccine

Some vaccines are made from a live virus. The vaccine from a live virus can rarely cause the actual disease in a person. Patients who are immunosuppressed are less able to fight the disease and can become sicker. Patients who have had a transplant should not have vaccines from a live virus. It is very unlikely that a transplant patient would get an infection from contact with a person who received a live vaccine. Still, it is a good idea for transplant patients who never had chicken pox to avoid contact with a recipient of the shingles or chicken pox vaccine who develops a rash. Patients also should avoid direct contact with the body fluids (such as changing diapers) from a recently vaccinated individual.
Examples of live virus vaccines include:

- Chicken pox
- Flumist (nasal flu vaccine, flu shot is OK)
- H1N1 nasal spray
- MMR (Measles, mumps and rubella)
- Shingles vaccine
- Small pox

_Flu Shots and Pneumonia Shots_

Transplant patients are encouraged to receive a **flu shot every year** and a **pneumonia shot every five years**. Close contacts of transplant patients should also receive flu shots so they do not get the flu and transmit it to the transplant patients. It is recommended that all persons over the age of six months receive a flu shot.

_Tetanus and Pertussis Booster Shots_

Transplant recipients should receive a tetanus booster (dT) every 10 years. On one occasion, the tetanus shot should include a pertussis booster (dTAP).

_Chicken Pox_

If you have never had chicken pox or been vaccinated against chicken pox, you should avoid exposure to any person with chicken pox. Chicken pox is contagious for one or two days before the rash occurs and remains contagious until the sores crust over. If such an exposure occurs and you are not immune to chicken pox, you should contact your doctor to arrange treatment to prevent chicken pox, which can be very severe in transplant patients.

_Shingles (Varicella Zoster)_

It is estimated that up to 50% of immunosuppressed persons develop shingles. **Shingles is NOT caused by a new virus; it is caused by reactivation of the chicken pox virus.** Shingles is caused by the reactivation of the chicken pox virus that remains in the body after the disease appears to have gone away. Even though patients recovered from chicken pox many years ago, the virus remains in the body without the patient being aware of it. The chicken pox virus can become active again and when it does, it is in the form of shingles.
Shingles starts out as a pain or a tingling sensation, followed by blisters. It is treated with anti-viral medication and pain medication. Patients are contagious while they have blisters. This means they can give the chicken pox virus to someone else who does not have adequate immunity for this virus. The shingles vaccine is a live virus and transplant patients cannot receive this vaccination.