

Liver Transplants at University of Michigan Hospital

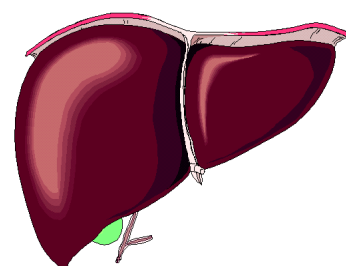
The University of Michigan is a national leader in liver transplantation, as well as the surgical and medical management of patients with liver disease. In the past 25 years, our physicians and staff have provided care to more than 1,800 adult liver transplant recipients. At the University of Michigan Health System (UMHS), state-of-the-art equipment and facilities ensure patients the highest quality care. Electronic records are continually updated, meaning patient records are available to caregivers 24 hours a day, seven days a week. This system also allows for the tracking of all outside lab work and diagnostic studies for each patient.

Normal Liver Function

The liver is the largest solid organ in the human body and plays a vital role in regulating many life processes. In an average adult, the liver weighs approximately three pounds and is about the size of a football. It is located in the right side of the abdomen and is protected by the rib cage.

The liver plays a major role in the composition and circulation of blood, therefore, it impacts all body systems. Some of the liver's many jobs include:

- Making proteins to help blood clot
- Clearing some wastes from the body
- Making bile, a yellowish-green fluid needed for digestion and absorption of food and vitamins
- Storing food to be used as energy (glycogen)
- Storing vitamins, minerals and iron
- Purifying blood by breaking down and removing medications and poisons, such as alcohol and nicotine



A Healthy Liver

Why You May Need a Liver Transplant

The liver can continue to perform with quite a bit of damage. However, when the liver becomes badly damaged, it cannot grow enough new liver tissue to heal itself. When this happens, normal liver tissue is replaced with scarred liver tissue and the liver cannot continue to do the work it is supposed to do. When the majority of normal liver tissue is replaced by scar tissue, the liver is said to be **cirrhotic** and a liver transplant may be the only effective treatment. **The indication for liver transplantation at the University of Michigan Liver Transplant Program is severe, irreversible, acute or chronic liver failure for which there is no other effective medical or surgical therapy.** Patients with rare liver-based metabolic defects also may be considered for liver transplantation.

Liver failure happens when the liver is unable to perform its normal functions. A diseased liver can result from a sudden (acute) failure as a result of an infection or a drug or toxin reaction, or it may result from a gradual failure (chronic) due to a large number of long-term diseases.

The causes of **acute liver failure** include (but are not limited to) drug-induced liver injury, fulminant (sudden/severe) liver failure, and Budd-Chiari syndrome.

The causes of **chronic liver disease** include (but are not limited to) hepatitis B, hepatitis C, alcohol abuse, primary biliary cirrhosis, primary sclerosing cholangitis, autoimmune hepatitis, fatty liver, drugs, toxins and others. Some liver diseases are inherited, such as Wilson's disease, alpha-1 antitrypsin deficiency and hemochromatosis. When the cause of chronic liver failure cannot be determined, the diagnosis is cryptogenic cirrhosis (meaning we cannot find the cause of the liver disease). Other causes of liver diseases for which the only effective treatment is liver transplantation include early-stage primary liver cancer, severe cystic disease, or rarely other tumors in the liver which are causing severe symptoms.

The signs of liver failure may include:

- Feeling very tired, fatigued
- Forgetfulness, confusion or even coma (encephalopathy)
- Tendency to bruise and bleed easily
- Itching (pruritis)
- Yellow skin and eyes (jaundice)
- Buildup of fluid in the abdomen (ascites)
- Bleeding in the stomach, esophagus or intestines (varices)
- Muscle wasting
- Weight loss



Cholangiocarcinoma

Some patients diagnosed with cholangiocarcinoma (cancer of the bile ducts) may benefit from and be eligible for liver transplant. The University of Michigan follows a UNOS-approved protocol that allows some patients access to deceased donor livers based on specific criteria. Patients may be eligible for transplant if their cholangiocarcinoma is not fast growing or extensive.

The Referral Process

You can be referred for consideration as a candidate for liver transplantation either through self-referral or by a physician, which may be your primary care physician (PCP) or a specialist.

Prior to scheduling an evaluation appointment, a transplant coordinator will discuss pertinent information with you and must receive your medical documentation from your referring physician. Patients who self-refer must have copies of their medical information sent to the transplant coordinator prior to scheduling an appointment.

After receiving the medical records and insurance information, the financial coordinator begins the work of verifying insurance coverage, benefit levels and authorization requirements.

Once an appointment has been scheduled, the transplant coordinator will provide the referring physician's office with the date and time of the appointment. You will then be asked to complete two questionnaires and bring them to your appointment. The first questionnaire requests very basic medical information. The other questionnaire requests extensive information regarding your personal and family history – which will be reviewed with the social worker during the evaluation appointment.

The Initial Pre-Transplant Evaluation Appointment

A liver evaluation appointment is actually a series of visits with several physicians and other members of the transplant team, generally all occurring on the same day.

During the initial evaluation appointment you will generally see the liver specialist (hepatologist) first. If your medical condition indicates a liver transplant would be appropriate, you will meet with several other members of the transplant team. Team members you are likely to see on evaluation day include a transplant coordinator, social worker, transplant nurse, transplant surgeon, financial coordinator and nutritionist.

Each member of the team has a specific role in the evaluation process.

You Should Know

The role of each transplant team member is explained in the Transplant Team Section of this guide.

Transplant Evaluation Testing

The testing required to assess whether you are an appropriate candidate for liver transplant is quite extensive. Many of the initial tests are ordered on evaluation day, but are often scheduled on other dates.

Testing is important to the transplant committee as it provides information regarding your medical status that is used to help determine your placement on the transplant list. Testing also helps assess whether you have other medical issues which would impact the outcome of transplantation, such as significant heart disease, lung disease, kidney disease or liver cancer which may be too advanced for transplant.

You will be given written orders for the tests you need. You also will receive instructions for completing the testing through your physician and/or dentist. As testing is completed, the results need to be faxed to the transplant coordinator at the fax number below. Occasionally, transplant physicians will require some testing be performed at UMHS. You will be advised when that is required.

Other testing may be ordered by the transplant team if there are abnormalities in your initial testing or if the team needs further information to determine whether you are an appropriate liver transplant candidate. These tests can include pulmonary function tests, additional blood work, CAT Scan/MRI, heart catheterization, etc. If any of these tests are recommended, you will be given the information regarding the test before the appointment is made.

You Should Know

Blood tests and other required tests are explained on page 12.

Reports from tests done outside UMHS should be mailed or faxed to:

Transplant Center, Liver Program

University of Michigan Health System
1500 E. Medical Center Drive
3862 Taubman Center, Box 0391
Ann Arbor, Michigan 48109-0391

(800) 395-6431 (prompt #2 for Liver Transplant)

(734) 998-2384 Fax

No patient will be put on the transplantation list until all tests are completed and the results confirm that liver transplant is appropriate. Therefore, please make sure all tests are completed and results are sent in to the transplant office as soon as possible.

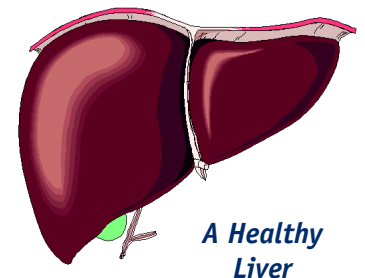
Inpatient Transplant Evaluation

There are times when a patient is admitted to the hospital and their entire evaluation is completed as an inpatient. They complete all of the same standard testing that would normally be done in the outpatient setting. This is typically done when patients are acutely ill and would be fairly high up on the transplant list.

Living Donor Livers

Living donor liver transplantation occurs when a healthy adult donates a portion of their liver to a family member or close friend. The liver is a very complex organ that does many things necessary to keep us alive. A healthy liver also has an amazing ability to regenerate itself. When a portion of a healthy liver is removed, the liver grows back to its original size within a month. No other organ (except skin) is able to regenerate in this way.

Living donor liver transplants may be advisable for some patients with liver failure. The decision whether a living donor operation is advisable is determined by the surgeons and liver specialists who care for the recipient. Factors considered include the severity of the recipient's illness, the likelihood of getting a deceased donor organ offer, blood vessel structure, and the size of the liver needed. The decision can change as the potential recipient's health changes. If the surgeons and liver specialists determine a patient may benefit from a living donor liver transplant, the option will be discussed thoroughly with the patient. Additional printed material will be made available and the risks will be explained in detail to allow the patient and their family to make an informed decision. Other factors considered include the patient's insurance coverage and the availability of a potential living donor. Please refer to Living Donor Liver section for more information. If friends or family members are interested in possibly becoming living liver donors, please ask them to call the Liver Transplant Office at (800) 395-6431.



The Liver Transplant Evaluation Committee

Every patient case is discussed at the Liver Transplant Evaluation Meeting at which time their medical, personal and family history, and support system are reviewed. This is a time when all of the committee members review each patient's case and test results to determine whether there are any issues which need to be further addressed before the patient can be placed on the liver transplant list.

There are three potential decisions that may be made regarding a patient by the Liver Transplant Evaluation Committee:

- The patient meets the criteria and is approved to be listed
- The patient does not meet the criteria and cannot be listed
- More information or testing is needed to make the determination and the decision is deferred until the information can be obtained.

If it is determined that you are an appropriate candidate for placement on the transplant list, you have completed all of the appropriate tests and have received authorization from your insurance company, you are then listed for liver transplant. At that time, you and your referring doctors would receive a letter about the Transplant Committee's decision.

Some Patients Cannot be Listed for a Liver Transplant

When a patient has one of the following conditions, they will not be able to be listed at the University of Michigan because a transplant for these conditions is considered to be either improper or not in the best interest of the patient:

- AIDS
- Untreated cancer occurring outside the liver – except benign tumors and minor skin cancers
- Irreversible brain injury
- Uncontrolled infection of the blood, originating outside the liver
- Severe impairment of vital organs system function such as heart, lung or kidney that would limit anticipated survival
- Presence of another disease for which anticipated survival is poor
- Active alcohol or substance abuse
- Strong history of non-compliance with medical care/advice



The following conditions require careful review and may prevent transplantation at the University of Michigan:

- HIV positive
- Under three months or over 65 years old
- Rapidly growing or extensive cholangiocarcinoma
- Extensive previous bile duct, gall bladder or upper abdominal surgeries
- Rapidly growing or extensive primary liver cancer

- Clots within major blood vessels into and out of the liver
- Problematic, poorly controlled psychiatric disease
- Limited social support system

Patients with insufficient insurance coverage or financial resources to cover the transplantation and necessary medications will not be approved as candidates for transplant.

Patient and Family Education Class

The Liver Transplant Patient Education class is designed to provide you and your caregivers an explanation of the entire liver transplant experience. **All liver transplant patients and/or support persons are required to attend with their intended caregivers prior to being listed for a transplant.**

A pre-transplant nurse will talk about medical care prior to transplant. A transplant social worker will explain the transplantation team and process up to the surgical procedure. A transplant nurse will talk about the surgical procedure, the inpatient stay and your life-long care. A transplant financial coordinator will also give an overview of how insurance coverage works for transplant.

The four-hour class is taught in a friendly, informal environment that encourages patient, family and caregiver interaction. The class concludes with introductions to some previous liver transplant patients, and a question and answer session. You cannot be placed on the liver transplant list until you have attended the class. Classes are offered multiple times a month to make it as convenient as possible for you to attend.

You Should Know

All liver transplant patients and/or family members are required to attend an education class (with their caregivers) prior to being listed for a transplant.

Financial and Insurance Matters

Planning ahead and being well informed will help you maximize your coverage and be financially prepared for transplant services. Financial coordinators will begin working with you and your insurance company during the pre-transplant evaluation phase to verify your coverage. Transplantation is a very complex and costly treatment for organ failure. It is important for you to understand your coverage, your potential out-of-pocket expenses, and have a long-term plan to cover transplant services.

You Should Know

Post-transplant medications can cost between \$5,000 and \$7,000 monthly and must be taken for the life of the transplant. It is essential to have adequate insurance to cover this expense, or have resources to pay for the medications.

Following transplantation, taking immunosuppressive (anti-rejection) medications is vital to the success of the organ transplant. For this reason insurance coverage or financial resources for medications is necessary. Many insurance

companies also offer a mail order option for medications, which can lower out-of-pocket costs. When prescription coverage is limited, careful planning is essential and patients may need to have funds set aside prior to the transplant. Fundraising through an outside organization or your community might be a helpful option. Some drug companies offer programs to assist needy patients with their medications. The transplant social worker or transplant financial coordinator can provide additional information about applying for these programs.

The key to financial success throughout the transplant process is for you and your family to know your insurance coverage, have a sound financial plan and stay in contact with the transplant financial coordinator. You are encouraged to contact the financial coordinators for assistance at **(734) 763-1528**, **(734) 615-1833** or **(800) 333-9013**.

Understanding Your Insurance

Often there are insurance limitations or exclusions for certain services. It is crucial that you understand your insurance coverage for transplant services and medications. We have developed a questionnaire called “Understand Your Insurance Coverage” to assist you in communicating with your insurance company and guide you in developing basic insurance knowledge about their transplant coverage. It is not intended to cover all aspects of insurance requirements for transplantation, but to provide a helpful overview of issues to consider.

You Should Know

You can find the “Understand Your Insurance Coverage” questionnaire in the Resources Section of this guide.

Not Covered By Insurance

While you might have adequate health insurance coverage, there may be services your insurance will not cover, such as:

- Transportation to and from the transplant center for frequent clinic visits
- Temporary lodging and meals for family members during and after the transplant
- Parking fees for visits to the transplant center
- Insurance premiums, copays and deductible amounts
- Possible loss of income while out of work for the transplant
- Child care

Changes in Coverage

While planning ahead, there are some important things to consider that may change your coverage.

- Reaching the maximum limit the insurance company will pay per year or per lifetime.
- Divorce or separation from a spouse can lead to cancellation of coverage on the spouse's policy.
- Changes that may impact the insurance coverage, including a change in job status due to health, lay-off, change in student status or other causes.
- Changes in your insurance policy that can lead to increased copays and/or deductibles.
- Children becoming adults and no longer being covered under their parents' insurance or state-funded health plans.

To ensure no lapse in authorization for transplant, call a transplant financial coordinator for any change to your insurance. Organ transplants require written approval from the insurance carrier prior to the transplant. If a change in insurance occurs and no authorization is in place, you are responsible for full payment of all services rendered. The authorization process is lengthy; the sooner an insurance change is identified the faster you can be re-authorized through the new insurance carrier. In addition, it is recommended that you contact a transplant financial coordinator prior to making any changes during an open enrollment period.

Health Maintenance Organizations

Health Maintenance Organizations (HMOs) require patients to have a referral from their primary care physician (PCP) prior to seeing a specialist. A referral is documentation from your primary care physician that he or she is referring you to a specialist. You must obtain the referral prior to the date of the appointment.

You Should Know

With an HMO, you must have a referral. If you do not, the HMO will not pay for the visit and you will be responsible for the bill.

In addition to PCP referrals, some insurance companies require prior plan authorization to begin the transplant evaluation process. You should call your insurance company prior to making the initial appointment to see what is required by your insurance company.

Networks

Many insurance companies are part of a larger network of hospitals and physicians. Insurance companies often contract with transplant networks to manage their transplant cases. Some insurance networks will not approve transplants at the University of Michigan and will require the patient to use a transplant center within their network, even if the preferred center is in another state.

Medicare News

If you have chronic liver disease and need to be listed for transplant, you should apply for **Social Security Disability** as soon as possible. Medicare requires two years of a documented disability before you would qualify for Medicare based on disability. Once you begin receiving **Social Security Income (SSI)** it is important for you to request an extension on any COBRA policy you may be covered under, extending the coverage until the effective date of the Medicare coverage. You must request this as soon as you start receiving SSI payments because the extension may not be allowed if requested at a later date.

When Medicare coverage becomes effective, it is strongly recommended that you obtain both Part A and Part B of the Medicare coverage. **Part B covers 80% of immunosuppressive medications as long as the patient was on Medicare at the time of the transplant.**

Patients with Medicare coverage and a Medicaid “spend down” plan will benefit by enrolling in a Medigap program.

Listing

Getting Listed

All patient cases are presented at the Liver Transplant Evaluation Meeting, at which time their medical condition and social history are discussed.

Committee members review each case to determine whether there are issues which need to be addressed further before you can be placed on the wait list for a liver. To be listed:

- You must attend the Patient Education Class
- The Transplant Evaluation Committee has determined you are an appropriate candidate
- You have completed all the requested testing
- Your insurance company has authorized you to have the transplant at the University of Michigan.

Questions

If you have questions, contact a transplant financial coordinator at **(734) 763-1528, (734) 615-1833** or **(800) 333-9013**.

Model for End-Stage Liver Disease (MELD)

MELD is a national system used to allocate livers. Patients are assigned their MELD score when they are listed. Your score is based on lab results of your liver and kidney function. A higher MELD score means a higher risk of dying prior to transplant.

The labs used for the calculation include bilirubin (a measure of jaundice or yellowing of skin and eyes), INR (measure of ability of liver to make clotting factors), and creatinine (measure of kidney function). The MELD score is recalculated each time labs are drawn. The score can range from 6 to 40. To remain actively listed, weekly lab tests are required for scores above 24. Lab tests are rechecked monthly for patients with scores of 19-24. Lab tests are rechecked every three months for patients with scores of 10-18. If you know the results of your lab tests (INR, creatinine and total bilirubin) you can calculate your MELD score using the MELD calculator at www.optn.transplant.hrsa.gov. There are exceptions that may increase the MELD score, including but are not limited to, some patients with primary liver cancer, kidney failure, acute liver failure and primary non-function or hepatic artery thrombosis in a new liver transplant.

Multi-Listing

Multiple listing allows a patient to be listed at two or more transplant centers in different donation service areas (DSA). Our transplant center receives organ offers through the donation service area coordinated by Gift of Life Michigan (GOLM), so our patients interested in multiple listing might want to consider a transplant center outside the GOLM area.

If you are interested in multiple listing, you may want to consider the following:

- You must be evaluated and accepted at each transplant center that lists you.
- Each transplant center sets their requirements for listing.
- You will want to be sure your insurance coverage will cover you at each center where you are listed. Many insurance carriers do not allow for or agree to cover the expense for services that can be provided in a more local area.
- You will need to consider transportation time, transportation costs, and your mode of transportation to each center.
- You will need to consider where you want to receive your post-transplant care. Should you choose to multi-list and are accepted and transplanted at another center, you should plan to receive your follow-up care at the transplanting center for at least one year (longer in some cases) following transplant.
- You will need to maintain current labs, other testing and contact information at each transplant center that lists you.

There is no guarantee that multiple listing will shorten your time waiting for an organ, although it may afford more chances for an individual patient to receive an organ offer sooner.

The University of Michigan Transplant Center will multi-list and will transfer your records to other centers upon your written request.

After Being Listed

Once you have completed all of the requested testing, attended the Transplant Education Class and are cleared for listing by the Transplant Committee, the transplant coordinator will place you on the waiting list. You will be notified of your listing status in two ways. First, the transplant coordinator will telephone you to tell you of the listing. In addition, the transplant coordinator will mail a letter to your home explaining the listing status.

To remain active on the waiting list, you must keep up with the listing requirements which include:

- Provide blood and urine samples as ordered to monitor your liver and kidney function, as well as any potential substance abuse
- Regular follow-up visits, providing the Transplant Office with any new testing or records that are requested
- A yearly cardiac stress test
- A yearly dental clearance
- Liver ultrasound with Doppler, every six months
- MRI or CAT scan may be required in addition to, or in place of, the ultrasound
- Yearly mammogram, (for women over the age of 40 or with a family history of breast cancer)
- Yearly pap smear (or pelvic exam if the woman has had a total hysterectomy)



Patients With Liver Cancer Have the Following Additional Requirements:

- Repeat AFP (alpha-fetoprotein, MRI/CT every three months if listed for their HCC (hepatocellular carcinoma) or CCA (cholangiocarcinoma)
- A chest CT is required

If these requirements are not met, you may be placed “on hold,” making you inactive. Patients on hold cannot be offered donated livers. You must meet the requirements and have your listing reactivated before you will be eligible for a liver transplant. A new set of labs will be required prior to reactivation. It is in your best interest to keep your testing current when listed. **It is your responsibility to make sure testing is completed and the results are sent to our office. You should contact your nurse to review your test results.**

Other medical issues can cause a patient to be placed on hold, such as infections, stroke, heart attack, other significant illness or significant operations. Patients may be placed on hold for non-medical reasons too, including change or loss of insurance, social support issues, compliance issues, and/or the patient's going out of town. You must keep the transplant team informed of any changes in your health, insurance or personal situation.

Maintaining Health While Waiting for a Liver

Maintain a Healthy Lifestyle

Staying as healthy as possible, physically and emotionally, prior to transplantation is very important. We recommend you learn all you can about your disease, testing, medications and the transplantation process prior to your operation.

Staying physically healthy includes the following:

- **Stay as active as possible.** You should take care to keep your muscles toned within your physical limitations. The effects of a diseased liver such as tiredness, feeling sick, poor appetite and depression can take a toll on your ability to perform routine daily activities. A reduced activity level can lead to decreased endurance, decreased flexibility of the muscles, and a decrease in the ability of the lungs and the heart to function which result in an increased surgical risk. A daily program of regular exercise, as well as normal activities, can help maintain general strength and energy levels. If you are unsure of your physical limitations, you should discuss this with your physician.
- **Eat a well-balanced diet.** The nutritional goals for patients with liver disease include:
 - Taking in adequate calories to correct or prevent weight loss
 - Improving nutritional status
 - Restricting sodium in the diet when a build-up of fluid in the abdomen occurs
 - Getting as much protein as possible without inducing hepatic encephalopathy
 - Taking in adequate calories and protein from your diet to help in liver cell regeneration and improve liver function
 - Preventing vitamin and mineral deficiencies
- **Patients who smoke need to quit.** If you have difficulty quitting, you should ask your physician or nurse for help locating a resource to assist you in quitting.

You Should Know

See page 19 for more specific information on nutrition and liver disease.

You Should Know

See page 24 for our policy on smoking.

- **Patients who are overweight should lose weight.** This will reduce the risk of complications before, during and after transplantation.
- **Patients with chronic liver disease should not eat raw shellfish such as oysters, mussels or clams.** There is a risk of rare, but potentially fatal, infection by the bacterium *vibrio vulnificus*.
- **Prevention of illness.** Avoid people with colds and the flu or other contagious illnesses. The best way to avoid transmission of illness is by frequent handwashing, using tissue when coughing/sneezing and by refraining from touching your face with your hands.

Staying emotionally healthy includes the following:

- **You are encouraged to share your feelings.** Feelings such as guilt, anger, frustration and irritability are normal prior to liver transplantation. Depression is common among people awaiting transplantation. If you begin to feel overwhelmed by emotions, you are encouraged to talk to your transplant team social worker. Social workers are trained to assist patients and their loved ones in coping with the challenges of chronic illness and treatment. Joining a support group can be helpful. The forum for these groups involves sharing and learning, which can be very valuable to you and your family.
- **You are encouraged to stay involved.** Keeping life as normal as possible helps maintain stability during the waiting period. Waiting for a liver transplant does not require you to put other parts of your life on hold. You should try to stay involved in work and leisure activities. Sometimes health issues will interfere with your ability to do normal activities. You may need to be creative and find new outlets for your energy to accommodate your individual health needs.
- **You are encouraged to learn to relax.** You should identify those activities that you find relaxing and make commitments to yourself to do at least one relaxing activity each day. Some activities that help reduce stress are taking a walk, listening to or playing music, reading, relaxation classes, talking with friends or family, writing, drawing, painting, as well as many other activities. Avoid unhealthy outlets of stress such as abusing drugs or alcohol, overeating, or isolation from friends and family.
- **You are encouraged to accept offers of help.** Sometimes it is hard to ask for help or to say “yes” to an offer of help, but it can be very helpful for patients to ask for help. If someone asks how they can help, allow them to do something for you, like pick up groceries, cook a meal, run an errand or provide transportation to a doctor appointment. Any suggestion that saves you time or energy, or brings you enjoyment, is a good suggestion.

Family Members and Friends

Having supportive friends and family members is very important for transplant patients, not only for the emotional support they provide, but for the assistance you will need before and after transplant, such as driving to follow-up appointments and staying with you as needed before and after transplant. It is important to remember that chronic illness can add stress to the entire family. When a family member becomes ill, it can change the roles and responsibilities for all family members. There are often changes in daily routines, plans for the future and relationships. It is common for friends and family members to use coping strategies to protect themselves from their own fears about the patient's illness. This can interfere with family communication. You are encouraged to be honest with yourself about how you are feeling and communicate those feelings to your loved ones.

What to Know About Medications Prior to Transplant

It is important for you to be familiar with all of your medications. The Transplant Team (including physicians, nurses and physician assistants) will help you understand your medications and the importance of taking them. The team can assist you in making good decisions about the best times to take your medicines. You are encouraged to keep a written list of your medications, doses, and the times they are taken. The written list should include all over-the-counter and herbal medications, as well as prescribed medications. Since medications are frequently changed to meet medical needs, it is important that you update your list of medications when changes occur. **Medication doses frequently change and may not be the same as the directions on the bottle. Take the dose as instructed by the clinic or office.**

Bring a current list of medications to each office visit.

You should know the following about your medications:

- Name of each medication
- When to take each medication
- How to take them
- Why you are taking each drug
- What are the major side effects
- What food or other drugs to avoid when taking them
- What to do if a dose is missed
- When and how to order refills
- What the medication looks like

You Should Know

Medication doses frequently change and may not be the same as the directions on the bottle. Take the dose as instructed by the clinic or office.

You should know the following about storing medications:

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

You should call the Transplant Team about medications if:

- You cannot take your medications for any reason
- You get a skin rash, fever, nausea, vomiting, diarrhea or any unusual symptoms
- You are not sure what dose to take
- The medication looks different than what you've had before
- If you believe you need over-the-counter medications – pain relievers, cold medicines, etc. **you should not take aspirin or non-steroidal anti-inflammatory drugs such as Motrin® (ibuprofen), Advil®, Aleve® (naproxen sodium), etc.** Tylenol® (acetaminophen) is the recommended pain reliever for patients with cirrhosis, as long as they do not exceed 2000 mg of acetaminophen per day (about four extra strength (500 mg) or six regular (325 mg) Tylenol®, or 10 grams per week (20 extra strength or 30 regular Tylenol®). Since many pain medications, as well as over-the-counter medications, contain acetaminophen, it is important to read labels to ensure that you are not exceeding the maximum daily dose.
- If another physician prescribes or changes any of your medications
- If you have any doubts or questions
- If you need a refill before your next clinic visit

You Should Know

See page 21 in the Resources Section for more information on the safe use of acetaminophen.

You should be aware of the following related to refills of medications:

- **Refills should be obtained at your clinic visits.** Ask your physician for any prescriptions which will run out before your next clinic visit with your pre-transplant liver physician.
- If you need a refill of medication before your next clinic visit, you should call the Pre-Transplant Liver office at **(800) 395-6431 (prompt #1)**. A 72-hour notice is required for all prescription refills. Please do not wait until you are out of medication before calling. You will need to leave the following information with the clerk or on the answering machine:
 - Your name
 - Your CPI number, as shown on the blue U-M hospital card
 - Your date of birth
 - A telephone number where you can be reached between the hours of 8 a.m. and 4:30 p.m.
 - Your pharmacy name and telephone number
 - Medication name and dose
 - How often the medication is taken (one time a day, two times a day, one time a week, etc.)
 - How much of the medication you have left
 - Please allow a minimum of three days for refill requests to be processed. While a sincere effort will be made to process requests in less than three days, it cannot be guaranteed.
 - The Pre-Transplant Liver Office can refill only those medications prescribed by pre-transplant liver physicians. For all other medication refills, you will need to contact the physician's office that ordered the medicine.

Medication Chart *(Bring to each clinic visit)*

Patient Name _____ CPI # _____

Medication Name	Dose	Time	Time	Time	Time	Purpose

- Medication Tips:*
- Take medications at the same time every day as prescribed by your physician.
 - Wear a watch to keep track of medication dosing times.
 - Use a pillbox to organize your medications at the beginning of each week.
 - Keep extra medication handy when you are on the go.
 - Plan ahead for refills. Refill medications seven days before your meds run out – 14 days if you use a mail order pharmacy.

Nutrition

Nutrition Goals

Liver transplant patients should have these nutritional goals:

- Consume adequate calories to correct or prevent weight loss and improve nutrition status.
- Restrict sodium in the diet to 2,000 mg per day when swelling of the legs or feet occurs or when a buildup of fluid in the abdomen occurs.
- Consume small frequent meals and bedtime snacks to prevent long periods of going without food. During fasting, glycogen stored in the liver become depleted and muscle and/or fat are used for energy in the body.
- Consume as much protein as possible without inducing hepatic encephalopathy.
- Consume adequate calories and protein from the diet to help in liver cell regeneration and to improve liver function.
- Prevent vitamin and mineral deficiencies.

Sodium-Restricted Diet

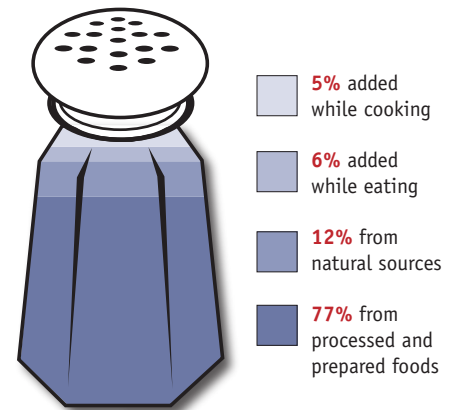
A low-sodium diet consists of no more than 2 grams (1 tsp or 2,000 mg) of sodium in a 24-hour period.

The Facts About Sodium

Sodium, also known as sodium chloride, is a mineral found in the body and in the food we eat. Salt is the main source of sodium in the diet. Sodium facts include:

- A food product may contain little salt, but may still contain sources of sodium.
- Salt is the main source of sodium in the diet, with one teaspoon containing 2,000 mg of sodium.
- The average diet includes 4,000 to 6,000 mg of sodium each day.
- A low-sodium diet allows about 1/8 teaspoon of salt per day in food preparation.
- Some sources of sodium are not obvious in the food we eat. Softened water, bottled water and some medications (such as antacids, laxatives and antibiotics) are sources of hidden sodium.

Common Sodium Intake








Read the Labels


Foods which contain greater than 400 mg of sodium per serving should be avoided as a general rule. Limit foods with 200–400 mg of sodium per serving. A good choice would be foods which contain less than 200 mg of sodium per day.

Healthy Food Choices

Eating a low-sodium diet helps us to feel better and lower fluid buildup in the abdomen. The following tool is designed to assist you in making healthy low-sodium choices in your diet.

GOOD CHOICES	AVOID
<p>Meats and Meat Alternatives: Fresh beef, pork, veal, lamb, poultry, fish Eggs Dried beans, peas, lentils Unsalted nuts, unsalted peanut butter</p> 	<p>Processed meats, such as bacon, sausage, pepperoni, hot dogs, ham, luncheon/deli meats, chipped beef, corned beef, anchovies, sardines, caviar Meat alternatives/vegetarian entrees Dried meat, smoked fish Salted nuts, salted peanut butter Microwave/frozen meals</p>
<p>Milk, Yogurt, Cheeses: Milk or yogurt Frozen yogurt, ice cream, ice milk Natural swiss cheese Low-sodium cheeses Low-sodium cottage cheeses</p>	<p>Buttermilk, malted milk Processed cocoa Processed cheese Bleu, feta, and other high-sodium cheeses Cottage cheese</p>
<p>Breads, Cereal, Rice and Pasta: Bread, rolls, breadsticks Taco shells, tortillas Pasta, barley, rice cooked without added salt Unsalted cooked cereal Low-sodium crackers Homemade soup with low-sodium ingredients</p>	<p>Breads, rolls, breadsticks made with garlic salt, onion salt, or cheese Stuffing mixes Pasta or rice mixes with seasoning packets Instant hot cereals, ready-to-eat boxed cereals Salted crackers Regular canned or dry soups, broths, bouillons Baking mixes such as cakes, pancakes, waffles or muffins</p> 

GOOD CHOICES	AVOID
<p>Vegetables: Fresh or frozen vegetables without salt added Homemade tomato sauces</p> 	<p>Canned vegetables Vegetable juices Pre-made spaghetti/tomato sauce Instant mashed potatoes, boxed Potato mixes Sauerkraut, pickles, olives or other pickled vegetables</p>
<p>Fruits: Any kind of fruit or fruit juice, fresh, frozen or canned</p>	<p>Adding salt to fruits (such as on watermelon) Glazed or crystallized fruit</p>
<p>Snacks: Fresh fruits and vegetables Unsalted popcorn Unsalted pretzels Unsalted nuts Unsalted crackers</p> 	<p>Potato chips, taco chips, corn chips, Regular popcorn Regular pretzels Regular nuts Regular crackers Other salty snack foods</p>
<p>Beverages: Water Milk Coffee, decaf coffee Teas Cocoa made with milk Soda with no- or low-sodium (limit 24 ounces or less per day) Fruit juices Powdered drink mixes</p>	<p>Gatorade® Powerade® Vegetable juices Instant cocoa mixes Instant cappuccino mixes</p>
<p>Desserts: Gelatin desserts Fruit ice Homemade tapioca, rice and cornstarch pudding Custard made with milk Hard candy Homemade cake, cookies, pie, sherbert, ice cream and ice milk (limit to one serving or less per day)</p>	<p>Instant pudding or other pre-packaged dessert mix Whipped topping Frozen pies Minced meat pies</p> 

GOOD CHOICES	AVOID
<p>Fats, Oils (use sparingly): Vegetable oil and mayonnaise Unsalted butter or margarine Regular butter or margarine in small amounts (less than 1 teaspoon per day) Unsalted salad dressing Low-sodium salad dressing Low-sodium cream, non-dairy creamers Unsalted nuts Avocado Cooking fat or oil</p>	<p>Salt, salted spices such as garlic salt, onion salt or other flavored salts Nu-salt or lo-salt, lite salt, Butter Buds Soy sauce, tartar sauce, teriyaki sauce Salsa, worchestershire sauce, bouillon Sweet & sour sauces, steak and barbeque sauce Monosodium glutamate (MSG) Prepared horseradish, prepared mustard Ketchup, relish, seasoning/coating mix, meat tenderizers, flavored vinegar Cooking wine</p> 
<p>Seasonings and Condiments: Herbs and spices without salt Hot sauce Lemon Garlic Onion Fresh horseradish Low-sodium ketchup Low-sodium chili sauce Low-sodium steak sauce</p>	<p>Salad dressings containing sodium Bacon and bacon fat Gravy made with mixes or bouillon Cream cheese Snack dips made with processed cheese or instant soup mixes</p>

Suggestions to assist in controlling sodium intake:

- Cook low-sodium meals at home and freeze them
- When eating convenience or processed foods can't be avoided, read the labels and use these guidelines to make low-sodium choices:
 - *Convenience or Processed Foods:* Select one containing 200 mg or less of sodium
 - *Frozen Meals:* Select one containing 500-600 mg or less of sodium
 - *Canned Foods:* Select sodium-free brands or rinse the food before preparing. Rinsing canned food under water does help to decrease the amount of sodium
- Experiment with salt-free spices and herbs to flavor food without sodium
- Softened water is higher in sodium. Use bottled water or use a calcium salt in the water softener

- Some bottled drinking water may have sodium in it; read the label to make sure no sodium is in your bottled water
- When dining out follow these guidelines:
 - AVOID FAST FOOD RESTAURANTS
 - Order broiled meat or fish
 - Order sauces, dressings, gravy on the side and limit the amount used
 - Use condiments in limited amounts, such as mustard, ketchup and salad dressings
 - Avoid bacon bits, cheese and croutons on your salad

You Should Know

For more information on reducing sodium from your diet, please visit the American Heart Association website at www.americanheart.org or call (800) 242-8721.

You should read the labels to be aware of serving size and sodium content of foods when selecting food items. All foods contain a certain amount of natural sodium; however, certain food types are higher than others. The sodium content of food is usually labeled in milligrams (mg) on food labels. Look for these labels:

- Sodium-free – less than 5 mg per serving
- Very Low Sodium – less than 35 mg per serving
- Low Sodium – 140 mg or less per serving
- Reduced Sodium – 75% reduction from usual sodium content
- Unsalted, Without Salt, or No Salt Added – no salt added during processing to a food which is normally salted.

Low-sodium recipe books are often helpful and can be obtained from local bookstores.

Why You Need to Restrict Sodium in Your Diet

Sodium in the diet encourages the body to retain water. The fluid may gather in the feet, legs, abdomen or other body tissues. Patients with cirrhosis and chronic liver disease are particularly prone to sodium retention. Medications, called diuretics, help the body get rid of extra sodium and water in the body. Since ongoing sodium intake renders the diuretic medications ineffective, it is important for patients with liver disease to restrict sodium intake. Eating a low-sodium diet helps patients to feel better and to lower fluid buildup in the body.

Why Patients With Low Blood Sodium Levels Need to Restrict Salt

A serum (blood) sodium level of less than 135mEq/l is often the result of total body fluid overload – not too little sodium in the diet. Blood sodium levels decrease when fluid levels build up in the body, diluting the blood sodium level. A sodium restriction, along with a fluid restriction, may be necessary with low blood sodium levels.

Resources:

- Low-salt cookbook, 3rd Edition, American Heart Association
- www.liverfoundation.org, Diet and Your Liver
- umaine.edu/publications/4059e/ University of Maine, Sodium Content in Your Food

Smoking Policy

Patients are encouraged to follow healthy lifestyles both before and after liver transplantation, which includes abstaining from all tobacco products, including cigarettes, cigars and chewing tobacco. Multiple studies have shown that cigarette smoking accelerates heart disease and hardening of the arteries throughout the body, chronic lung disease, and significantly increases the risk of developing multiple forms of cancer including primary liver cancer. In patients with hepatitis C, recent studies have suggested that smoking cigarettes may also increase the rate of disease progression and development of cirrhosis. For patients with cirrhosis, recent studies also have demonstrated that smokers are at substantially greater risk of developing liver cancer over their lifetime compared to non-smokers which may make subsequent transplantation impossible.



In liver transplant recipients, smoking is associated with a greater risk of post-transplant complications, including the need for longer stays in the Intensive Care Unit (ICU) on a breathing machine, as well as pneumonia. In addition, smokers are at greater risk of developing blood clots within blood vessels in and out of the liver which can lead to damage to the new liver. Finally, prior smokers are at increased risk of developing head and neck cancer many years after liver transplantation than non-smokers.

Because of the well-established hazards of smoking, we encourage all of our liver transplant candidates and recipients who smoke to enroll in a formal smoking cessation program. Enrollment in a structured program at a hospital or local clinic not only provides practical advice on seeking substitute activities and dealing with nicotine cravings but also has been associated with a higher sustained success rate in smoking cessation compared to unsupervised efforts of patients trying to quit on their own. Smokers with liver disease can be treated with a nicotine patch, nicotine gum and/or Zyban® (Wellbutrin®) as needed in a medically supervised manner.

Available smoking cessation programs include:

- Kick the Habit
UMHS Tobacco Consultation Service
(734) 936-5988
quitsmoking@med.umich.edu
- Michigan Department of Community Health
(800) 537-5666

Many local hospitals also have programs and support groups to facilitate smoking cessation and our social workers can provide referrals as well.

Substance Abuse Policy

Liver disease due to alcohol and hepatitis C infection are the leading causes of liver failure in the United States. Not surprisingly, these two diseases also are the most common indications for liver transplantation. Since alcohol and illicit drugs can damage the liver, it is very important that all liver transplant candidates completely abstain from these substances both before and after transplantation.

The UMHS Liver Transplant Program has developed a substance abuse policy that all adult patients are required to read, sign and follow both before and after transplantation regardless of prior use or non-use of alcohol or illicit substances. The written policy is explained to all patients and their families during their pre-transplant evaluation clinic visit. **The policy strictly forbids the use of any alcohol and illegal or illicit drugs including cocaine and marijuana (even for medicinal purposes), both before and after transplantation.** In addition, the program reserves the right to randomly screen liver transplant candidates and recipients for illicit substances at any time. Listed patients who violate this program policy will have their listing status immediately changed to “inactive.” Upon further investigation, those with documented non-compliance to our written policy will be removed from the list.

It is important to use only alcohol-free cough syrup and alcohol-free mouthwash. Do not drink alcohol-free beer (it does contain alcohol). Do not eat foods cooked in alcohol.

Prior to transplant listing, most patients with a history of substance abuse will be required to undergo inpatient or outpatient substance abuse counseling, rehabilitation or treatment. Specific recommendations and referrals will be made on an individual basis. All patients recommended to undergo these treatments will be responsible for following up with the transplant team to ensure that all rehab and treatment goals have been met. Listing will occur only after the transplant social worker confirms that the goals have been met.

You Should Know

Although medical marijuana is now legal in the State of Michigan, the UMHS policy on the use of marijuana by transplant patients remains unchanged. The use of marijuana (even for medicinal purposes) is prohibited.

Complications Which May Occur While Waiting for a Liver Transplant

If You Need Immediate Medical Care

Many of the signs or symptoms shown below may indicate a life-threatening complication requiring immediate medical care. If you experience any of these signs and/or symptoms, you should contact your nurse.

- Increased fluid in the abdominal cavity
- Swelling of legs and feet from retained fluid
- Trouble concentrating or forgetfulness
- Fever, greater than 100.5°
- Black, tarry stools or blood in stool
- Blood in the saliva or vomiting blood
- Yellowing of eyes or skin or dark-colored urine
- Shortness of breath or difficulty breathing
- Stomach or abdominal pain
- Persistent nausea and vomiting
- Itching
- Weight loss
- Weakness

Medical Emergency

Inform family and friends to call **9-1-1** if you are vomiting more than a few mouthfuls of blood or become unconscious and cannot be aroused.

The following additional information is provided to assist patients in recognizing, understanding and appropriately managing the symptoms they may experience.

Recognizing Ascites

Ascites is an accumulation of fluid in the abdominal cavity. When this occurs the following steps are recommended:

- You should weigh yourself each morning and keep a record of your weight history.
- You need to restrict your sodium to less than 2,000 mg a day.
- You may be placed on medications, called diuretics (water pills), to help remove some of the retained fluid. The most commonly used water pills are Lasix (furosemide) and Aldactone® (spironolactone).
- If the diuretics do not resolve the retention of fluid, you may need to go to the hospital to have the fluid drained through a procedure called a paracentesis (abdominal tap).

You Should Know

See page 19 for guidelines on sodium intake.

- If an infection is present in the fluid, you will be placed on antibiotics to prevent future infections.
- You should call the Transplant Office if you have ascites and gain or lose more than five pounds in one week, become short of breath, run a temperature of 100.5° or greater, or have severe abdominal pain.

Know About Encephalopathy

Encephalopathy is a condition of the brain and central nervous system caused by toxins not filtered out of the blood by the liver. It is characterized by personality changes, intellectual impairment and a depressed level of consciousness. Patients with mild and moderate encephalopathy demonstrate decreased short-term memory and concentration. Patients may also show signs of asterixis, which is a flapping tremor of the hands.

- Patients who show confusion will be placed on a medication called Lactulose (Duphalac® or Kristulose™). This medication changes bacteria in the intestines and increases the number of bowel movements. The patient will need to adjust the dose of Lactulose according to the liver physician's order to have three to four bowel movements daily. The dose may be increased if there are fewer bowel movements or if the patient is slightly confused, and decreased if there are too many bowel movements. All dose changes should be supervised by a physician.
- Patients who are becoming confused, whether or not they are on Lactulose, need to call the Transplant Office.
- Sometimes, antibiotics – Neomycin and Metronidazole (Flagyl) are given to patients who do not respond to Lactulose.

Understand Esophageal Varices

Esophageal varices are dilated veins in the walls of the esophagus or sometimes in the upper part of the stomach. These are varicose veins in the food pipe resulting from increased blood pressure in the portal vein (called portal hypertension) due to resistance to blood flow in the liver. The increased pressure causes the veins to distend and may rupture (break), which would cause the patient to vomit blood, have bloody stools or black tarry stools.

You Should Know

If you experience any acute shortness of breath, light headedness, bleeding or dark stools, you should call 9-1-1, the Transplant Office or your local doctor immediately. This is a medical emergency and requires treatment in a hospital setting. Bleeding must be stopped as soon as possible to prevent shock and death.

- Patients with esophageal varices may be placed on medication, such as a beta-blocker – Propranolol (Inderal®) or Nadolol (Corgard) to help prevent bleeding. The medication lowers the heart rate and blood pressure and helps prevent bleeding by decreasing the blood pressure in the portal vein.
- Other medical or surgical treatment may be needed to help prevent future esophageal bleeding. Other treatments may include:
 - Endoscopic therapy involves using a device with a light, called an endoscope, that allows a physician to look into the esophagus. The physician may directly inject the varices with a blood clotting medicine or place a rubber band around the bleeding veins (banding of varices).
 - Transjugular Intrahepatic Portosystemic Shunt (TIPS) is a medical procedure that helps correct blood flow problems in the liver. It is performed in the Radiology Department. The radiologist will make a small tunnel through the liver with a needle connecting the portal vein to one of the hepatic veins through which blood can flow out of the liver. After the tunnel is made, the physician will insert a small metal tube (called a shunt or stent) into the tunnel to make sure the tunnel stays open.

About 20-30% of patients will have a new encephalopathy or worsening of pre-existing encephalopathy after TIPS. Therefore, TIPS is used only when other procedures have failed.

Where and Who to Call When You're Sick – Prior to Transplant

Many problems occur while awaiting a liver transplant. It is extremely important the patient remain in contact with the Liver Transplant Team.

Pre-Liver Transplant Office

(800) 395-6431 (prompt #2)

(734) 763-4574 Fax

Hours: Monday - Friday, 8 a.m. to 4:30 p.m. Closed holidays

Call if:

- You are hospitalized outside the University of Michigan Hospital
- Another doctor changes your medications or prescribes a new medication
- Your medical condition changes
- Your telephone numbers change
- Your medical insurance changes
- You need to travel out of town
- You or your family have questions or concerns

Due to the high volume of telephone calls, you may need to leave a message on the answering machine. Messages are retrieved several times throughout the day. While every effort is made to return all calls on the same day, sometimes this is not possible. Telephone calls are prioritized – with calls from sick patients receiving the highest priority. To ensure the calls are prioritized appropriately, please include the following when leaving a message:

- State clearly your first and last name, spelling the last name
- Provide your CPI number as shown on the blue U-M hospital card
- Provide a telephone number where you can be reached between 8 a.m. and 4:30 p.m.
- Briefly state the reasons for the call or concern
- If you are sick, give the nature of the sickness
- Provide your nurse or physician name

To schedule an appointment, please ask the clerk answering the telephone to assist with this.

To request a prescription refill, please call the prescription refill line at **(800) 395-6431** (option #1) and leave the following information:

- Your name
- Your telephone number
- Your CPI number, as shown on the blue U-M hospital card
- The name of the medication to be refilled
- The dose and how frequent the medication is taken
- The pharmacy and their telephone number
- The amount of medication remaining on the current prescription

Please allow a minimum of three days to have prescription refills processed.

You Should Know

For sick calls after hours or on weekends, please call **(734) 936-6267** and request the GI fellow-on-call be paged. Provide your name, CPI number and contact number to the operator. The after-hours operator will take the contact information and will have the GI fellow-on-call return your call.

For questions regarding your listing status, contact the transplant coordinator. Please refer to the Liver Transplant Team Section of this guide.

For questions regarding your insurance, contact the financial coordinator. Please refer to the Liver Transplant Team Section of this guide.

