

Liver Transplants at University of Michigan Health

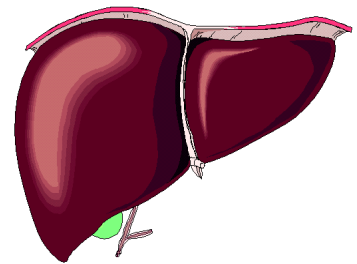
University of Michigan Health is a national leader in liver transplantation, as well as the surgical and medical management of patients with liver disease. Since 1985, our physicians and staff have provided care to more than 2,700 adult and pediatric liver transplant recipients. At University of Michigan Health, state-of-the-art equipment and facilities help to 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. **MyUofMHealth.org** allows patients to review test results, request prescriptions, request clinic visits and send non-urgent messages to their health team.

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 certain liver tumors or 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



The Pre-Transplant Evaluation Appointment

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

During the 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 dietitian.

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 Should Know

Blood tests and other required tests are explained on page 5.

You will be given written orders for the tests you need outside of University of Michigan Health. Tests done at University of Michigan Health do not require written orders as they are entered electronically. You also will receive instructions for completing the testing through your doctor 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 additional testing be performed at University of Michigan Health. 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, CT Scan/MRI, heart catheterization, etc. If any of these tests are recommended, you will be notified before the appointment is made.

Reports from tests done outside University of Michigan Health should be mailed or faxed to:

Transplant Center, Liver Program

University of Michigan Health
1500 E. Medical Center Dr., SPC 5244
Room F6511A
Ann Arbor, MI 48109-5415

(800) 333-9013

(734) 998-2384 Fax

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

Summary of Tests for Liver Transplant Patients

| TEST | INFORMATION OBTAINED |
|---|--|
| Urine Tests | Screens for infections, renal (kidney) disease and to test for illicit drugs and/or other drug abuse. |
| Chest X-ray | Determines the health of the patient's lungs and lower respiratory tract. |
| Liver Ultrasound with Doppler Abdominal CT or MRI/MRV | Examines the patient's liver and other abdominal organs for the presence of tumors and/or fluid in the abdomen, and to see if the major blood vessels of the liver are open. |
| Dobutamine Echocardiogram or 2D Echocardiogram | Provides information to ensure the patient has no heart diseases that may prevent transplantation. |
| Quantiferon or PPD | Provides information regarding the patient's prior exposure to tuberculosis and whether or not treatment is needed after the patient's transplant. |
| Dental Clearance | Determines the health of the patient's teeth and gums. |
| Mammogram <i>(For female patients over 40 or with a patient/family history of breast cancer)</i> | Screens for any breast masses. |
| Pelvic Exam with Pap Smear | Screens for cancer of the reproductive organs and/or any sexually transmitted diseases. Patients who have had a hysterectomy do still need a pelvic exam. |
| Colonoscopy <i>(For patients over 50 or bleeding)</i> | Screens for colon cancer and polyps, evaluates bloody diarrhea and anemia. |
| Upper Endoscopy (EGD) | Screens for esophageal varices, ulcers, upper GI bleeding, or other upper GI disorders. |
| Nuclear Medicine Pet Scan | Pet scan produces pictures of the heart. We are able to diagnose coronary artery disease with this test. It shows healthy and damaged heart muscle. |

Inpatient Transplant Evaluation

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

The Liver Transplant Evaluation Committee

Each patient's case is discussed at the Liver Transplant Evaluation Committee meeting. Topics include his/her medical, personal and family history, insurance, support system and all test results. After the transplant evaluation meeting, you and your referring doctors will receive a letter about the Liver Transplant Evaluation Committee's decision. One of three decisions will be given:

- All criteria is met and the patient can be listed for liver transplant.
- The patient does not meet the criteria and cannot be listed.
- More information or testing is needed and the decision is delayed until that information can be obtained.

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 University of Michigan Health 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



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

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

- 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

Patient and Family Education Class

The Liver Transplant Patient Education class is designed to provide you and your caregivers with an explanation of the entire liver transplant experience. **All liver transplant patients are required to attend with their intended caregivers before being listed for a transplant.** There are times (such as during the COVID-19 pandemic) the class may be offered virtually. When that is the case, copies of the slide presentations are sent to families before the class.

You Should Know

All liver transplant patients are required to attend an education class (with their caregivers) before 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

Please refer to the Finance section for further information.

Listing

Getting Listed

All patient cases are presented at the Liver Transplant Evaluation Committee meeting, at which time their medical condition and social history are discussed. Committee members review each case to determine whether there are additional issues which need to be addressed before you can be placed on the wait list for a liver. To be listed:

- The Transplant Evaluation Committee has determined you are an appropriate candidate.
- All required testing has been completed.
- Your insurance company has authorized your transplant at University of Michigan Health.
- You have attended the Patient Education Class.

Much information is required at the time a patient is listed for a deceased donor organ. Each piece of information is necessary and is used to make determinations. Below are four categories of information that are required at listing:

- **Model for End-Stage Liver Disease (MELD) Score**
A mathematical method that attempts to assess the patient's risk of dying before a transplant.
- **Blood Type**
The patient's blood type is used in the process of matching a donated organ to a recipient.
- **Weight Range**
The patient's normal weight is used in the matching process to ensure the donated organ is a good fit with the patient's physical size.
- **Demographics**
The patient's demographics (location) is used in the matching process to ensure the donated organ and the recipient can get to the transplant center in time to be transplanted.

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 before a 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.

Exceptions to MELD

There are exceptions to the MELD score that would result in a higher score than the standard calculation would determine. Some of the exceptions may occur before a patient's first transplant and others may occur following a transplant. While exceptions are never guaranteed, the following conditions may warrant consideration for an exception.

- Some conditions allow for a lump sum of extra points to a patient's MELD score, including:
 - Liver (Hepatocellular) cancer (HCC)
 - Hepatopulmonary syndrome
 - Some metabolic diseases
- Status 1 – Pre-Transplant:

In patients without any previous history of liver disease, the following situations may warrant a Status 1 designation. Status 1 is not awarded to a patient with chronic liver disease.

 - Acute decompensating Wilson's disease
 - Sudden liver failure with death being imminent, occurring in an otherwise healthy individual
- Status 1 – Post-Transplant:
 - Primary non-function of a transplanted organ within seven days of a liver transplant
 - Clotting of the hepatic artery within seven days of a 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 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 Health Transplant Center will multi-list and transfer your records to other centers upon your written request.

Remaining Active on the Transplant List

To remain active on the wait 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
- Yearly cardiac stress test
- Yearly dental clearance
- Liver ultrasound with Doppler every six months
- MRI or CT 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)



Additional Requirements For Patients With Liver Cancer

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

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 before 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 going out of town. You must keep the transplant team informed of any changes in your health, insurance or personal situation.

You are Listed

Communication

Communication with the transplant team is vital. When an organ becomes available for you, the transplant nurse coordinator has only **ONE HOUR** to reach you before the offer must move on to the next patient on the list. For the organ offer to be accepted, you must be prepared for the transplant. You should take the following actions when you are added to the list:

- Make a written list of important phone numbers. This should include the numbers given as contact numbers to the transplant team as well as numbers you will need should an offer be made.
- Make arrangements for a safe driver to take you and your family to the hospital. This should be someone other than a spouse or significant other. Always have a backup plan just in case the designated person is unavailable when the call comes in.
- Make arrangements for someone to care for children and/or pets. Again, have a backup plan just in case the designated person is unavailable when the call comes in. In developing your plans, remember that there is no way to predict the length of your hospital stay.
- Identify a spokesperson to communicate with the transplant team if you are unable to do so. The spokesperson needs to be someone consistently involved in your care plan – before, during and after transplant.

- Pack a suitcase with the items you will want to take with you to the hospital. For your comfort, you are encouraged to bring loose fitting clothing to wear after the transplant. Make sure your family members are prepared by packing clothing and other items they may want while they are at the hospital.
- **Bring your *Liver Patient Education Guide* with you.** This guide will be referred to and used for education while you are in the hospital.

Communicate

It is imperative patients stay in regular contact with the transplant team.

- The **Transplant Nurse Coordinator** is the primary person who will contact you when an organ becomes available. Since the coordinator has only one hour to reach you, it is imperative the contact telephone numbers on file are current. You are encouraged to contact the transplant coordinator with new information.
- The **Social Worker** will assist you in planning for the transplant process and in developing a support team. The social worker should be contacted when any significant life changes occur for you or your support team.
- The **Financial Coordinator** works with you regarding insurance coverage and financial issues relating to transplantation. The financial coordinator should be contacted if you have any indication of a change in employment or insurance coverage.
- The **Pre-Transplant Nurse** team will stay updated on your medical condition while you wait for a transplant.

On Hold

Patients who have been listed and are waiting for a deceased donor organ can be given a status of “on hold” which makes their listing inactive. Patients who are on hold are still on the wait list, but will not be offered an organ should one become available. The on hold status is appropriate for the following situations:

- **Infections.** For the patient’s safety, a transplant cannot occur if there is an uncontrolled infection in any area of the body.
- **Insurance issues.** The patient’s insurance must have authorized the inpatient stay before a transplant admission. If insurance changes, we must obtain authorizations from the new insurance carrier.

- **Social issues.** Patients need a reliable support system established and stabilized before the transplant. The support system will be involved throughout the transplant process and afterward to help with care after transplant, including transportation, attendance at clinic appointments, home care, help with medications, wound care, possible IV meds and emotional support.
- **Second thoughts.** Some patients have a period when they reconsider their decision to have a transplant. Being placed on hold provides them the time to determine whether they wish to proceed with transplantation. Patients are encouraged to discuss their concerns with their social worker, nurse and doctor who can listen, answer questions and help them in making an informed decision.
- **Getting better.** Some patients begin to get better. In this case, it is best not to proceed with transplant at the current time.

Off the List

Patients may be removed from the wait list for one of the following reasons:

- **Complications** of liver disease, either medical or surgical, that make the patient too sick for transplantation.
- **Non-adherence to substance abuse policy:** Substance abuse will complicate the disease process before a transplant and will damage a transplanted liver. Substance abuse is an example of a patient's lack of self care. Patients who do not comply with the substance abuse policy will be removed from the list.
- **Non-adherence to medication regimens, clinic appointments and lab tests:** Transplant patients need to take medications, see their doctors and have lab tests throughout their lifetime. Patients who do not comply before transplantation by taking their medications, keeping their clinic appointments and getting their lab tests are not able to maintain a healthy liver following their transplant. Patients who do not comply in these ways will be removed from the list.
- **Liver disease improves.** Some patients experience improvements in their liver disease and they no longer need a transplant.

Maintaining Health While Waiting for a Liver

Maintain a Healthy Lifestyle

Staying as healthy as possible before transplantation, both physically and emotionally, is very important. We recommend you learn all you can about your disease, testing, medications and the transplantation process before 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
 - 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 stop 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, 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.

You Should Know

See page 18 for our policy on smoking.

You Should Know

Refer to the Nutrition section for more specific information on nutrition and liver disease.

- **Keep you immunizations up to date.** All vaccinations may be done at your primary care physician's office. (See page 40 in the Resources section for more immunization information.)
 - Hepatitis A vaccination – if you do not have immunity
 - Hepatitis B vaccination – if you do not have Hepatitis B or immunity
 - Yearly flu shot (no nasal vaccination such as FluMist)
 - Pneumococcal vaccination – one vaccination with booster after five years
 - Diphtheria Pertussis Virus vaccination – if you have not had one as an adult
 - Human Papillomavirus vaccination – if recommended by your primary care physician
 - For measles, mumps, rubella, varicella or herpes zoster – please check with your hepatologist/pre-liver transplant RN before receiving any of these vaccinations

Staying emotionally healthy includes the following:

- **You are encouraged to share your feelings.** Feelings such as guilt, anger, frustration and irritability are normal before liver transplantation. Depression is common among people waiting for 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 help patients and their loved ones in coping with the challenges of chronic illness and treatment. We also have a liver transplant psychiatrist/psychologist for patients. Your pre-liver transplant nurse can connect you. 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, etc. 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 accept an offer of help, but it is important to do so. 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 help that brings you enjoyment or saves you time or energy should be accepted.

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 help you will need 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 Before 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 help 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 the major side effects are
- 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 be aware of the following about refilling your 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) 333-9013** or request a refill through your patient portal at **MyUofMHealth.org**. 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 registration number (medical record number)
 - 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.**

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 lots 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

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. Request refills of your medications seven days before your meds run out (14 days if you use a mail order pharmacy).

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 2,000 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

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 suggest 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. University of Michigan Health requires all patients to stop using all tobacco products in order to be listed for transplant.



In liver transplant recipients, smoking is associated with a greater risk of post-transplant complications, including longer stays in the Intensive Care Unit (ICU), more time on a breathing machine and 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 liver damage. Finally, prior smokers are at increased risk of developing head and neck cancer many years after liver transplantation.

Available smoking cessation programs include:

- Kick the Habit
University of Michigan Health
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. Our social workers can also provide referrals.

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 reasons 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 University of Michigan Health Liver Transplant Program has developed a substance abuse policy that all adult patients are required to read, sign and follow before and after transplantation regardless of prior use or non-use of alcohol or illicit substances. The written policy is explained to all patients

You Should Know

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

You Should Know

Refer to the Resources section for the Smoking and Substance Abuse policies.

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) before and after transplantation.** 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 as it does contain some alcohol. Do not eat foods cooked in alcohol.

Before 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.

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°F
- 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 help patients in recognizing, understanding and appropriately managing the symptoms they may experience.

You Should Know

Refer to the Nutrition section about sodium intake.

Recognizing Ascites and Edema

Ascites is an accumulation of fluid in the abdominal cavity. Edema is swelling caused by fluid in your body tissues. 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).
- 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 or edema and gain or lose more than five pounds in one week, become short of breath, run a temperature of 100.5°F 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, reversed sleep pattern, impaired speech 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 – rifaximin, neomycin and metronidazole (Flagyl®) are given to patients who do not respond to lactulose.
- Eat small meals throughout the day with a late night snack of complex carbohydrates.
- Follow no ammonia diet. Avoid jello, jelly beans, ripe (aged) cheeses, deli meats and frozen fish.

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.

- Patients with esophageal varices may be placed on medication such as the 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. The goal of this medication is to keep your pulse rate in the 60s.
- 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 doctor 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 doctor 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.

Who to Call – Before Transplant

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

Pre-Liver Transplant Office

(800) 333-9013

(734) 763-4574 Fax

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

For general or non-urgent issues, you may contact the Liver Transplant Team through the patient portal. You should call if:

- You are hospitalized outside University of Michigan Health
- 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

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.

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 medical record number
- 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, please state that you are sick and give the nature of the sickness
- Provide your nurse or physician name

To schedule an appointment, please ask the clerk answering the telephone to help with this. Appointments may also be scheduled through the patient portal at MyUofMHealth.org.

To request a prescription refill, please call **(800) 333-9013** and leave the following information:

- Your name
- Your telephone number
- Your medical record number
- 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 may also request refills through the patient portal (**MyUofMHealth.org**). We will only refill prescriptions your hepatologist prescribed. All other prescriptions are to be refilled by the ordering provider, primary care physician or other doctors who help manage your healthcare.

Getting a Liver

When will I get the liver? Where am I on the list?

While these are the most frequently asked questions, there is no direct answer to these questions.

The MELD system was created to allocate livers to all patients listed in a consistent manner that provides livers to those patients who are at the greatest risk of dying before a transplant. The system is complex. There are many factors in determining to whom an organ will be offered.

Patients are encouraged **NOT** to focus too much attention on their MELD score. Some people believe that their MELD score is an indicator of when they will receive a liver. Unfortunately, a patient's MELD score is not

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 and the operator 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 for more information.

For questions regarding your **INSURANCE**, contact the financial coordinator. Please refer to the Liver Transplant Team section for more information.

a predictor of when they'll be offered an organ. The average MELD score at the time of transplant varies by blood type. Since your MELD score is based on your lab values on a given day, it will fluctuate up and down over time. It is important to remember that while your lab values (and MELD score) are going up and down, they are fluctuating for all the other patients on the wait list as well. The list is constantly changing.

Who Gets a Liver?

There are many factors that are significant in the allocation of livers to potential recipients. The major factors include:

- **Blood Type** – Generally organs are offered to patients with the same blood type as the donor. Exceptions may be made for patients who are critically ill – those listed as a Status 1 or with a very high MELD score. The transplant team may choose to use an organ from a compatible blood type.
- **Recipient/Donor Weight and Height** – The size of a liver is a factor in the allocation of the organs. The donated liver must “fit” within the potential recipient and the transplant team must be confident the liver’s capacity will support the recipient.
- **Location of Donor/Location of Recipient** - Donated organs must be transplanted within a limited window of time following donation. If the distance is great between the locations of the donor and recipient, the organs will be offered locally. Most organs transplanted at University of Michigan Health come from Michigan and neighboring states.

Some factors are not considered in the equation for allocating livers to potential recipients.

Factors that **DO NOT** matter include:

- **Age** – Once the patient is listed, the age of the recipient is not a data element in the allocation process.
- **Sex** – The sex of the recipient is not a data element in the allocation process.
- **Race** – The race of the recipient or donor are not data elements in the allocation process.
- **Cause of Liver Disease** – Once the patient is listed, the cause of the recipient’s liver disease is not considered in the allocation process.

When the Call Comes

The call advising of an available liver to be offered to you can come at any time. The first notification comes to the transplant coordinator, who works in collaboration with the surgeon.

Time Considerations

For the **Transplant Team**:

- **Coordination of organ retrieval.** The transplant coordinator activates a team to go to the location of the donor. The team meets at the donor hospital, participates in the donation process, the surgeon reviews the condition of the liver, and returns to University Hospital with the donated organ.
- **Organ preservation time.** Donated organs remain viable for a specific period of time. Surgeons generally prefer to transplant a liver within eight hours after donation.
- **Coordination of recipient operation.** The transplant coordinator makes the necessary arrangements for the recipient's operation by coordinating the necessary facilities and medical teams.
- **Adequate travel time for the patient.** The coordinator contacts the patient to extend the organ offer and considers the patient's travel time in setting the time for the operation.

For the **Patient**:

- **Do not speed to the hospital.** Since your travel time has been considered in setting the operation time, it is not necessary to speed to the hospital. **Drive safely.** Wear a seat belt!

When You Get to University Hospital

- Park in the parking structure P2 and proceed to the Main Hospital entrance at Taubman Center 1st floor lobby.
- **From the Main Hospital Entrance, go directly to the unit of University Hospital identified by the transplant coordinator.**

If you are asked to go to an inpatient unit (for example, 5C), please go directly to the unit as directed by your coordinator and check in at the nurses' station. Staff at the hospital entrance can guide you to this location.

If you are asked to go directly to Pre-Op, please proceed to the Red Pillar (University Hospital 1st floor). You will check in via the Surgery Reception front desk or, if you're arriving after hours and the desk is closed, call the OR front desk via the phone number listed on signage next to the Red Pillar.

- **Do not check in at Admissions or Emergency Room.**
Going to the Admissions area or Emergency Room will cause an unnecessary delay.
- **Patients arriving after 10 p.m.**
The number of hospital entrances after 10 p.m. is limited. You will need to enter via the Main Hospital entrance at Taubman Center. There will be staff available 24 hours a day to guide you.

Insurance Coverage for Lodging

Some insurances include coverage for the living expenses of family members while a patient is hospitalized. Patients should check with their insurance to determine if they have coverage and learn the requirements for being reimbursed.

Need Help?

Finding and selecting appropriate lodging can be challenging. A social worker is available at all times to assist families in this endeavor. During the normal work week (Monday through Friday) call your transplant social worker for help.

If your family needs the assistance of a social worker at night or on the weekends, they can ask any staff member to call the paging operator **(734) 936-6267** and ask to have the social worker on call paged.

Advance Directives

It is always a good idea for patients to discuss their wishes related to their care with their family before the family is under pressure to make decisions. Your wishes should be documented in a written advance directive, also called a Living Will. In addition to discussing patient care-related issues, it is advisable to discuss general issues related to daily living such as finances.

Advance directives give written direction to healthcare providers about treatment choices for you in certain circumstances. There are two types of advance directives:

- **Durable Power of Attorney** – A durable power of attorney for healthcare allows a person to name a “patient advocate” to act for them and carry out their wishes.
- **Living Will** – A living will allows the patient to state their wishes in writing but does not name a patient advocate.

You should consider how daily life decisions – including those about money and paying bills – will be handled in the event you have an extended hospital stay.

Protection of Privacy (HIPAA) ensures the privacy of a patient's health information. It is important to understand that the transplant team cannot release medical information without explicit permission from the patient.