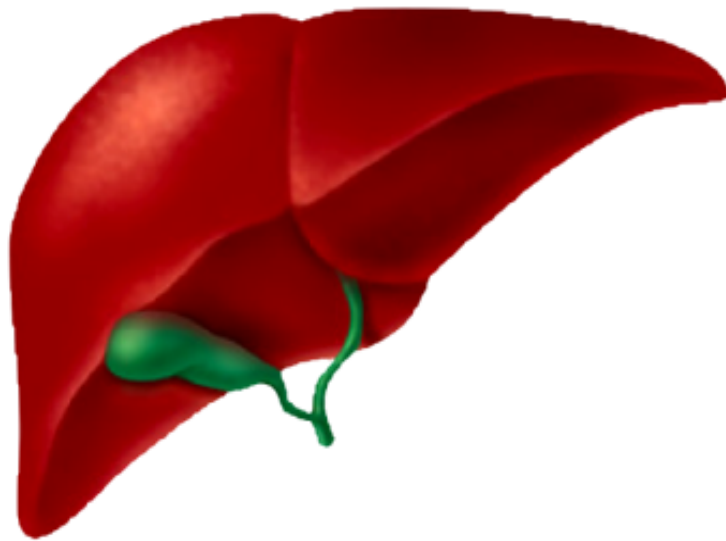


RECANATI / MILLER TRANSPLANT INSTITUTE



ADULT LIVER PRE-TRANSPLANT PATIENT EDUCATION GUIDE

**MOUNT SINAI HOSPITAL
NEW YORK, NEW YORK**

Dear Patient:

We hope that you find this a helpful guide as you go through the transplant process. We recognize that there is a lot for you to do and learn during this time. Take your time in reviewing this material; there is no rush to read everything in one day. This manual is meant to be a resource guide to you and your caregivers and should not be used in the place of seeking medical attention. Always contact your transplant coordinator for any questions that you have.

In the education material that you have received you will also find a medication sheet. Since you may be on many medications and they can be difficult to keep track of, you may find this a helpful tool to have when you go to your different doctors appointments.

In an effort to further improve upon the information we give you, please take the time to fill out the brief questionnaire on the last page. Any suggestions you have are appreciated and will be considered for future revisions.

For your convenience

Thank you,

The Adult Liver Pre-Transplant Staff.

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PRE TRANSPLANT PATIENT EDUCATION MANUAL

Recanati/Miller Transplantation Institute at Mount Sinai Medical Center

If you are reading this material, you or someone you care about needs a liver transplant. Your primary care physician has probably already explained your specific medical problem to you. The purpose of this book is to provide you with some basic information about the transplantation process at Mount Sinai. We hope that by helping you learn more about liver transplantation and how to prepare for it, this book will allay some of your fears and answer many of your questions. The prospect of a liver transplant can indeed be terrifying, but at the Recanati/Miller Transplantation Institute (RMTI) we have had over 15 years of experience performing liver transplants and are here to help you and your family throughout this life saving procedure.

Mount Sinai is one of the nation's leading adult liver transplant centers, performing more than 130 liver transplants yearly with outstanding success rates. The Mount Sinai Liver Transplant Program began in 1988 when RMTI founder Dr. Charles Miller performed the first liver transplant in New York State. Since its fledgling days, the program has grown to become the third largest in the world: nearly 2000 adult liver transplants have been performed, including over 100 living donor transplants.

The Mount Sinai Hospital reaffirmed its commitment to organ transplantation in 1998 with the establishment of the Recanati/Miller Transplantation Institute (RMTI). Named for businessman and philanthropist Raphael Recanati (who received a liver transplant at Mount Sinai in 1996) and for Mount Sinai surgeon Charles M. Miller, the RMTI is a comprehensive program for adults and children with end-stage organ disease.

Dedicated to providing compassionate care of the highest quality, the RMTI team is comprised of world-renowned physicians, surgeons and scientists in a wide variety of organ transplant and medical specialties. Expert integration of multidisciplinary medical services is one of the major principles on which the RMTI has been built. Working hand in hand with nurses, social workers and support staff, RMTI physicians and surgeons coordinate the complex treatments that characterize a patient's course both before transplantation and afterward.

The RMTI focuses on three areas----patient care, research, and education. The clinical divisions----liver, intestine, kidney and pancreas----draw upon Mount Sinai's long tradition of excellence. Well before organ transplants were possible, Mount Sinai's reputation for medical care and research drew patients with liver, kidney and other gastrointestinal diseases from around the world.

In 1967, Mount Sinai opened one of the region's first kidney transplant programs. In 1988, Mount Sinai surgeons performed New York State's first liver transplant. Since then, more than 2,000 patients have received new livers at Mount Sinai. This program is now the second largest in the world. The first heart transplant at Mount Sinai was performed in 1986, the first lung transplant in 1992, and the first pancreas transplant in 1994. The first pediatric living donor liver transplant in New York State was also performed at Mount Sinai in 1993. In keeping with their mission to offer the most innovative surgical techniques, RMTI surgeons also became the first in New York State to perform isolated intestinal transplantation, in 1998. The first adult-to-adult living related transplant in New York State was also performed at Mount Sinai in 1998. First Pediatric and adult living donor liver transplantations should be added.

Associated with liver transplantation at Mount Sinai has been the growth of an outstanding program of clinical hepatology and hepatobiliary surgery for liver and bile duct tumors. This program too is a clinical component of the RMTI, providing state-of-the-art care for patients with liver disease who may best be served through surgical techniques or innovative medical treatments other than transplant.

The mission of the RMTI also includes research and education. RMTI researchers are working, independently and in major collaborations, to improve organ preservation, reduce rejection, minimize post-surgical complications and the side effects of immunosuppression, and prevent recurrence of disease.

RMTI educational initiatives include a highly acclaimed multi-organ surgical transplant fellowship program, a clinical hepatology fellowship program, conferences for community physicians and other health care professionals, development of a medical school curriculum on transplantation and critically important public education activities to increase organ donation.

The RMTI faces an exciting future. By uniting its experts as a caring, well-balanced team and by integrating the strengths of its components, the RMTI expects to broaden the scope and possibilities of transplantation, and to answer questions that are critical to treatment of disease and to patients' quality of life.

Milestones at Mount Sinai

- 1967 Kidney Transplant Program begins – one of the first of its kind in the region
- 1988 The First Liver Transplant in New York State
- 1993 The First Pediatric Living Related Liver Transplantation in New York State
- 1996 The First Laparoscopic Donor Nephrectomy in New York State
The 1000th Liver Transplant at Mount Sinai
- 1998 The First Isolated Intestinal Transplantation in New York State
The First Adult Living Donor Liver Transplantation in New York State
Liver Transplants at Mount Sinai exceed the 1500 mark
- 1999 The First Multi-Visceral Transplant in New York State
- 1999 The First Pediatric Liver-Intestine Transplant in New York State
- 2000 The 2000th Liver Transplant at Mount Sinai
- 2001 The First Domino Liver Transplant

RMTI Mission Statement

- To provide compassionate, comprehensive care of highest quality to patients suffering from end- stage organ related diseases;
- To prolong patients' lives safely throughout the waiting period and postoperative period, through closely monitored medical care and well-designed clinical pathways;
- To perform organ transplantation in accord with the most advanced medical and surgical techniques and with state of the art equipment in order to maximize desirable patient outcomes;
- To achieve excellence in basic scientific and clinical research innovation and education and to share it with the community;
- To expand the donor pool through enhanced public awareness, creative public education programs and new technologies;
- To accomplish the above in the most efficient, cost-effective manner attainable, thereby providing as many patients as possible with opportunities for transplantation and meaningful, productive lives.

Core Values

Integrity

Straightforward, Plainspoken Honesty

Respect

For the Individual, Team and Society

Humanity

Commitment to Caring, Empathy, Compassion and Concern

Innovation

Pursuit of Creativity, Answering the Difficult Questions and Problems

Excellence

Patient Care, Teaching, Research

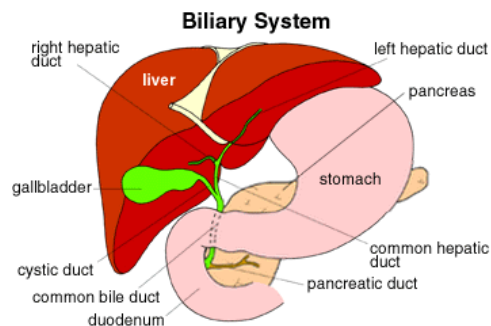
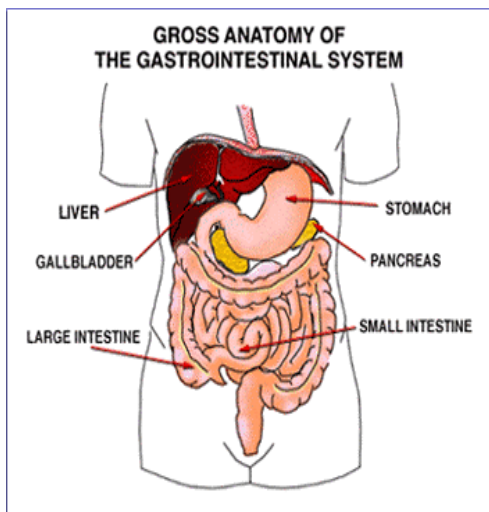
Who's Who on Your Transplant Team
The Interdisciplinary Team
Many people, many experts

Transplant Surgeons	Surgeons who specialize in organ transplantation. The transplant surgeon performs the actual transplantation procedure and monitors a patient's medication before, during, and after the surgery. They will assess the quality of the donor liver before surgery, and monitor the patient's general and liver status following transplant. It is expected that you will meet with one of the transplant surgeons during the evaluation process. During this visit, the surgeon will explain the UNOS listing criteria, the organ allocation policy, how the quality of the donor liver is assessed, the use of marginal livers, various types of transplant operations (such as split liver and living donor), the actual surgical procedure, the early postoperative course and complications related to transplant surgery. It is important that you bring your family members or those who will be participating in your postoperative care to this visit.
Transplant Hepatologists	Physicians who specialize in the field of liver disease and transplant medicine. The transplant hepatologist will see you during your office visits, monitor the status of your liver disease as well as complications, review test results, and make adjustments to your medications as needed.
Transplant Fellows	Fully trained general surgeons who are specializing in liver transplant surgery.
Hepatology Fellows	Fully trained gastroenterologists who are specializing in the field of liver disease
Transplant Psychiatrists	You may find it helpful to talk to a professional before and after surgery. Discussion may help you and your family cope with the transplant experience before and after surgery, as well as with the changes is will make in your life.
Infectious Disease	Physicians who specialize in caring for patients with infections. As part of our program, patients are seen by these physicians to determine any special needs that they may have before, during and after liver transplant.

Transplant Coordinators	Registered nurses who specialize in the care of liver transplant patients. They coordinate all events leading up to and following transplantation as well as monitor your medical condition. They will also provide information and education regarding the transplant process to you and your family.
Physician Assistants	Specially trained and licensed professionals who provide patient care under the direct supervision of physicians
Social Workers	Professionals who provide psychosocial assessment and assistance to liver transplant patients. The social worker will assist the patient in finding services and people in the community who can help with the transplant process.
Pharmacist	Licensed professional who rounds on the inpatient service to ensure that medication doses are right and monitors for drug interactions and toxicity.
Nutritionists	Licensed individuals who provide nutritional assessment and counseling to liver transplant patients
Research Coordinators	Staff members who coordinate the various research studies conducted by the Recanati/Miller Transplant Institute.
Financial Coordinators	Staff members who are responsible for screening patients' transplant insurance coverage and advising patients on possible financial options
Coordinator Assistants	Staff members who assist the transplant coordinator in scheduling appointments for patients, taking messages, faxing and mailing of letters, lab reports, and obtaining pre-certification for procedures and consultation letters.

About Your Liver

The liver is the largest organ in your body. It is located behind the lower ribs on the right side of your abdomen, weighs about three pounds and is roughly the size of a football. The liver is divided into four lobes: the right (the largest lobe), left, quadrate and caudate lobes. A normal liver is soft and smooth and is connected to the small intestine by the bile ducts, which carry bile formed in the liver to the intestine. Nearly all the blood that leaves the stomach and intestines passes through the liver via the portal vein. The portal vein carries blood-containing nutrients from the stomach and the intestines to the liver. The portal vein also receives blood from pancreas and spleen. It supplies 80% of the liver's blood. The hepatic artery supplies oxygen rich blood to the liver and supplies the remaining 20% of the liver's blood. The hepatic vein drains blood from the liver. The bile ducts drain bile from the liver into the small intestine.



The liver performs numerous of complex functions each day. Some of these include:

- Converting food into chemicals necessary for living and growth
- Manufacturing and exporting important substances for the rest of the body (such as proteins)
- Processing drugs absorbed from the digestive tract into forms that are easier for the body to use
- Detoxifying and excreting substances that otherwise would be poisonous
- Metabolizing alcohol

- Regulating blood clotting
- Aiding in the digestive process
- Regulating transport of fat stores
- Producing quick energy when needed by the body
- Monitoring and maintaining the proper level of many chemicals and drugs in the blood
- Maintaining hormone balance
- Controlling the production and excretion of cholesterol
- Storing iron
- Regenerating its own damaged tissue
- Helping the body resist infection by producing immune factors and removing bacteria from the bloodstream

What is Cirrhosis?

Cirrhosis of the liver is a degenerative disease where liver cells are damaged and replaced by scar formation. As scar tissue is accumulated, blood flow through the liver is diminished, which causes more liver cells to die. The healthy liver cells are permanently destroyed and the scarring is irreversible. The liver then becomes nodular in appearance. The scar tissue that forms in cirrhosis harms the function of the liver. The loss of normal liver tissue slows the processing of nutrients, hormones, drugs and toxins by the liver, as well as production of proteins and other substances made by the liver.

Cirrhosis of the liver



ADAM.

There are a number of conditions that can lead to cirrhosis. The following are some of the causes:

- Excessive intake of alcohol
- Chronic viral hepatitis (such as hepatitis B and C)
- Inherited or congenital diseases such as hemochromatosis, Wilson's disease, alpha-1 antitrypsin disease, and autoimmune hepatitis
- Prolonged obstruction of the bile ducts such as primary biliary cirrhosis and primary sclerosing cholangitis
- Prolonged exposure to environmental toxins
- Some forms of heart disease

- Severe reactions to drugs
- Parasitic infections

When the liver becomes cirrhotic, it cannot properly perform its many important functions. Regardless of the cause of cirrhosis, the consequences are the same. The following are some of the signs and symptoms of a sick liver:

- Vomiting of blood frequently occurs from swollen, ruptured varices (veins that burst), in the lower end of the esophagus (food pipe) due to the increased pressure in these vessels.
- Encephalopathy or mental changes ranging from sleep disturbances and confusion to coma. This results from an accumulation of toxic substances in the body that the damaged liver can no longer eliminate
- Ascites (abdominal swelling due to an accumulation of fluid caused by the obstruction of blood flow through the liver)
- Jaundice (yellow discoloration of the whites of the eyes and skin because bile pigments can no longer be removed by the liver)
- Kidney function impairment
- Bleeding tendencies
- Increased susceptibility to infection
- Generalized muscle wasting and malnutrition
- Increased sensitivity to drugs, due to the inability of the liver to metabolize them
- Abdominal pain
- Enlargement of the liver (hepatomegaly)
- Enlargement of the spleen (splenomegaly)
- Loss of appetite
- Nausea and vomiting
- Weight loss
- Fatigue
- Dark colored urine
- Gray, yellow, or light colored stools
- Itching (due to the retention of bile products in the skin)
- Abnormal blood sugars
- Loss of sexual drive or performance
- Change in or loss of taste

Please note that not everyone with cirrhosis will have all of the above mentioned signs and symptoms. Many patients may not have any symptoms and are found to have cirrhosis only on physical examination and laboratory tests; this is called compensated liver cirrhosis.

Indications for Liver Transplant

What is Viral Hepatitis?

Hepatitis A, B, C, and D are viruses that primarily affect the liver. Hepatitis A usually causes “acute” hepatitis and is cleared within six months from exposure and does not usually lead to chronic liver failure. Hepatitis B and C on the other hand can lead to “chronic” hepatitis, lasting many years and can lead to cirrhosis and the development of hepatocellular carcinoma (HCC). Hepatitis D is only seen in patients who are exposed to Hepatitis B. Other viruses like CMV (Cytomegalovirus), EBV (Epstein-Barr Virus), and HSV (Herpes Simplex Virus) can also affect the liver and cause hepatitis. Hepatitis A is usually spread via fecal-oral route and unsanitary environments. Hepatitis B, C, and D are spread by receiving contaminated blood products, sharing tainted intravenous or tattoo needles, sharing of an infected “straw” used for intranasal drugs, sexual contact, and contact with the blood or body fluids of infected individuals.

What is Autoimmune Hepatitis?

Autoimmune hepatitis is a liver disease characterized by the formation of antibodies made by the individual’s immune system that affect the function of the liver, thereby destroying the cells and leading to cirrhosis. Diagnosis is made by the clinical presentation of the individual and blood testing for ANA (anti-nuclear antibody), AMA (anti-mitochondrial antibody), and LKM (liver, kidney, muscle) antibody.

What is Primary Biliary Cirrhosis?

Primary Biliary Cirrhosis is a chronic, progressive cholestatic liver disease that is indicated by the destruction of the small intrahepatic bile ducts leading to fibrosis and cirrhosis characterized by four stages.

What is Primarily Sclerosing Cholangitis?

Primary Sclerosing Cholangitis is a chronic progressive cholestatic liver disease that is characterized by ongoing inflammation, destruction, and fibrosis of both the intra- and extra-hepatic bile ducts. There is an increased incidence of Primary Sclerosing Cholangitis in patients with ulcerative colitis. Patients with primary sclerosing cholangitis have a greater risk of developing cholangiocarcinoma.

What is Alcoholic Liver Disease?

Alcohol related liver disease is associated with the excess use of alcohol. It can be connected to heavy binge drinking or daily use of alcohol, more than 45 grams per day. Women are more susceptible to develop alcoholic liver disease than men. Heavy

alcohol use is described as drinking more than 20 grams per day in women and more than 80 grams per day in men. For example, 12 ounces of beer, 5 ounces of wine and 1.5 ounces of hard liquor equals 14 grams of alcohol.

What is NASH?

NASH (non-alcoholic steatohepatitis) is accompanied by the presence of fat deposition within the liver cells that causes inflammation, fibrosis, and cirrhosis, which is not related to alcohol use. Some predisposing conditions linked to NASH are obesity, type 2 diabetes, and high lipid levels in the blood.

What is Cryptogenic Cirrhosis?

Cryptogenic cirrhosis is liver disease with an unknown cause. Basically, every possible cause for impaired liver function must be excluded.

What is Fulminant Hepatic Failure?

Fulminant Hepatic Failure (FHF) is described as a progressive and rapid onset of liver failure in an otherwise healthy individual who did not have any previous history of liver disease. The overall survival of these individuals is 7-30% without transplantation. Some common causes are; acute viral hepatitis, acetaminophen (Tylenol) overdose, Wilson's disease, Budd-Chiari Syndrome, mushroom poisoning, and drug-induced hepatitis (INH toxicity for example).

What is Budd-Chiari Syndrome?

Budd-Chiari Syndrome is associated with an acute blockage of the hepatic veins. Patients usually develop fluid accumulation in the abdomen (known as ascites), abdominal pain, enlarged liver and spleen, gastrointestinal bleeding, yellowing of the skin (known as jaundice), and changes in their mental status.

What is Hemochromatosis?

Hemochromatosis is an inherited disorder that causes an overload of iron deposited into the cells of an organ that disrupts its function and can eventually lead to failure of that organ. Hemochromatosis primarily affects the liver but can also affect the heart and other organs as well. Diagnosis is usually made by measuring iron levels in the blood and with an MRI to look carefully at the organs.

What is Wilson's disease?

Wilson's disease is characterized by a copper storage abnormality associated with an enzyme deficiency that is made in the liver. Copper may be stored in many organs or

tissues, but primarily affects the overall function of the liver cells. Diagnosis can be made by measuring ceruloplasmin levels in the blood and urine, and careful examination of the eyes by an ophthalmologist.

What is alpha-1 antitrypsin disease?

Alpha-1 antitrypsin disease is associated with an inability of the liver cells to get rid of this particular enzyme. This disease can affect the lungs as well.

A WORD FOR OUR HEPATITIS C PATIENTS

If you have been referred to the liver transplant team for cirrhosis due to Hepatitis C, you may be asked to undergo medical treatment prior to proceeding to transplant. Treatment includes the use of two medications, interferon injections (usually once per week) and daily ribavirin tablets, for up to a year. Treatment may be recommended whether or not you have been treated in the past, depending on your individual circumstances. Treatment can be done through your local physician in consultation with one of our hepatologists, or you may opt to be treated here at Mount Sinai with one of our Hepatitis C specialists.

Optimally, we would like you to be cured of your Hepatitis C infection prior to receiving a transplant. Recurrence of Hepatitis C post-transplant is expected in patients who have not received treatment, or have had sub-optimal treatment, and we know that Hepatitis C progresses at a much quicker rate in the post-transplant patient compared to the pre-transplant patient. If you undergo successful treatment, it would greatly benefit you post-transplant because the likelihood of recurrence of your Hepatitis C would be low; you may not require any treatment for Hepatitis C after transplant if you successfully eradicate the infection beforehand. Please keep in mind that there is always a risk for recurrence of Hepatitis C, regardless of how long you have been treated or how successful the treatment appeared to be prior to transplant.

Some patients are not appropriate candidates for Hepatitis C treatment prior to transplant for a variety of reasons, including medication side effects. This does not necessarily preclude your treatment post-transplant since your condition will be regularly evaluated. Our transplant center has had success in treating Hepatitis C post-transplant in appropriate candidates.

Please contact your transplant coordinator if you would like to discuss the appropriateness of Hepatitis C treatment in your individual case. If you are referred for treatment, you may call 212-241-0034 to schedule an appointment with one of our Hepatitis C specialists.

Complications of Liver Disease

There are many potential complications of liver disease. Occurrence of these complications will vary for individual patients, ranging from few to many of the following complications.

Complications of early liver disease may be vague. These include fatigue, malaise (a general unhealthy feeling), anorexia (loss of appetite), epistaxis (nosebleeds), weight loss, skin fragility (skin weakness), easy bruiseability, pain in the right upper quadrant of the abdomen (over liver), change in color of stool (clay colored) and urine (tea colored), muscle cramping in hands and legs, as well as a decrease in libido and sexual function.

Complication of more advanced liver disease include:

Gastrointestinal Bleeding- bleeding that takes place in the esophagus, stomach or intestines. People with cirrhosis have a tendency to bleed. This is both because the liver cannot produce enough of the proteins needed to clot the blood, and because cirrhosis causes the spleen to enlarge (splenomegaly) and trap platelets (small particles in the bloodstream that start the clotting process). Portal hypertension causes enlargement of veins in the wall of the stomach and the esophagus (where the food passes between the mouth and the stomach). These veins called varix have thin walls and are under high pressure that sometimes rupture and bleed. This bleeding is complicated by the fact that blood clotting is not normal. Variceal bleeding causes 1/3 of all deaths in people with cirrhosis. Screening for these varicose veins is done with the use of endoscopy. At that time of bleeding, a varix can be banded or tied off to prevent further bleeding. Patients can also be started on medicine (beta-blockers) that decreases the pressure in the varices to prevent the bleeding from occurring. TIPS- Transjugular intrahepatic portosystemic shunt is another potential treatment for gastrointestinal bleeding. Things to look out for with bleeding are melena (dark tarry foul smelling stools) and vomiting blood or “coffee grounds” (old blood). If this happens to you, go to the nearest hospital emergency room for immediate treatment. As this is a life-threatening situation, you should not take the time to come to Mount Sinai Hospital if we are not the closest hospital to you. You must seek immediate medical attention by calling 911.

Ascites- Accumulation of fluid in the abdomen which can lead to an increase in abdominal girth (size) and in severe cases, shortness of breath. Ascites is caused by the high pressure from the portal hypertension forcing fluid to leak out into the abdominal cavity. The decreased ability of the cirrhotic liver to produce proteins also contributes to the build-up of fluid. In its early stages ascites can often be treated with sodium restriction (<2000 mEq a day). Diuretics are a group of medicines that can be used to help mobilize fluid so that it can be excreted through a person’s urine. Large

volume paracentesis can also be performed in cases where sodium restriction and diuretic therapy does not work. This is when the fluid in one's abdomen is manually removed through the use of a needle. A TIPS, can also be used to help mobilize the excess fluid. The development of ascites in a person with cirrhosis is a signal that the end-stage is approaching. Approximately 50% of patients will die within two years of when ascites first appears.

Spontaneous Bacterial Peritonitis (SBP)- This occurs when the fluid in a person's abdomen (ascites) develops a bacterial infection. This can present with symptoms such as abdominal tenderness, pain, and a fever. However, in most instances SBP is asymptomatic. SBP occurs in 10-30% of people with cirrhosis. The chance of occurrence of SBP is greater when a patient undergoes frequent paracentesis. This is a very serious infection: a person with SBP has a 20% risk of dying during that hospital stay. About 70% of people who get SBP once will get it again within one year. Treatment includes admission to the hospital and administration of intravenous (IV) antibiotics.

Hepatic Encephalopathy- is a disturbance in the central nervous system due to the inability of the liver to remove ammonia from the bloodstream. Some patients may experience changes in personality, lethargy, confusion, memory loss, poor coordination, tremor and drowsiness. In severe cases it can lead to coma. Patients can appear intoxicated or as if they had a stroke. It is usually detected by asterixis (a forward flapping of ones hands when arms are extended). Treatment is pharmacological (medical); lactulose/kristalose is the most common medicine and works by causing ammonia to be excreted through a person's stool.

Hepatorenal Syndrome- is found in patients with severe end stage liver disease and is characterized by a decrease functioning of the kidneys. It can occur without any precipitating factors but infection, bleeding, dehydration, and medications may all contribute to kidney failure. When the kidneys start to fail it is a very serious sign, and the outlook for survival without a transplant is very limited: approximately 95% of people will be dead within 2-3 months. . Kidney function may return with a timely liver transplant.

Infection- People who have cirrhosis are more likely than others to get infections and once they do, the infections are much more difficult to clear up. This is because cirrhosis leads to a weakening of the body's immune defense system. Being in the hospital raises the risk of infection for all patients, but the risk of getting an infection in the hospital is even higher for patients with cirrhosis. There is a high risk of infection when patients develop internal bleeding from varices. The risk of pneumonia is also high, especially in patients with mental status changes due to the build-up of toxins in the blood (encephalopathy). Since many people with cirrhosis are also malnourished, wounds do not heal properly and commonly get infected.

Hydrothorax-Pleural effusions are an infrequent complication of portal hypertension. It is a result of a direct passage of fluid into the pleural space (around the lungs) from the abdomen (ascites). Treatment is similar to that of ascites. It can be removed manually, or with the use of diuretics.

Peripheral Edema- Is an excess of fluid in persons' body tissues. It can be caused by a variety of reasons. The main reason is low serum albumin level due to liver cirrhosis. Albumin is essential to help maintaining normal water distribution within the body. A high sodium diet is another contributing factor to retaining water, which with the combination of low albumin and portal hypertension can lead to an increase in peripheral fluid, and swelling in the legs

Jaundice- Yellowing of the skin and whites of the eyes caused by excess of bile in the blood.

Muscle Wasting- Patients with muscle wasting present with decreased muscle mass, and is found to be in the temporal area, shoulders, arms or legs. This can occur due to the cirrhotic liver's inability to produce essential proteins, poor appetite and malabsorption of nutrients mainly proteins.

Gynecomastia- Is when male patients present with enlarged breasts. This can occur as a result of hormonal imbalance from liver disease or as a side effect of a medication called spironolactone (Aldactone) that is given to patients with ascites or edema.

Pruritis- Itching- This can lead to a limitation of normal activities as well as causing sleep deprivation. It can also lead to skin excoriation/lesions (open areas) that have the potential to become infected. Treatment can include pharmacological (medicine) as indicated by ones physician. It is important to keep the skin intact, as it is a persons primary means of protecting against infection. Proper skin care includes the use of a moisturizing soap and non-perfumed moisturizing lotion.

Hepatocellular Carcinoma- Patients with cirrhosis of the liver are at increased risk of developing cancer of the liver. This is detected and monitored through abdominal imaging (MRI or CT Scan), and an alpha feto-protein blood test (tumor marker), which may become elevated in the presence of liver cancer. This does not necessarily eliminate a patient as a transplant candidate but it does mean that you will have to be monitored very closely, undergo additional tests, and be referred for possible treatment

Components of Pre-Transplant Evaluation for Listing

Your physician referred you to our program because it is felt that you should be evaluated for a transplant. While transplant may not be urgent in every case, each patient that we see is required to undergo a complete and comprehensive evaluation. Prior to your visit with us, we will have requested that your referring physician provide us with copies of your medical records.

We will be in contact with your referring physician and your primary care physician on a routine basis. It is important that you provide us with their addresses and phone number so that we can easily contact them. If you change doctors, please call our office or inform us at the time of your office visit so that we can update your records. We will work in collaboration with your doctors to complete your evaluation and monitor any changes in your liver disease and overall medical condition.

If you do not have a primary care physician, then it is in your best interest to obtain one. Your primary care physician will play an integral role in your overall medical care before and after liver transplant. One of the easiest ways to obtain a list of physicians in your area is to contact your insurance provider who will be able to provide you with the names and locations of physicians in your area.

On your initial visit with us, you will meet with core members of transplant team. These members are transplant surgeon; hepatologist who is a medical doctor specialized on liver diseases, transplant coordinator and transplant social worker.

One of our transplant surgeons will explain to you UNOS listing rules and organ allocation policy, waiting times in this region, how to assess the quality of the donor livers and use of marginal livers, various types of transplant operations (such as split liver transplant and living donor transplant), actual surgical procedure, postoperative course, immunosuppressive medication early and late complications related to transplant surgery. You will be also told of our logistical structure and availability of the transplant team and transplant center results. Generally patients meet with the surgeon once they have been accepted for placement upon the transplant waiting list.

The transplant hepatologist monitors all non-surgical aspects of patient's care. You will see the transplant hepatologist on every office visit. This physician will perform examinations, review test results, and adjust medications as needed.

The transplant coordinator is a registered professional nurse or healthcare professional who has trained training and experience in caring for transplant patients. The transplant coordinator provides education and instruction about the evaluation process and transplantation to patients and their families. They monitor a patient's condition and provide other members of the transplant team with appropriate patient information and test results. Your coordinator will facilitate your transplant evaluation, see you during your office visits, follow you during the waiting period and coordinate the transplant process.

Meeting with the social worker is an important part of initial evaluation for all patients. The social worker checks family dynamics, support, and other psychosocial issues. This is necessary to help you and your family with the many psychological and social issues involved in the transplant process. It is vital that all potential recipients have adequate support systems in place to assist them throughout the entire process.

You should not be shy in asking questions and alerting your physician and coordinator regarding any changes in the way you feel, no matter how insignificant it may seem.

Not everyone's evaluation is the same. Yours is determined on your initial visit with us. Following are some of the more common components of a transplant evaluation:

Consults (routine):

- 1) Cardiac – all patients must have echocardiogram and a stress test to rule out any heart disease
- 2) Psychiatry - for patients with a history of psychiatric illness, on psychiatric medications, alcohol and/or drug abuse within the past 1 year, or as deemed necessary by the transplant social worker and the transplant team.
- 3) Dental - all patients must be cleared by a dentist and be free of infection and oral disease
- 4) Gynecology - all women >18-years-old, screening includes examination and PAP smear
- 5) Cancer Screening:
 - Upper endoscopy - all patients (cancer screening + assessment for varices)
 - Colonoscopy – all patients >50-years-old, and those <50 with family history of colon cancer
 - Mammogram – all women >35-years-old, to rule out breast cancer
 - Prostate cancer screening – all men >50-years-old, check PSA level.

***Additional consults as indicated by clinical presentation/history may be required, such as pulmonary, oncology, nephrology, or hematology.

Imaging Studies:

- 1) Chest X-Ray - (for all patients) to rule out any lung disease, looks for infiltrates, enlargement of heart, fluid in the lungs.
- 2) CT Scan of abdomen - (for all patients) to rule out hepatocellular carcinoma (HCC) also called liver tumor, check patency of portal vein and other major blood vessels in the liver and abdomen. IV and oral contrast are needed to serve as a complete study.
- 3) MRI of abdomen - (for patients who can't have CT scan) more sensitive to fatty infiltrates and iron deposits in liver. Used with IV contrast to rule out liver tumor, especially for patients with allergies to contrast dye/seafood, and for patients with kidney dysfunction.
- 4) Abdominal Sonogram + Doppler - to check patency of liver blood vessels especially the portal veins, measures the velocity of TIPS (Transjugular Intrahepatic Portosystemic Shunt), identifies liver cysts from liver mass.
- 5) CT Scan of Chest - (clinically indicated for HCC patients) to identify in detailed pattern any lung nodules, rules out metastasis of liver cancer, and examines lungs for any active disease.
- 6) Bone Scan - (clinically indicated for HCC patients with larger tumors) to rule out any bone metastasis from liver cancer.
- 7) CT Scan and/or Sonogram of Pelvis - (clinically indicated) to rule out any pelvic abnormality such as an enlarged uterus, prostate, etc.
- 8) X-Ray of specific body parts (ribs, legs, arms) - (clinically indicated) to correlate abnormal bone scan to rule out metastatic bone disease vs. arthritis or fractures.
- 9) Bone Densitometry - to rule out bone thinning (osteopenia) and/or osteoporosis, particularly for patients with Primary Biliary Cirrhosis.

Please note that our office will be scheduling you for routine imaging studies every six months. This will be either CT scans of the abdomen or MRI of the abdomen. While your first study that is done with us may not show any evidence of hepatocellular carcinoma, due to the nature of your liver disease, it can develop. Early detection is key to successful treatment and in some cases can prioritize you higher on the waiting list after you have completed your evaluation. If in the event an abnormality is detected, but it is not definite to be a liver cancer, we will either have you undergo repeated imaging every three months or change from CT scan to MRI or vice versa.

Please note that certain components of your pre-transplant evaluation may be done with physicians in your community. These procedures include:

Mammography
Pap Smear
Dental screening

Colonoscopy
Endoscopy
Bone Densitometry

If you are having any of the above procedures with your local physicians, please have the necessary clearance forms and reports returned to your clinical coordinator. Please be aware that it will be your responsibility to ensure that the appropriate clearance forms and reports are forward to the transplant office. If you require clearance forms, you may request them at the time of your pre-transplant office appointment or from your transplant coordinator assistant.

In general, we require our patients to obtain radiological imaging here at Mount Sinai Hospital. This enables the transplant team easy accessibility to not only the reports but also the actual films. All patients who undergo CT scan of the abdomen, MRI/MRA/MRV of the abdomen, or sonogram w/ doppler of the abdomen will have the films reviewed by one of our transplant surgeons. If there are insurance issues that require you to have your imaging studies done elsewhere, please inform your clinical coordinator so that you can receive the necessary prescriptions to have the correct imaging studies performed. Please note that your primary care physician is responsible for obtaining the appropriate referral forms.

If you are having your endoscopy and/or colonoscopy done here at Mt. Sinai Hospital with one of our transplant physicians, you will be given instructions on how to prepare for these procedures. Ask your coordinator or coordinator assistant for a detailed instruction sheet and the necessary prescriptions. If your are unable to come to your appointment you must call your coordinator assistant immediately. If you will be late for the procedure, call the endoscopy suite for further instruction. There phone number is (212) 241-6277.

Laboratory Testing

As part of the evaluation for liver transplant there are many laboratory tests that need to be completed. Below are some of the most common. Lab tests will be ordered by the medical team based upon the individual needs of the patient. On a patient's initial visit he/she will undergo more comprehensive laboratory testing than on future follow-up visits.

The initial lab test visit will include: full chemistries, liver function tests, CBC with platelet count, prothrombin time and INR, alpha-fetoprotein, virologies (including: cytomegalovirus, epstein barr, syphilis, and a hepatitis panel), HIV, urine analysis, and blood typing.

On follow-up visits, lab testing will include: chemistries, liver function tests, CBC with platelet count, alpha-fetoprotein, prothrombin time and INR.

Alanine Aminotransferase (ALT)
Aspartate Aminotransferase (AST)
Gamma Glutamyl Transpeptidase (GGTP)
Alkaline Phosphatase (Alk Phos)

Liver cells have ALT, AST, and GGTP inside them. When cells die or are damaged, the enzymes leak out causing the blood level of these enzymes to rise, which is a way of determining if the cells in question are damaged. ALT is more specific for liver disease than AST because AST is made in more places (e.g. heart, intestine, muscle). GGTP and AP are said to be more specific for biliary disease since they are made in the bile ducts. The results of these tests do not always detect all liver disease. Some patients with severe liver disease will have normal or nearly normal enzyme levels.

Bilirubin - results from the breakdown of hemoglobin in the red blood cells. It's removed by the liver and is excreted into bile. Bilirubin levels in the blood become elevated in the presence of liver disease.

Albumin - a protein formed in the liver, helps to maintain normal distribution of water in the body. It becomes low in the presence of liver disease.

Prothrombin Time (PT) – measures function of clotting. It becomes longer in the presence of liver disease and makes it more difficult for one's blood to clot.

Liver function is measured by the bilirubin, albumin and prothrombin time, but clinical factors must be considered as well.

Blood Urea Nitrogen (BUN) - a waste product formed in the liver and excreted through the kidneys. Blood levels become elevated in the presence of kidney failure.

Creatinine - a by-product of the breakdown of muscle. Levels become elevated in the presence of kidney failure.

White Blood Cell (WBC) - cells that are found in the blood that are responsible for protecting against infection. They become decreased in the presence of liver disease.

Platelets – blood cells responsible for helping it clot

Serologies:

Hepatitis A viral antibody - used to detect Hepatitis A.

Hepatitis B surface antigen (HbsAg) - indicates presence of either acute or chronic infection with Hepatitis B.

Hepatitis B anticore antibody (HbcAb) - when positive, indicates either current or past infection. IgM signifies acute infection, while IgG signifies past infection.

Hepatitis B surface antibody (HbsAB) - positive in a person who is successfully immunized against Hepatitis B.

Hepatitis C - the test to detect Hepatitis C is an ELISA essay that detects the presence of the antibody to hepatitis C.

RPR - tests for the syphilis virus, a confirmatory test is done in the presence of a positive result.

HIV testing - all patients being evaluated for liver transplant must undergo screening for HIV. You may be required to have repeated testing but the transplant team will inform you if it is necessary.

Presentation to the Recipient Review Committee

Once you have completed your entire pre-transplant evaluation, your case will be discussed at the recipient review meeting. This is a weekly meeting that is attended by numerous members of the transplant team. This allows for a detailed discussion of your entire evaluation and allows for the input of the many team members involved to help in coming to the best decision. Members of this team include, but are not limited to:

- Transplant surgeons
- Transplant hepatologists
- Transplant clinical coordinators
- Transplant social workers
- Transplant psychiatrists
- Hepatology fellows
- Transplant fellows
- Ethicist
- Transplant research coordinators
- Consultants (such as cardiologist, pulmonologist, etc)

Each case is discussed in detail as to your need for a liver transplant. We will review your medical and surgical history, medical urgency (MELD, hepatocellular carcinoma, etc.) and any unresolved issues. At this time it will be decided if any further evaluation is needed, if you are “early” for transplant, the appropriate time to list (according to your MELD, medical necessity, and blood type), or if you are declined as a candidate for transplant. Our selection criteria are available upon request.

Following are some of the more common outcomes of cases presented at this meeting:

Listed - this is a category reserved for patients, who after completion of the pre-transplant evaluation, it is decided that he/she would be appropriate to transplant if a liver became available in the near future.

Work-up completed - this is for those patients who have completed their transplant evaluation, but do not have a MELD score high enough to print up on the regional waiting list. These patients have been accepted as appropriate transplant recipients with our center and will continue to be followed in our pre-transplant office at regular intervals. At such time that their MELD score increases and the transplant team feels they could be offered suitable cadaveric livers for transplantation, these patients will be placed upon the active waiting list. It is essential for you to know that in the MELD organ allocation system waiting time on the list is not important

Medically Early - this is a category reserved for patients who, after reviewing their evaluation, are found to be *stable from a standpoint of their liver disease*. They will continue to be followed by the transplant team and their referring physician. If their condition deteriorates, they will be reconsidered for placement on the active waiting list.

Deferred - this means that there is further evaluation needed by the transplant team to make a better determination as to the patient's candidacy. For example, if a patient has had extensive abdominal surgery in the past, we may require that he/she be seen by one of our transplant surgeons.

Declined - while it is not often that the transplant team decides a patient is not an appropriate transplant candidate, it does happen. There are many reasons that a patient can be declined. A medical history that would significantly decrease the patient's survival after transplant would be one reason (for example, severe heart disease). Other reasons why someone would not be considered as a transplant candidate are; lack of appropriate support, non-adherence with medical regimen, and active substance abuse. Please note that if you are declined as a transplant candidate, it means that our center does not feel you would be an appropriate person to transplant. You can go to another transplant center and undergo their transplant evaluation. In fact we encourage you to consider this and we will be happy to give you contact numbers and make your medical records available.

You may ask your clinical coordinator for an estimation of when your case will be presented to the recipient review committee. Remember that your case will only be presented upon completion of your pre-transplant evaluation. Once a determination has been made regarding your candidacy, you will be notified in writing.

Irrespective of when your evaluation is completed or whether or not you are placed on the waiting list, you are still required to come to your follow up appointments with the transplant team, undergo follow up imaging studies, and maintain your previously mentioned clearances (i.e. cardiac, yearly cancer screen, etc.)

The Role of the Liver Transplant Social Worker

The Social Worker is an active member of the Interdisciplinary Liver Transplant Team. As a member of the transplant team, the social worker helps to identify the type of interventions that may be needed. The responsibility of the social worker is to be available to provide individual and family short-term counseling related to the transplant process. In addition, social workers educate patients about various entitlement and resources, and refer to appropriate agencies. He/She is available to all Liver Transplant patients and their family members, both pre and post liver transplant.

Every potential liver transplant patient is seen by the social worker as part of the transplant evaluation. Social workers are available to assist the patients with any psychosocial issues that arise and may inhibit their candidacy for transplant. As part of the evaluation, they explore various areas that may require attention and assistance.

Some of our patients have history of alcohol/substance use and/or mental health issues. After the evaluation, the team determines whether further treatment will be required. If recommended, the social worker will assist the patient by locating an appropriate program to meet their needs. Patients will then need to follow-up in receiving adequate outpatient treatment, and possibly additional meetings with their Social Worker or the team Psychiatrist; this could determine their eligibility for transplant.

Any patient who has a history of alcohol and/or substance abuse will be required to sign a contract, stating the patient's commitment to abstinence, among other things (see attached). This is an important part of the evaluation process as it helps the team understand the patient's commitment. The patient is demonstrating their dedication to improving their overall health by complying with the regulations of the Liver Transplant Program. If you have any questions regarding the contract, your Social Worker is available to help guide you.

In addition, a main part of the evaluation is assessing if our patients have adequate social supports available to them, such as family or friends. Social supports play a vital role in assisting the patient during the transplantation process. It is very difficult to go through a liver transplant without the help from your family and/or friends. If the availability of supports is a concern to you, please speak with your social worker.

Every transplant patient/family has access to a social worker, whom can assist them in dealing with obstacles, as they arise. Patients and family members should feel free and are encouraged to contact their social worker anytime during the course of their transplant process.

Some Frequently Asked Questions:

How can my social worker help me? There is a social worker available to you and your family throughout the transplant process. Your social worker will listen to what your concerns are and address them appropriately. If you have any questions at all, please contact your social worker.

How do supports play a role in the transplant process? Family and friends play a significant role throughout the transplant process. During and after the transplant, you may have to rely on others to assist you at home and to attend medical appointments. Your social worker is available to discuss your concerns, and assist you if you foresee that finding appropriate supports and/ or transportation may be a problem.

Am I eligible for homecare services? Home care services are based on medical necessity and insurance coverage. If you believe that you are in need of homecare services, you can speak to your social worker, who can explore eligibility and medical need with the transplant team. If you are not eligible, you always have the option of private paying for home care.

How can I get in touch with other transplant patients? Mount Sinai Hospital has a weekly transplant support group that is held every Thursday from 1 p.m. to 2 p.m. in the Guggenheim Pavilion 9C pt/family visiting room. This group consists of pre and post transplant patients and their families/supports. Additionally, you can speak with your social worker who may be able to put you in contact with a transplant candidate/recipient that you can speak with individually.

I have limited medication coverage, what do I do? Adhering with your medication regimen is very important. If you have limited coverage, you need to speak with your social worker or transplant financial case manager, who may be able to give suggestions regarding resources and benefits that you may be eligible for.

I live far away and cannot afford a hotel, where can I stay? The Transplant Living Center is a comfortable, affordable facility for transplant patients and their families/supports. It is located a few blocks away from the hospital in a very convenient location, for those who live far away. It is a privately funded, not for profit facility. Although this center is not affiliated with Mount Sinai Hospital, it is available to our transplant patients. If interested in learning more about TLC, please speak to your social worker about obtaining information.

Education

Patients with liver disease are dealing with a very complex medical condition. It is extremely important that you and your immediate family understand the complications you may develop as a result of your liver disease. You need to know the warning signs of serious complications and what to do if you develop problems. Even if you have stable liver disease, you need to know what you must do to maintain your health as optimally as possible.

As you move closer to your transplant, it is also vitally important that you and your immediate family know what to expect during the normal recovery process after transplant, and that you know the possible complications and the risks involved in this surgery. To undergo liver transplant surgery, you must be an informed and educated patient. In addition to our written patient education material your coordinator will provide you with individual guidance during each of your visits. We encourage you to write down questions as they come to you and bring them in with you at your next office visit. Of course, your coordinator is also available to answer urgent questions.

There are a variety of resources available to patient regarding specific liver diseases, medications, and the transplant process. Towards the end of this guide, many of these resources are listed.

We also encourage all of our patients to bring their caregiver to all their appointments. Since a variety of information is shared, you may not remember everything that is discussed.

Nutrition

The liver plays an important role in the way the body handles nutrients. The goals of the nutritional management of pre-transplant patients are to improve and optimize nutritional status. The diet management takes into account the medical condition and other factors such as allergies, food intolerance, poor dentition, and cultural and religious practices. A nutritionist is available to clarify diet and answer questions regarding diet.

Calories:

Caloric needs vary depending on medical condition and nutritional status. There may be a need to lose or gain weight. To figure out your daily calorie needs, you will need a minimum of 15 calories a day for each pound you weight. (a 150-pound man would need a minimum of 2,250 calories a day)

Carbohydrates:

Carbohydrates, or sugars, are stored as glycogen in the liver and are released as energy between meals and when the body's energy demands are high. In this way, the liver helps to regulate the blood sugar level, and to prevent a condition called hypoglycemia, or low blood sugar. This enables us to keep a steady level of energy throughout the day. Without this balance, we would need to eat constantly to keep up our energy.

Protein:

Proteins reach the liver in their simpler form called amino acids. Once in the liver, they are either released to the muscles as energy, stored for later use, or converted to urea for excretion in the urine. Certain proteins are converted into ammonia, a toxic metabolic product, by bacteria in the intestine or during the breakdown of body protein. The ammonia must be broken down by the liver and made into urea which is then excreted by the kidneys. The liver also has the unique ability to convert certain amino acids into sugar for quick energy. To quickly determine your daily protein needs in grams, divide your weight in pounds by 2. (For example, a 150-pound man will need 75 grams of protein.)

Fats:

Fats are usually not restricted except in certain conditions. Fats cannot be digested without bile, which is made in the liver, stored in the gallbladder, and released as needed into the small intestine. Bile acts somewhat like a detergent, breaking apart the fat into tiny droplets so that it can be acted upon by intestinal enzymes and absorbed. Bile is also essential for the absorption of vitamins A, D, E, and K (the fat soluble vitamins).

Sodium:

Keep your sodium intake below 2,000 milligrams (mg) a day. A 2000mg (2gm) sodium diet is usually recommended when edema (swelling) and/or ascites is present. This means not shaking salt onto your food, and reading food labels carefully to determine their sodium content. To cut down on salt, eat more fresh foods, most of which are naturally low in sodium, and fewer canned, processed, and prepared foods, such as TV dinners, chips and fast food. Other salty foods include bacon, sausage, cold cuts, cheeses, canned soups, Chinese food, and pickles. In some instances your physician may recommend a 1000mg (1gm)-sodium diet. A referral to the nutritionist may be helpful. See below for a list of high sodium foods to limit or avoid:

SEASONINGS

Accent/Half-Salt/No-Salt
Barbecue Sauce
Capers
Celery salt
Chili sauce
Fish sauces
Garlic salt
Gravy mixed
Ketchup
Lemon pepper
Marmite/Veg-Mite
Meat tenderizers
MSG
Mustards
Onion salt
Oyster Sauce
Relish
Salt (any kind)
Soy sauce
Seasoning salts
Teriyaki sauces
Worcestershire sauce

MEATS and ALTERNATIVES

Anchovies
Bacon
Cheeses
Corned Beef
Cottage cheese
Ham
Hot dogs
Lox (or smoked salmon)
Lunch meats
Nuts, salted
Pickled herring
Salami/Pepperoni
Sardines
Sausages
Spam
Seeds, salted (pumpkin/sunflower)

SOUPS

Soups, canned or dry
Bouillon cubes
Bovril/Oxo
Broth

SNACKS

Cheetos/Doritos/Fritos
Popcorn, salted
Potato/Tortilla chips
Pretzels
Crackers

PACKAGED FOODS

Instant potatoes
Instant rice or noodles
Instant casseroles
TV dinners

OTHER

Canned vegetables
Canned meals
Cheese spreads
Olives and pickles
Pizza
Salad dressings
Salsa
Sauerkraut
V-8/canned tomato

Potassium:

Some patients have a tendency for high or low potassium levels. Kidney function and use of diuretics (water pills) can effect your potassium level. Consult with your health care provider if you should be on either a high or low potassium diet. **A list of high potassium foods is listed in the following page.**

Fluid restriction

Fluids would include such items as juices, jell, ices, ice cream, soup, milk, coffee, tea, soda, and water. There may be a need to limit fluids to 1000ml (4cups) or 1500ml (6cups) if you are having problems with fluid retention. Alcohol and caffeine drinks (coffee, tea, and cola) act as dehydrators, pulling water out of your system, and are not good choices. Your doctor or coordinator will inform you if you need to limit your fluid intake.

Vitamins and minerals

If you are having problems with eating, you may take a vitamin and mineral supplement that provides no more than 1 to 2 times the Recommended Dietary Allowances. **But before you start, discuss this with your doctor.** Certain fat-soluble vitamins, such as Vitamin A, and some minerals, such as iron, can be stored in the liver and can actually cause problems when taken in large amounts.

Food Labels:

Almost all food products are required to display nutrition information. Get into the habit of reading the Nutritional Facts section on packaged foods. Check the labs for the amount of sodium. This will help you in determining whether or not a food item is allowed in your diet. The recommendation is that a food item be less than 120mg Sodium. Read the ingredients and look for items such as salt, sodium, or monosodium glutamate.

Macaroni and Cheese

Check the serving size and the number of servings in the container.

Check the amount of fat, cholesterol, or sodium per serving in grams (g) or milligrams (mg).

Calculate the amount in your serving, and compare it to your daily limit.

$$\left(\begin{array}{l} \text{your} \\ \text{size} \end{array} \right) \times \left(\begin{array}{l} \text{amount} \\ \text{per} \\ \text{servings} \end{array} \right) = \left(\begin{array}{l} \text{amount} \\ \text{you} \\ \text{consume} \end{array} \right)$$

Nutrition Facts	
Serving Size 1 cup (228g)	
Servings Per Container 2	
Amount Per Serving	
Calories 250	Calories from Fat 110
% Daily Value*	
Total Fat 12g	18%
Saturated Fat 3g	15%
Cholesterol 30mg	10%
Sodium 470mg	20%
Total Carbohydrate 31g	10%
Dietary Fiber 0g	0%
Sugars 5g	
Protein 5g	
Vitamin A	4%
Vitamin C	2%
Calcium	20%
Iron	4%
* Percent Daily Values are based on a 2,000 calorie diet. Your Daily Values may be higher or lower depending on your calorie needs:	
	Calories: 2,000 2,500
Total Fat	Less than 65g 80g
Sat Fat	Less than 20g 25g
Cholesterol	Less than 300mg 300mg
Sodium	Less than 2,400mg 2,400mg
Total Carbohydrate	300g 375g
Dietary Fiber	25g 30g

When you don't feel like eating:

Keeping your portions small, so the amount of food in your plate does not seem overwhelming. If you feel up to it, taking a short walk before mealtime can be relaxing and may revive your appetite. Some people may have a better appetite in the morning. If you find that you do, take advantage of it by eating a big, healthy breakfast, and enjoying your meals. For example, you may try to include foods that provide 1/3 to 1/2 of your protein needs at this time, and use nutritional supplements later on when you don't feel like eating.

Changes in taste:

Certain foods you once enjoyed may no longer taste the same. Perhaps your medication is causing a bad taste in your mouth, or liver disease has harmed certain chemical pathways. Some foods with protein, red meat in particular, might taste bitter. But protein foods are important; they give you strength and help you fight off infection. If red meat doesn't taste good, try chicken, fish, or other high protein foods such as beans, yogurt, tuna, eggs, or peanut butter. Don't despair; taste changes do not last forever. Foods that you find unpleasant now may taste good again later. Keep trying as you begin to feel better.

Changes in smell:

Some patients notice that the smell of cooking or cooked food bothers them. If this happens to you, try serving foods cold or at room temperature. You can also turn on a kitchen fan during your meal and while food is cooking, open kitchen windows when possible, grill foods outside in the summer, or use the microwave or cook in boiling bags to cut down on odors. If the problem continues, you can even use a small fan next to your plate when you eat hot foods that have a strong smell.

When you feel nauseated:

No one wants to eat when they feel nauseated, but try not to go for long periods of time on an empty stomach. Eat small amounts of food every 2 or 3 hours and eat slowly. Don't worry about balanced meals at this point, eat what you can tolerate and make sure to replace any lost fluids. During periods of nausea, avoid citrus juices (orange, grapefruit, and pineapple). The acid may bother your stomach. Instead try apple or grape juice, ginger ale, chicken broth, weak tea, or sports drinks, and sip these drinks slowly. If morning nausea is a problem, eat some dry crackers when you first wake up. Also, get out of bed slowly. Avoid foods that have strong smells, or are spicy, greasy, or deep-fried.

When you feel full quickly:

If your liver is inflamed or enlarged it may press on your stomach and make you feel as if there's less room for food. To lessen these problems eat smaller portions of foods at meals. Beverages taken with your meals will leave less room for food. Instead of 2 or 3 big meals a day, try 6 small meals spread out over the day. You will eat less food at a time, but you will be eating more often.

Helpful hints:

Patients are strongly advised not to take megavitamin therapy or to use nutritional products bought in special stores or by catalogue without consulting a doctor. Some of these products may actually cause liver damage.

Remember that eating well may help you feel better since it can help your body better respond to treatment and its side effects.

By choosing foods carefully, you may not need a vitamin or mineral supplement.

Make the most of each mouthful. Be sensible, be moderate.

Nutrition is an important component in the management of liver disease. If you have any questions or concerns regarding your diet, consult the coordinator and ask for a referral to the nutritionist.

Insurance/Financial Issues

Paying for the physician, hospital and medications associated with transplantation is an important issue for all patients. We have dedicated Financial Coordinators who can assist you in this area. However you should also be aware of what the cost for transplant entails. Transplant costs usually break down into three phases. These phases include:

- The transplant evaluation
- The surgical procedure
- Follow-up care, lab tests and medications after transplant

The average outpatient cost for a transplant evaluation is about \$20,000. During the waiting period the average cost is about \$6,000. Transplant surgery is about \$200,000 and postoperative care for the first year after transplant including medication costs average approximately \$48,000. These costs do not include any required costs for transportation and lodging.

In order to allow our staff to help you assess your transplant coverage, it is absolutely necessary for you to provide us with your current health plan information and always keep us informed if your plan has changed or has been terminated. Upon verification of your insurance by our Financial Coordinators, you will be informed as to what your plan will cover and how you may meet the obligations of any remaining costs.

The most common coverage issues that transplant patient's face include:

1. Your policy has a life time maximum of benefits, or a transplant life time maximum
2. Limited or no medication coverage
3. Out of pocket expenses
4. Our hospital or physicians are not participating within your plan
5. In the case of living donor, no donor service coverage

Our financial team is committed to working with you to find ways as to how best you can meet the financial obligations associated with transplantation so that you may devote your energies to improving your health.

It is your responsibility and extremely important that any changes to your insurance coverage be reported to our Financial Coordinator immediately. Any change in benefits can and will effect your transplant expenses both before and after transplant. Our Financial Coordinator can be contacted at 212-659-8081.

Clinical Research Program

The core purpose of the Recanati/Miller Transplant Institute's (RMTI) Clinical Research Program is to efficiently study and apply developments in basic research to our ever-growing cohort of patients. It is our intent to enroll each of our patients into an appropriate clinical study, as this best assures the continued advancements of the field, as well as the best outcome for our patients.

An on-going scientific and clinical research program keeps the Mount Sinai School of Medicine (MSSM) at the forefront of discovery and assures that our patients have access to the newest and most effective medical, surgical and diagnostic treatments.

The overall goals of the Clinical Research Team include:

- Enhancing the RMTI's working relationship with federal agencies, including the National Institutes of Health, private drug manufactures, and other major medical institutions.
- Encouraging and supporting the collaboration between the basic science and clinical scientists from within MSSM as well as other institutions.
- Developing expertise in the field and to use the knowledge gained through our research to stay at the forefront of the development of better intervention strategies for limiting both disease progression and graft loss.
- We further expanded our program by enhancing the ability to market our growth to the research and development (R&D) industry, by attending conferences, participating at investigator's meetings and assisting in the development of protocols.
- Our reputation in the field of research is superior to other sites due to our commitment to protecting the rights and welfare of human subjects, enrolling the appropriate patients, following and monitoring those patients accordingly, and providing excellent and timely data with limited queries and protocol violations.
- Finally, the clinical research program also serves to train other health professionals interested in clinical research, including fellows, residents, nurse coordinators, floor nurses, OR techs and others.

The team is also assisting and collaborating with faculty from other departments within MSSM including, but not limited to, the Departments of Medicine; Infectious Diseases; Endocrinology; Psychiatry; Pediatrics; Pulmonology; Medical and Surgical Oncology; Radiology; Anesthesiology, etc.

We are currently coordinating the research projects for our liver/small bowel surgeons; kidney/pancreas surgeons; hepatologists; nephrologists; pediatricians; along with assisting faculty from infectious diseases; endocrinology; hematology; oncology, and psychiatry.

We attend various national and international meetings to represent MSSM and RMTI and to increase our knowledge in the field.

We train fellows, residents, nurse coordinators, floor nurses (in the Care Centers, SICU, MICU, PACU), OR nurses and staff at the GCRC on new therapeutic agents and research protocols.

We work closely with the Institutional Review Board (IRB), Pharmacy, and the General Clinical Research Center (GCRC) to assure good clinical and ethical conduct of research trials. Our expertise in the field of clinical research has invited us to participate in research committees within MSSM to assure the institution, as a whole, is compliant.

Pre Transplant Medications



Your liver does many important jobs to keep you healthy. It changes your food into energy which is needed for life and growth. It also stores sugar, iron, vitamins and minerals so your body can use them whenever needed. Your liver breaks down and removes medications, alcohol and other harmful substances from your blood stream. It makes a yellow green fluid called bile. Bile helps you digest fats and allows you to absorb some important vitamins. The liver regulates your hormones (sex, thyroid and adrenal) and also makes proteins that are needed for the blood to clot and to help fight infection.

Below is a list of the types of medications that you MAY be taking:

DIURETICS

The blood protein albumin is made in the liver. When the liver is not working well, it will not be able to make enough albumin. Albumin helps to hold fluid in the blood vessels. When the albumin is low, fluid may pass into your abdomen, legs or other parts of the body.

With advanced liver disease, the kidneys get confusing messages from the liver and start keeping extra salts and fluid in the body. When this extra fluid collects in the abdomen it is called ascites. Diuretics are prescribed to help reduce the swelling and fluid retention. Diuretics are also used to help treat high blood pressure.

LAXATIVE/BOWEL CLEANSING AGENTS

With advancing liver disease, certain toxins may build up in your body and affect your thinking. You may also become irritable, drowsy, or confused (encephalopathy). The bacteria that are normally in your gut can produce some of these the toxins (ammonia). Laxatives or bowel cleansing agents are prescribed to help reduce the bacteria producing the toxins. Sometimes these medications are used to treat constipation. Constipation can be related to taking

pain medications, calcium and iron pills. Constipation itself can cause encephalopathy.

BETA-BLOCKERS

The pressure in the liver veins may become high if the liver is unable to handle the blood that normally flows through it. In an effort to lower the pressure, varices (bulging veins) may develop in the stomach and swallowing tube (esophagus). If these varices bleed, a person can vomit bright red blood or it may look like dark coffee grounds. Sometimes there may also be black bowel movements. Beta-blockers are prescribed to lower the pressure inside these blood vessels. These medications are also used to treat and prevent many other conditions, such as high blood pressure, irregular heartbeat, uncontrollable shaking, and migraine headaches.

ACID SUPPRESSING AGENTS

Acid suppressing agents prevent the production of acid in the stomach. They are used to prevent the recurrence of ulcers and to treat other conditions where the stomach makes too much acid.

ANTI-ITCHING MEDICATIONS

Itching is common in liver disease. It is caused from the bile made by the liver. These bile salts deposit in the skin and cause irritation. Medications are prescribed to help the body dispose of the bile or to help improve the flow of the bile through the liver.

ANTIVIRALS

If your liver disease is caused from chronic Hepatitis B or Hepatitis C, you may be prescribed medications to help prevent the virus from multiplying.

REMINDER: Never stop taking medication or change the dosage without a physician's approval.

Before taking medications:

- **Tell your prescriber or health care professional about all other medicines you are taking, including non-prescription medicines, nutritional supplements, or herbal products.**
- **Check with your health care professional before stopping or starting any of your medications.**
- **Try to take each medication at the same time every day.**
- **DO NOT cut or crush a tablet unless advised to do so.**

If you miss a dose:

- **If you miss a dose or forget to take your medicine, take it as soon as you can.**
- **If it is almost time for your next dose, take only that dose and skip the missed dose.**
- **Do not take double or extra doses to make up for a missed dose.**

Storing medications:

- **Keep medications in the original container, tightly capped. If a special container is used to hold the pills, keep the container tightly sealed.**
- **Store at room temperature, away from heat, moisture and direct sunlight.**
- **Do not store medications in the bathroom – moisture can cause medications to lose their strength.**
- **Do not store medications in the refrigerator unless the physician or pharmacist advises to do so.**
- **Keep all medication out of reach of children in a container that small children cannot open.**

Medications called NSAID's (non-steroidal anti-inflammatory drugs) such as Advil, Aleve, Motrin, Nuprin, and Ibuprofen should be avoided as these drugs can cause problems with blood clotting and are associated with the development of ulcers in the stomach. For pain relief or fever, we recommend that you take regular-strength Tylenol, but no more than 2,000mg in a 24-hour period.

Who gets a liver? The UNOS Policy

Once you are accepted for transplantation, the search for a suitable donor begins. All patients are entered onto the national transplant waiting list maintained by UNOS (The United Network for Organ Sharing), a national organization that works 24 hours a day, 365 days a year to match donors to recipients. In order to fairly and efficiently distribute this scarce resource, the country is divided into regions, so most of the organs that come to Mount Sinai are from donors in New York State.

The amount of time you spend on the waiting list is determined by many factors including blood type and the urgency of your condition. Unfortunately, due to the shortage of donor organs, the waiting time can be long and it is very important that during this time you do your best to maintain good health.

What is UNOS?

The United Network for Organ Sharing (UNOS) is a non-profit organization that regulates and maintains the nation's cadaveric (from a person who is brain dead, but whose organs are still viable) organ transplant waiting list. The Organ Procurement and Transplantation Network (OPTN) was established by Congress to ensure that donated organs are fairly distributed regardless of an individual's age, sex, ethnicity, religion, lifestyle or social status through UNOS. Both UNOS and OPTN are regulated by the U.S. Department of Health and Human Services. As of February 27, 2002, UNOS implemented the Model for End-Stage Liver Disease (MELD) scoring system for cadaveric liver allocation. UNOS mandates that all transplant centers nationwide use this new policy.

What is the MELD Scoring System?

The MELD scoring system was developed as a way to predict the likelihood of death within 3 months for people with end-stage liver disease. One of the major responsibilities of the OPTN is to develop and implement new policies that will ensure that scarce donor organs are allocated to the patients that are medically in greatest need of a liver transplant. The idea behind MELD is that organs will be allocated more fairly because medical urgency is emphasized, while waiting time becomes less important than it had been.

How will a MELD score be assigned?

The MELD score will be calculated by using a mathematical equation that involves the following laboratory data:

- Creatinine – end product of metabolism that is used to monitor kidney function. Normal range is less than 1.2 mg/dL. Value becomes abnormally elevated with kidney dysfunction that is associated with advanced liver disease. If a patient is receiving dialysis as a result of kidney failure, they will be assigned a maximum creatinine of 4 mg/dL.

- INR - is a laboratory value used to help determine the liver's ability for making clotting factors and a patient's risk for bleeding. If prolonged, it is an indication that the liver disease is progressing. Normal range is less than 1.2.
- Bilirubin - is an indicator of the liver's ability to detoxify the blood. It's what makes a person appear jaundiced (yellowing of the skin and white of the eyes). When elevated it can cause an individual to feel itchy. Normal range for total bilirubin is 0.1-1.2mg/dL.

Schedule for re-certification of the MELD score:

Status 1	Status re-certification	Lab values must be no older than
MELD score 25 or greater	every 7 days.	48 hours
<= 24 but > 18	Re-certification every 7 days	Lab values must be no older than 48 hours
<= 18 but >11	Re-certification Every month.	Lab values must be no older than 7 days
<= 10 but >0	Re-certification every 3 months.	Lab values must be no older than 14 days
	Re-certification every 12 months .	Lab values must be no older than 30 days

A MELD score can range from 6-40 points. The higher the MELD score, the more frequently you will be required to have laboratory blood tests. Organs will be now be allocated to the patient with the highest MELD score versus the patient who has the longest time on the waiting list. If there are two patients with the same MELD score, then time waiting at that particular score will be used as a "tie breaker". Please note that you will be required to have your laboratory blood tests done here at Mount Sinai Hospital. UNOS has a website that you can access for further information: www.unos.org. A website that can calculate MELD scores has been set up by the Mayo Clinic: www.mayo.edu/int-med/gi/model/mayomodl-5-unos.htm

Make sure that you have an appointment for either a follow up visit in our office or for lab work before your MELD recertification is due. If you let your MELD recertification lapse past the due date, you MELD will automatically be downgraded by UNOS. If you do not have an appointment or need one, contact your coordinator assistant immediately for one.

What to Expect While a Patient is on the Waiting List

In order to have a close monitoring of your medical care, you need to continue to see your primary doctor and/or your gastroenterologist. They will serve as your primary providers and we will take care of your liver transplant status.

All transplant candidates have routine follow-up visits/physical examinations in the pre-transplant office every one, three, six, or twelve months or earlier, as necessary according to your MELD score and medical status. Education is continued on each visit based on individual patient needs. Medication lists and history of present illness are always updated with each office visit. Patients with hepatocellular carcinoma (HCC) are seen in the office every 2 months. Laboratory tests are done with each visit and updated with the UNOS website every time. Your compliance with your appointments is critical to keep your status on the waiting list.

CT scan of the abdomen or MRI of the abdomen should be done every 6 months so a liver tumor is not missed. For those already diagnosed with HCC, CT scan or abdominal MRI is done every 2 months. These HCC patients also need to have repeated CT scan of the chest and bone scan every 3-6 months, according to tumor size.

Patients with TIPS need to have an abdominal sonogram and doppler every 3 months for the first year of the TIPS placement, then the frequency of the test depends on the medical status of the patient afterwards.

Cardiology evaluation and follow-up should be done every year or more frequently for those with pulmonary hypertension and/or cardiac disease.

Any surgeries, hospitalizations, and changes in medical status should be reported to the transplant team. If hospitalized in another institution, please make sure to have your doctor in charge of the care call us to inform us about medical status, whether they want to transfer you to Mount Sinai Hospital or not. This is critical information that enables us to fully participate in your medical care. Ideally if you require hospitalization we would like it to be at Mt. Sinai so we can catch your liver condition carefully.

While waiting for the liver transplant, stay in your best medical condition by eating a proper diet (low salt), exercise as necessary, no smoking, no drinking of alcohol at any time, take your prescribed medications, see your doctors (dentist, gynecologists, primary doctors, gastroenterologists, etc.).

Medical care of transplant candidates is a collaborative effort between the patient, their family, transplant team and the referring/primary care physician.

It is imperative that you inform the transplant office of any changes in your insurance, address, telephone number, or other demographic information so that we may update your records.

Continue to follow up with your primary care physician

Continue to be seen in the pre transplant office on a regular basis.

Take your medication as prescribed. Never adjust dosages of your medications without discussing with your physician.

If you are have labs work or procedures outside of Mount Sinai Hospital, have copies forwarded to your transplant coordinator.

Notify your transplant coordinator of any changes in your medical condition or if you have had any hospital admissions.

Do not drink any alcohol! This includes wine coolers and non-alcoholic beer!

Do not take any NSAIDs (Non Steroidal Anti-Inflammatory Drugs) such as Motrin, Advil, Aleve, Ibuprofen, etc. If you have questions, call your transplant coordinator.

Keep active, daily and regular exercise as tolerated.

Eat healthy. Follow a low fat, low cholesterol, and low sodium diet.

Avoid raw or undercooked shellfish.

Avoid high doses of vitamins A, D, iron, and niacin—the can be toxic to your liver.

Avoid all refined, processed and canned foods as they can contain a lot of sodium.

Make sure that you have an appointment for either a follow up visit in our office or for lab work before your MELD recertification is due. If you let your MELD recertification lapse past the due date, you MELD will automatically be downgraded by UNOS. If you do not have an appointment or need one, contact your coordinator assistant immediately for one.

Please note that at anytime in the pre-transplant phase, you have the right to refuse transplant. Your decision will have no consequences upon your place on the UNOS waiting list.

Where Do Livers Come From

The majority of liver transplants performed in the United States use the livers from cadavaric organ donors. These are people who have been declared brain dead and through the generosity of their family members their organs were donated.

Most commonly the person died unexpectedly by means of “brain death”. Brain death occurs when blood is no longer flowing to the brain tissue because of a severe injury to the brain causing swelling inside the skull (cerebral edema). In this situation, the brain dies and for medical and legal purposes the patient is declared officially dead. Through modern technology including respirators and medication to maintain blood pressure, it is possible that the remaining organs in this person are still alive. This is the situation in which organs can be removed and successfully transplanted into other people that require such organs in order to go on living.

Allocation of Cadaveric Liver Organs

Liver allocation depends on the waiting list printed by the procurement center from the UNOS list. Livers will be offered to Local Status 1-based on their waiting time as status 1 in descending order, then to Regional Status 1. Then they go to Local MELD score descending order and to Regional MELD score descending order. If a recipient is not found in the region, the liver will be offered to National Status 1 patients. Then to other patients based on their descending MELD score.

ADULT DONOR LIVER ALLOCATION ALGORITHM:

Local

- 1) Status 1A candidates in descending point order

Regional

- 2) Status 1A candidates in descending point order

Local

- 3) Candidates with MELD/PELD Scores ≥ 15 in descending order

Regional

- 4) Candidates with MELD/PELD Scores ≥ 15 in descending order

Local

- 5) Candidates with MELD/PELD Scores < 15 in descending order

Regional

- 6) Candidates with MELD/PELD Scores < 15 in descending order

National

- 7) Status 1 patients in descending point order
- 8) All other patients in descending order of mortality risk based on MELD score

Donor families can also do direct donation when they decide who should get their donor's organs. These are initiated by the donor families and relayed to the local procurement team at the donor hospital.

Deceased Donor Evaluation

When a donor liver becomes available, the procurement coordinator at the organ procurement organization (OPO) where the liver is located contacts the transplant coordinator on call. The transplant coordinator obtains extensive information on the donor. Some of the information that obtained includes, but is not limited to the following:

- Age, height and weight of the donor
- Cause of brain death
- Hospital course of the donor
- “Downtime” or length of cardiac arrest if it occurs
- Medical, surgical, and social history of the donor
- Laboratory evaluation including liver function, kidney function, electrolytes, complete blood count, coagulation profile, serological testing for HIV, HBV, HCV, CMV, VDRL (RPR), blood gas analysis
- Hemodynamic status (blood pressure, central venous pressure, heart rate)
- Use of vasopressors (medication given intravenously to maintain blood pressure)
- Which patient is this organ being offered to.

Afterwards, the transplant coordinator will contact the transplant surgeon on call to discuss the donor information. The transplant center will then have one hour to either accept or decline (pass) on the donor organ. During this time, discussion on the recipient will also take place to ensure that the liver being offered for donation is suitable for the recipient it is being offered to.

Factors in the Donation Process

When an organ is donated, it is made available to eligible patient on the waiting list. Before the transplant can take place, however several things happen:

1. The local OPO (Organ Procurement Organization) gathers information about the organ (size, condition, blood type) and sends it to UNOS.
2. A patient on the UNOS list who is most qualified for the organ (based on the MELD system, waiting time, blood type match, and other factors) is selected and that patient's transplant center is notified.
3. Although a patient meets all the criteria and appears to be a good match for the organ, the organ still has to be accepted by the transplant center. The transplant team has one hour to consider several factors before accepting the organ for the patient it is offered to. If, in the physicians' judgement, the organ offered presents undue risk to the patient, it may be refused or declined for use. There are a number of reasons for refusing to use an organ, such as:

Patient condition—the patient may be currently too ill to undergo transplant surgery or the patient may be otherwise unavailable for surgery at that time

Donor Condition—the donor may have some other illness that would preclude donation.

Organ Condition—if an organ has been outside the donor's body for too long it might not work as well and may not help the patient. The organ might have been damaged during recovery from the donor or during transportation to the transplant center. Sometimes, final examination of the organ shows previously unseen risks, such as too much fat or badly formed blood vessels.

There are some differences among transplant centers overall in terms of how often organs are accepted or refused.

A cadaveric liver is offered to a patient not to the transplant center.

Extended Donor

One way the waiting time may be shortened is when your surgeons accept a donor liver that falls into a higher risk category. Donor livers that are considered not standard or ideal are also called "expanded criteria" or "marginal organs". The most common reasons that donor livers are not considered standard include the following:

- The donor has a history of hepatitis B or C.

When the donor has active hepatitis B or C, we will only consider transplanting the organ into a recipient who also has hepatitis B or C. In all cases we will assess the donor liver prior to transplantation, sometimes with a liver biopsy, to ensure that there is no evidence of damage to the donor liver from hepatitis.

When the donor is an inactive carrier of hepatitis B, we may consider transplanting the organ into a recipient without hepatitis B, especially if they are already immunized. In some situations, additional treatment (usually an oral antibiotic called *Lamivudine*) after the transplant may also be required to reduce the chance of active hepatitis B developing in the recipient.

- The donor liver contains some fat (steatotic)

Fat in the liver is very common in the general population and generally goes unnoticed with no ill effects, but the presence of fat in the liver may prolong the time it takes for the donor liver to function optimally after transplantation, which is why such livers may not be suitable for some patients who may not tolerate a period of transient poor function.

- The donor is from an older age group (over age 65)

We do not know what the natural life span of the human liver is, and carefully selected livers from older age donors function as well as donor livers from younger donors.

- DCD donors (Death after cardiac death)

DCD donors are ventilated patients with do-not-resuscitate orders, where a decision has been reached by the physician and the family to withdraw life support. Organ donation does not occur until after cardiac arrest, hence the term "donation after cardiac death." This is in contrast to the majority of donors we use who are "brain-dead donors." These DCD donors may experience more ischemia time and hence they are considered in the spectrum of extended-

criteria donors. The results with these organs appear to be equivalent however the experience is more limited.

The decision to utilize a particular liver is based on your specific needs at the time the liver is offered and, therefore, changes constantly. The transplant surgeon may advise you to consider accepting a liver from one of the above groups because of your particular medical condition. For example, if you are already infected with hepatitis C virus, there is no difference in function of livers taken from donors also infected with hepatitis C, and there is no higher likelihood of post-transplant recurrence of hepatitis. Consequently, acceptance of a liver from a hepatitis C donor may shorten your waiting time without increased risk. In other cases, such as “fatty” liver donors or older age donors, there may be an increased risk of the liver not functioning as well immediately after transplantation, but this increased risk may be offset by your specific medical condition and the necessity of reducing any delays in transplantation. Other reasons also exist for turning down livers, but in general, the decision to accept the higher risk associated with an expanded criteria liver must be balanced with the risk of dying or becoming too sick for transplant while on the waiting list.

After you have been placed on the waiting list, one of the transplant surgeons in our team will discuss with you the risks and benefits of expanded criteria donor livers with you. If you want to be considered for an expanded criteria donor liver, we will keep your name on file and when a liver is available that is declined by another center, you may be contacted to come in for transplantation. Your surgeon can discuss with you the specifics of the organ donor when you are called, and you will always have the option to decline to proceed with transplant at any time. **Declining an expanded criteria liver will not influence your status on our waiting list.**

Finally, we want to make sure to explain the operational structure of our transplant program. We are a team of surgeons, hepatologists, and healthcare workers who work together as a team to care for you. You will see various physicians and healthcare workers in the course of your time in the evaluation process, while on the list and through the transplant process. We have a team of surgeons who rotate their time in the operating room so that any one of them may be the surgeon who performs your transplant and/or cares for you in the postoperative period.

Getting Called in for Transplant

Once you are placed on the active waiting list for transplant, your transplant coordinator will notify you. At this time you should ensure that we have all contact numbers for you. If you have a pager number or cellular phone number, this will be helpful to us if we need to contact you and you are not home. It is very important that you make travel arrangements in advance should you be called in for transplant. Keep in mind that you should know how you are going to get to Mount Sinai, how you are going to pay for transportation, who will accompany you and how you can reach them quickly. If you are planning on being out of town, you should also notify your transplant coordinator and provide a phone number in which you can be reached.

When a cadaveric liver becomes available within our region, UNOS will generate a waiting list for patients with the same blood type, listing the patient with the highest MELD score at the top of that list. The organ procurement coordinator will call our transplant center and speak to the clinical coordinator who is “on call” for the day. Remember that an organ is offered to a patient on the waiting list. If that patient is listed with our center we will collect all the information on the donor and discuss the case with our transplant surgeon who is “on call” for potential cadaveric donors. Our transplant surgeon will decide, based on the information that is given to us, if we will consider using this organ for the patient it is being offered to. If we decide to proceed, we will notify you and have you come in to be admitted. Remember, we will give you as much notice as we are given. Often these calls occur late at night, but they can happen at any time during the day or evening.

When you are called to come to the hospital, the coordinator will let you know exactly where to go (nursing unit, admitting office, etc.). You should notify any family members/significant others that you are coming to Mt. Sinai Hospital for your transplant. They may accompany or meet you at the hospital. Identify a “point person” or spokesperson that will relay information regarding your progress to other people. The coordinator will give you an estimated time for your surgery. At this point you should not have anything to eat or drink, as your stomach must be empty when you are taken to the operating room. Make sure to bring the following items with you to the hospital:

- A list of all your medications
- A list of all your allergies
- Your health insurance information/cards

If you have any acute illness such as fever or infection you must inform the transplant coordinator at this time. This may impact on whether or not you can undergo transplantation.

Do not bring any valuables! Bring only basic toiletries that your family member/significant other will be able to carry.

When you are admitted, you will meet the transplant surgeon and transplant fellow. At this point a pre-operative assessment and testing will be done. Some of the tests and procedures that you will undergo include, but are not limited to:

- Blood tests
- Chest x-ray
- EKG
- Physical examination
- Review of medical history
- Review of medications
- Insertion of IV lines
- Review and consent for surgery
- Review and consent for special medications and/or research studies you have enrolled in.

Remember that a liver transplant is not definite until the liver is at Mt. Sinai Hospital. Even though our surgeons may go to procure the liver, often we will require a biopsy to make the final determination. If the biopsy reveals the liver is not suitable for transplant the case will be cancelled. Of course there are other reasons that the case may be cancelled, such as anatomical problems or size of the liver. Don't be discouraged. If you are brought in for a liver transplant and it doesn't happen, remember our surgeons are making a decision that will give you the best possible outcome for liver transplantation.

While the "on call" coordinator is available through the emergency service, please limit the number of calls that are placed. The coordinator is responsible for not only arranging for your transplant, but also for arranging for our team of surgeons to procure the liver. Other responsibilities include: arranging for anesthesia, booking the operating room, pathology, perfusion, blood bank, and many other departments that need to be involved in your transplant.

If the decision is made to go ahead with your liver transplant, you will be brought down to the operating room. Your family and friends can wait in the surgical waiting area located in the Guggenheim Pavilion, 2nd Floor. Remember that liver transplant surgery can take anywhere from 6 to 12 hours. At the end of the case, the transplant surgeon will look for your family in the surgical waiting area. Your visitors will be able to see you once you are in the Surgical Intensive Care Unit (SICU) after the doctors and nurses have "settled" you in and you are stable. These visits must be brief as both the physicians and nursing staff will be busy taking care of you.

Liver Transplant Surgery

Liver transplant surgery is extremely complex and may last 6 to 12 hours, depending upon the patients' condition.

The liver transplant is three operations:

- removal of the donor's liver
- removal of the recipients liver (major blood vessels that feed and drain the liver are left in place, which will be attached to the new liver)
- implantation of the donor liver into the recipient

The recipient surgery can further be divided into three stages:

- removal of the diseased liver
- replacement with the new liver
- reconstruction of the biliary tracts

Removal of the recipients liver is the hardest of the three stages for many reasons:

-the liver makes the parts of the blood that cause clotting. People with liver disease do not make enough of these clotting substances, leading to a tendency to bleed during surgery.

-liver disease causes "portal hypertension" which is a state of congestion of the blood trying to be filtered by the liver. This makes the operation more difficult.

-cirrhosis, a scarring process, causes the liver to be more difficult to be separated from adjoining tissues, which can be further complicated if the patient has had prior abdominal surgery.

Post Transplant Care

Following surgery, patients are taken to the Surgical Intensive Care Unit (SICU), located in the Guggenheim Pavillion 6 East, for recovery. This unit has the equipment and specially trained nursing staff for quick response if a problem occurs. The patient will wake up in the SICU after anesthesia wears off and will remain in there until their condition is assessed by a physician and found to be stable, usually 24 to 48 hours. In the SICU, there is collaborative care between the ICU and Transplant teams.

This is what the patient should expect:

Some pain and discomfort, which medication will help to relieve.

A tube will be inserted through your nose, which will run down into the throat and stomach. This tube will keep the stomach empty, to help prevent nausea and vomiting.

A tube will be inserted into your throat through the mouth to help provide enough oxygen. It will be connected to a ventilator. You should try to relax and let the machine breathe for you. You will not be able to talk with this tube in place, but it will be removed as soon as you are fully awake and able to breathe on your own.

You will be asked to cough and take deep breaths periodically to keep the lungs clear.

You will be placed on a monitor that will continuously assess blood pressure, heart rate, oxygenation, and other hemodynamic parameters.

You will have multiple intravenous lines (IV), which will be used to give fluids, medications and monitor hemodynamic status.

For several days after surgery, you will have a catheter in your bladder to drain urine.

During surgery, several drains will be placed in or near the incision. They will be removed 5-10 days after surgery.

As soon as you are medically stable, you are transferred from the SICU to the transplant unit. There you will be cared for by specially trained nurses until you are ready for discharge home.

While in the transplant (9 Center):

You will begin exercising. This will consist of getting out of bed to the chair, walking, and possibly physical therapy.

Your diet will slowly be advanced from a liquid diet to a regular diet. This will occur over 2-3 days only if you are able to tolerate it.

Activities, which will contribute to your recovery, include the following:

1. Walking - you will need some assistance from your nurses at first, but you will build your strength gradually and regain ability to walk by yourself.
2. Coughing & Deep Breathing - it is important to continue practicing the coughing and deep breathing exercises you learned in the Intensive Care Unit by using a device called the incentive spirometer several times daily which will get your lungs back "into shape" and prevent pneumonia.
3. Eating - when you are permitted to eat, your diet will be gradually increased from clear liquids to solid food. Your body will need many calories to heal, so it's important that you eat well-balanced meals. Your dietician will review your diet and discuss your food preferences with you.

You will see the transplant team twice a day during morning and afternoon rounds. Interdisciplinary patient care rounds occurs everyday at approximately 2pm and consists of a transplant surgeon, transplant hepatologist, transplant coordinator, social worker, nutritionist, physical therapist, primary nurse, physicians assistant, pharmacist, etc. If you have questions regarding your care, this is an opportune time to ask. Patient and family participation in care are very important.

You will receive a Post Transplant Teaching Manual, medication sheet, and a list of "On Demand" videos. Our Patient Education Video Program is an additional source of education for our post-transplant patients. This is a channel on the hospital TV system that includes 200 interactive educational videos, many of which are specific to transplant, and is free of charge. Both physicians and nurses will use this system to help you understand what to expect during your stay in the hospital. You and your family will be required to attend the patient teaching group that is held on the unit. You will also receive one-on-one teaching with your primary nurse and transplant coordinator.

The transplant team begins discharge planning right from the beginning. Your coordinator will discuss what your needs are, if any, with your social worker. You will be assessed for any homecare needs such as visiting nurse services for diabetic teaching, wound care and physical therapy. Depending on your post-operative course, you can expect to be discharged anywhere from 5-8 days after surgery. Of course, if your hospitalization is complicated by any episodes of infection or rejection, you can expect to be here longer.

Before you leave the hospital after your transplant, you must have:

- An updated medication sheet
- At least one month supply of all your medications
- Prescription for pain medication if required
- Follow up appointment date and time with the transplant team
- Diabetic supplies if you are a diabetic
- Follow up for diabetes care
- Home care services if applicable
- Transportation arrangements and family member to accompany you.

Visiting Hours

Visiting Hours are 11:00 AM - 9:00 PM daily with the following exceptions:
Intensive Care - Hours vary in each unit.

Appointment Schedule After Transplant

The following is the general appointment schedule for post transplant patients.
Naturally, it may be adjusted depending upon your progress.

- Twice a week for month one
- Once a week for month two
- Every other week for month three
- Return to your primary care physician, gastroenterologist or hepatologist at three months

Post Transplant Care

Three months after your transplant, if you are stable, your care will be returned to your primary care physician. Your care may also include disease specialists as indicated (for example, diabetes). Your care will be a collaboration between your designated physician and the transplant team. You will be required to have blood testing on a regular basis in between appointments to monitor your liver function. You are responsible for making sure that all lab tests drawn locally are forwarded to your transplant coordinator.

Blood Test Schedule

Following is the schedule for blood tests. Again, if you need to have your blood testing more frequently, you will be notified by you transplant coordinator:

Twice a week for month one during your visit
Once a week for month two during your visit
Every other week for one month
Monthly or as directed by the transplant team

Complications After Transplantation

Hepatic Artery Thrombosis

A blood clot can form in the hepatic artery that prevents blood flow to the liver and causes the liver to malfunction. A sonogram and doppler study is performed on the day after transplant to look for this complication. While the cause is unclear, it can be a result of technical problems and rejection. If hepatic artery thrombosis is found you may need to have a surgical repair. It should be noted that re-transplantation might be indicated if surgical repair is unsuccessful.

Bile Duct Leaks

The bile duct from the new liver is attached to the bile duct of the recipient. This connection can leak and drain bile into the abdomen causing infection. If a bile leak occurs, a catheter may be inserted into the abdomen to allow the bile to drain externally. This is temporary and can usually be managed without surgery, however surgical repair or re-transplantation may be necessary in severe cases of damage to the bile duct. Bile duct leaks may present with fever, jaundice, elevated WBC count, or bilious drainage from the incision. It can be diagnosed by sonogram, CT scan, MRCP or ERCP.

REJECTION

Without special drugs known as immunosuppressive medications, your body would try to reject the transplant liver. This occurs because the body has a defense system that works to destroy foreign substances, such as viruses and bacteria that invade the body and make you feel unwell. Unfortunately, the body cannot distinguish between an unwelcome invader (infection) and your new liver. This means that the immune system treats the new liver like it would any foreign substance and it attacks the new liver. A “successful” attack is called rejection

Rejection can happen even though you take your immunosuppressive medications. Most patients (60-70%) experience some degree of rejection, but it is usually easily reversed with medications. The first rejection usually occurs during the first three months after transplant. You will be monitored closely during that time so early signs of rejection can be identified and treated. A biopsy of the liver may be necessary to diagnose the extent of the rejection and eliminate other problems. Results will determine which treatment is best for you. In the past decade, major improvements have occurred in the ability to control rejection. It is uncommon for patients to lose their new liver to rejection, provided they take their anti-rejection medication as prescribed.

Treatment for rejection may include additional steroids or more potent anti-rejection medications. The transplant team may need to change your immunosuppression regimen as necessary.

Rejection may occur at any time after transplant, sometimes without any symptoms of illness. Some patients will experience fever and/or right upper abdominal pain while other will have abnormal liver function test without feeling ill. That is why it is extremely important for transplant recipient to not miss having routine blood testing to monitor their liver function.

Below are some (but not all) off the common signs and symptoms of rejection. You may not experience any of these symptoms:

- jaundice (yellow eyes and skin)
- fatigue
- dark yellow/orange urine
- elevated liver tests
- clay colored stools
- fever
- abdominal pain and tenderness

INFECTION

Your immune system is suppressed after a transplant because of the immunosuppressive medication you are taking; as a result you are more at risk for certain infections. Opportunistic infections (infections that occur in people with a compromised immune system) would not usually be harmful to most people, but can be to transplant recipients. You will be prescribed several different medications to prevent the more common post-transplant infections. You will need to monitor your temperature at home and make certain adjustments in your daily life to avoid harmful infections.

Such infections include the following:

Type of Infection:	Example:
Bacterial	Pneumonia Urinary tract infection Wound infection
Fungal	Mouth/Throat Blood Vaginal
Viral Infections	Herpes Shingles Cytomegalovirus (lungs, liver)

The immunosuppressive medications which you will be taking post transplant make it hard for the body to fight infections. The types of infections that we are

most concerned about are called “Opportunistic Infections”. These may be caused by viruses, fungi or bacteria.

Some of the more common infections seen in transplant recipients are:

Viral infections –

- Cytomegalovirus (CMV) – one of the most common viral infections that occur in transplant recipients. The risk of CMV is highest in the first 3 months after transplant. This disease can affect the eyes, liver, lungs, stomach and esophagus
- Epstein-Barr Virus (EBV) - This can cause a disease known as post transplant lymphoproliferative disease. It can occur in transplant recipients who receive immunosuppressive medications. The early symptoms are nonspecific, including fever, malaise, and weight loss. It is important to observe for any signs of lymph node/gland swelling, as this infection is an infection of the lymph tissue. A favorite site for PTLTD is in the intestines therefore it is important to look for signs of changes in bowel habits e.g. – bloody stools, abdominal pains.
- Herpes infections – these viruses usually infect the skin in the form of herpes simplex (cold sores) or herpes zoster (shingles) Although Herpes cannot be cured, it can be treated.
- Varicella Zoster (Chicken Pox) – may appear as a rash or small blisters. If your family is in contact with anyone who develops chicken pox please contact your Pediatrician or Clinical Nurse Coordinator immediately for further information.

Bacterial infections –

- Pneumocystic Carinii Pneumonia (PCP) –is a bacterial infection for which transplant recipients are at greater risk of contracting due to their weakened immune system. Giving prophylactic medication – Bactrim, reduces the incidence of this infection.

Fungal infections –

- Candida – is a fungus that can cause a variety of infections in transplant recipients. If there is infection in the mouth or throat it is called thrush. Thrush causes white raw areas, pain or tenderness, a white film on the tongue and difficulty swallowing. Candida can also infect the esophagus (the “tube” that goes from the throat to the stomach). If a fungal infection develops this will be treated with either intravenous or oral medications.

Common Signs and Symptoms of Infection

Below are some (but not all) of the common signs and symptoms of rejection and infection. You may experience several or none or any of these symptoms:

- Fever greater than 101.4 F or 38 C
- Dizziness or light-headedness
- Loss of appetite
- Sore throat
- Increasing irritability
- Shortness of breath
- Nausea or vomiting
- Chills fever and fatigue
- Elevated liver tests/CBC blood tests

Avoiding Infection

Because immunosuppressive medications interfere with a transplant recipient's natural immune system, you will need to protect yourself from infection after the surgery by taking the following precautions:

- Wash hands often.
- Maintain good nutrition, exercise and rest.
- Keep hands away from face and mouth.
- Stay away from people with colds or other infections.
- Ask friends to visit only when they are well.
- Wash hands after coughing or sneezing, and throw tissues into the trash immediately.
- If someone in your family becomes ill with a cold or flu, have that individual follow normal precautions (use separate drinking glasses, covering their mouths when coughing, etc.)

Recurrence of Liver Diseases after Liver Transplantation

It is important to understand that many causes of liver failure or cirrhosis can and will return after liver transplantation. Some disease can recur quite soon after a transplant and can in some cases cause the new liver to fail. This is obviously a very important factor to be aware of and although it is distressing to think that this may happen to you, being prepared for all possibilities will help you and your family cope. In the following paragraphs, we will discuss some of the more important disease that can recur and what can or will be done to try and prevent this from happening.

Hepatitis C

Cirrhosis caused by the hepatitis C virus is a leading indication for liver transplantation throughout the United States. As you know, hepatitis C is a virus that attacks healthy liver cells and over time, causes cirrhosis to develop. As the cirrhosis progresses, you begin to develop life threatening complications and it is at this time that you are recommended to proceed with a liver transplant.

However, because hepatitis C is a virus that is in the blood stream and may be in other tissues besides the liver, it will not be "cured" by a liver transplant. The virus will remain in your system and may lie dormant for many years or it may be re-activated and begin to cause damage to your new liver very quickly. It is very difficult to know before the transplant which patients will do well with a new liver and which patients may not. Some factors such as the genotype of your hepatitis C or the amount of virus in your blood may help predict which outcome you are more likely to have. However, this is not nearly an exact science yet and there is still a lot unknown about this virus.

To help put this in perspective for you, we can present information in the following way: Out of every 100 patients who receive a liver transplant for hepatitis C cirrhosis, approximately 60- 70% of them will have signs of the virus in the blood stream within a few months after the transplant. Many of these patients will feel relatively well and may only be aware of some fatigue. But for many others, there will be significant fatigue and problems with their new liver. About 10% of these people will lose their new liver within one year after the transplant. Another 20% will have a slower more progressive course over five years before they develop cirrhosis again. Now as you know, cirrhosis took many years to develop and you probably had cirrhosis for many years before you even were aware of it. The big difference after a liver transplant is that your immune system is being altered by the immunosuppressive medications you must take to prevent rejection. It is possible that this is one of the reasons that many patients after a liver transplant get sicker from hepatitis C in the new liver much quicker.

As hepatitis C can be a very problematic and difficult disease to deal with after a liver transplant, we will try to make sure that when you do proceed with a transplant that you do not have any other treatment choices available. It is also possible that we will recommend some type of treatment for the hepatitis C virus before your transplant to try and deplete the amount of virus in your blood. We

may also recommend treatment after your transplant. It is important to realize though that these treatments may not be pleasant to take and there is no guarantee that they will work. However, we do know that to have a second liver transplant when the first one failed due to the hepatitis C virus, is very difficult to survive even if we can get a second liver for you in time. Only about 50% of patients who undergo a second liver transplant for hepatitis C survive past the first year. Given these very depressing statistics, we will try to do everything to prevent the disease attacking the new liver and to try and prevent the liver being damaged.

Hepatitis B

This is a less common indication for a liver transplant. It is also a viral infection that is in the blood and other body tissues that can recur in the new liver after a transplant. However, this is now quite rare because of the medications that all patients who have hepatitis B are required to take after liver transplantation. Hepatitis B has gone from being a very difficult disease to prevent recurring in the new liver, to being one of the more easily prevented diseases. Every patient who undergoes a liver transplant for hepatitis B cirrhosis will be required to take a medication called Hepatitis B Immune Globulin (HBIG) and/or medications called Lamivudine or Adefovir or other similar drugs. These drugs help “mop up” the remaining hepatitis B virus at the time of the transplant when they are first given, and then work very successfully to prevent the hepatitis B virus from recurring. You will be on these medications for life.

However, the virus can recur despite these medications and you certainly run an extremely high risk of getting into trouble if you ever discontinue the medications without your transplant teams guidance. In comparison to the hepatitis C virus, the hepatitis B virus only comes back into the new liver in about 2-5% of patients.

Hepatocellular Carcinoma (HCC)

Hepatocellular carcinoma or HCC is a very common cancer of the liver that develops in patients with cirrhosis. If you have a hepatocellular carcinoma at the time of liver transplant, it is possible for this cancer to re-occur either in the transplanted liver or elsewhere in the body. In most cases, we have diagnosed this cancer before the transplant by blood tests and CT or MRI scans of the liver. Occasionally however, we only find it after we have removed the liver. In either circumstance, the factors that determine the chances that this cancer can re-occur are based on the pathological examination of the removed liver. We look at the number of tumors you had and the size of the tumors. We advise more frequent scans of the liver in patients we feel are more at risk of the tumor recurring. More specific information will be given after your transplant as to the frequency of you follow up scans but everyone will probably get a scan at three months after the transplant and then either every three months thereafter or every year thereafter. If you do develop recurrent hepatocellular carcinoma, the treatment options available to you will be largely based on where in the body the tumor recurs. However, it is important to know that re-transplantation of the liver would not be an option.

Autoimmune Hepatitis

This disease may also continue to be present after your liver transplant and may cause damage to the new liver over time. However, this happens less frequently and does not generally cause significant damage to the new liver that would require a second transplant. In fact, the medications you will be taking to prevent rejection also have the effect of controlling the autoimmune hepatitis. It is likely though that you will be advised to take Prednisone for life at a low dose to try and prevent Autoimmune hepatitis from recurring. We may suspect the disease has re-occurred in your new liver if your blood tests become abnormal. Additional medications may be recommended to help treat the autoimmune disease. We recommend our female patients who have this disease to discuss future pregnancy after transplant with us as it has been shown that pregnancy can activate the autoimmune hepatitis.

Primary Biliary Cirrhosis

This disease may also re-occur after your transplant and cause damage to the new liver. However, this is not common and generally if it does re-occur, it does not cause significant damage. Sometimes patients may continue to take Actigall after transplant to prevent it re-occurring.

Primary Sclerosing Cholangitis

This cause of liver failure may also come back after your transplant and like primary biliary cirrhosis. It is quite rare and generally does not cause significant damage or cirrhosis again. But there are reports of some patients developing cirrhosis and needing a second liver transplant for this disease. We might suspect the disease recurring if your liver enzymes became abnormal or your bilirubin began to rise. Adjustments in your medications may be made to help control the progression of the damage to your liver and occasionally a stent might be used to help the bile flow out of the liver more freely.

Alcohol Cirrhosis

The only way you can develop alcohol cirrhosis after your transplant is if you drink alcohol! So preventing this cause of liver damage is something you have control over. If you needed a transplant because of a diagnosis of alcohol induced cirrhosis, you cannot **ever** drink **any** alcohol again. There is no exception to this irrespective of what individual physicians may say – it is the policy of our program not to re-transplant any patient who suffers damage to their liver if they return to drinking alcohol after the transplant. You may be advised before you are transplanted to attend an alcohol rehabilitation program or to attend counseling in an effort to help prevent the possibility of you returning to alcohol use after transplant. If you are so advised, do so! It is in your best interest and is not intended to punish you for your behavior. It is not uncommon for you to lose your desire to drink alcohol when you are feeling very sick but once you become well again, you may well be faced with the urge to drink alcohol. Remember, this is the one disease that will definitely not come back after your transplant unless you drink again. There are many resources available to you to assist you in enrolling in a rehab program so talk to your Clinical Transplant Coordinator or Social Worker.

Life After Your Liver Transplant

There are many new things a person will experience after a liver transplant. You will be instructed on how to care for yourself before you leave the hospital. Most patients recuperate fully within the first three months, return to work and lead active lives. The goal is to provide excellent care and follow up in concurrence with your PCP in order to make the length and quality of life appreciably better than before.

Returning to work

Returning to work is different for each person depending upon the type and number of hours of work they do. It will also depend on your postoperative course, incidence of post transplant complications, and how you feel.

Activity/Sports

We do not recommend that you participate in any heavy lifting or contact sports for the first three months after your transplant. This will allow the abdominal muscles to heal after the surgery. Consult with your transplant team if you have any questions.

Pets

If you have a pet or if you want to get one, it is important to take note of the following recommendations:

Hygiene

- Avoid any contact with your pets' body fluids – saliva, urine etc
- Don't let your pet lick your wound or face

Litter box care

- Keep the box away from the kitchen and eating areas
- Disinfect the litter box at least once per month

Animal bites

Immediately tend to the animal bite by rinsing the wound with cold water and applying an antiseptic solution
Contact your primary care physician or Clinical Nurse Coordinator for additional instructions

Some pets have been found to carry diseases that can spread to humans so we do not recommend that you keep exotic birds or animals in your household after transplant. These include stray animals, wild animals and monkeys. These animals are susceptible to many infections including toxoplasmosis which can be potentially life threatening to transplant recipients.

Travel

We advise you to wait at least three months after transplantation or until you are medically stable before you begin to travel. This is due to the fact that you will continue to follow up with the transplant team on a regular basis for the first three months. Also, many complications can occur during this period and you should be able to come to the hospital quickly if necessary. Travel to exotic destinations may require extra precautions with vaccinations. Please call your Clinical Nurse Coordinator to discuss any travel plans.

Skin care

Some of the medications that you will be receiving after transplant can cause increased susceptibility to the sun. It is important to use sunscreen whenever you are outdoors. If you notice any suspicious lesions please contact your primary care physician for evaluation.

Medical Alert Tags

The Transplant Team recommends that you obtain a Medic Alert tag for you in order to ensure that you can be identified as a transplant recipient in the event of an emergency. A Medic Alert tag is an emblem that can be worn around the neck or wrist. Engraved on the back of the emblem is vital information that can save your life in an emergency. The medic alert tag will identify you as a transplant recipient requiring special attention. You should list the following on the tag:

- Liver transplant recipient
- Any medical conditions that you may have
- All medication and drug allergies that you may have
- If possible the telephone number of the Transplant Center.

We have enclosed a Medic Alert application form inside this transplant teaching package.

Please discuss with your Clinical Nurse Coordinator any other information that should be engraved on the emblem.

Nutrition and Diet Therapy after Liver Transplantation

Good Nutrition is important to speed your recovery and maintain your health after a liver transplant. Eating a wide variety of food is usually the easiest way to ensure an adequate intake of most necessary nutrients. Some vitamin and mineral supplements may be prescribed for you. These may include a multivitamin, iron, calcium, vitamin D, folic acid or magnesium.

Use of USDA Dietary Guidelines for Americans to help select a healthy diet:

Eat a variety of foods

Maintain a healthy weight

Choose a diet low in fat, saturated fat and cholesterol

Choose a diet with plenty of vegetables, fruits and grain products

Use sugars only in moderation

Use salt and sodium only in moderation.

Weight and Appetite:

You may notice that your appetite is markedly increased and that you may begin to gain unnecessary weight after transplantation. The anti-rejection drug Prednisone is a powerful stimulant to your appetite. You and your nutritionist should discuss what your normal, ideal weight should be and how many calories are needed each day. With your nutritionist's help, you can decide if you need to decrease, increase or maintain your present caloric intake and weight.

If you need to lose weight or to stop unnecessary weight gain, the following suggestions may help:

Decrease your calories by decreasing portion sizes or choosing foods with lower calories and fat (e.g. choose skim or 1% milk instead of whole milk)

Increase your activity and develop a regular exercise program

Eat at the table—never watch TV or read while you eat

Eat slowly and only eat three meals a day—if you skip a meal you may end up eating twice as much later

Keep fresh fruit and cut up raw vegetables in the refrigerator for snacks. Do not buy tempting high calorie snacks or desserts

Always broil, steam or boil food—never fry food

Avoid sugar (e.g. cakes, candy and sweetened drinks.)

Plan to lose 1-2 lbs per week as a realistic goal.

Protein:

Prednisone can cause your body to waste protein. Protein is vital for growth and maintenance of body tissue. Therefore, it is important to eat a serving of protein at every meal. Your nutritionist will discuss with you how much to include each day. Pick sources that are high in protein but low in fat and cholesterol.

These include the following:

Lean beef, pork or lamb

Poultry without skin

Fish and shellfish

Eggs (but limit egg yolks to three times per week)

Low or non-fat cheeses (less than 4grams of fat per ounce)

Dried beans and legumes

Low-fat tofu

Low or nonfat yogurt

AVOID sausages, franks, luncheon meats, ham and bacon, since these are all high in sodium as well as fat.

What can you do to help make your transplant a success?

- Know your medication, doses and frequency
- Always take your medications as prescribed
- Never adjust medication dosages yourself
- Only the transplant team can change your immunosuppression
- Never allow a prescription to run out
- Never take medications that are not prescribed by your own doctor or the transplant team
- Get an annual physical check up with your PCP
- Cancer screening---Prostate, Colon, Breast, Uterine, Skin
- Cholesterol check
- Blood pressure management
- Diabetes care
- Flu shot, pneumovax, Hepatitis vaccinations
- Dental check up every 6 months
- Good nutrition
- Regular exercise
- Emotional well-being: return to work, school, hobbies, interests, volunteer work, etc.
- Never lose your health coverage

Never lose contact with your transplant team

Post Transplant Medications

After liver transplantation there are certain medications that must be taken every day for the rest of your life. These medications are needed in order to prevent rejection of the transplanted liver and to prevent infections. These medications work by reducing the body's natural defense system (immune system). The defense system attacks "foreign bodies" such as bacteria and viruses. The body will see the new liver as being "foreign" and will automatically try to get rid of it. This is called rejection. To prevent rejection you be taking immunosuppressive medications, which will trick the body into thinking that the new liver has always been there. Every medication has some side effects. This does not mean that you will experience every side effect but we want you to know that the possibility exists. Please do not take any other medications without informing the transplant team as side effects and drug interactions may occur.

Below is a list of the types of medications that you will be taking:

- IMMUNOSUPPRESSIVE MEDICATIONS – medication used to prevent rejection of the liver
- ANTIBIOTICS – medication used to prevent or treat bacteria infections. A transplant recipient is at high risk for infection due to the anti-rejection medications that suppress the immune system.
- ANTIVIRALS – medication used to prevent or treat viral infections
- ANTIFUNGALS – medication used to prevent or treat fungal infections

You will not be taking all of the medications listed below, as many of the listed medications have the same mode of action.

Your transplant coordinator will discuss ordering medications with you. There is a wide range of choices available for pharmacies – some are mail order pharmacies and deliver the medications directly to your home. Local pharmacies require that you collect the medication. We will ensure that you have at least one-month supply of medication before you go home. We will review these medications thoroughly with you before you leave the hospital.

There are some post transplant medications that may need to be given by infusion.

An intravenous catheter may be placed into your arm while you are admitted to the hospital but in some cases the Home Care RN will place an IV when she/he comes to give the infusion. If the Home Care RN places the IV, it will be removed once the infusion is finished.

Who to Call for What

Your Transplant Coordinator:

- Change in your medical condition
- Questions regarding medications
- Questions regarding your plan of care

Your Social Worker

- Transportation issues
- Referrals to community based assistance programs
- Resolving problems in the home
- Psych/social and family matters
- Advise about Medicare/Medicaid

Your Insurance Coordinator:

- Change in your insurance provider or current policy

Your Coordinator Assistant:

- Appointments
- Faxing or mailing of records
- Copies of test results
- Pre-authorization for procedures
- Prescriptions for lab work and medications

Calling the Emergency Service

When to call the emergency service:

- Shortness of breath
- Chest pain
- Severe abdominal pain
- Blood in your stools or vomiting blood
- Fever

When not to call the emergency service:

- Appointments
- Medication refills
- Lab and study results
- Waiting several days when you are sick and calling after hours. Call as soon as you feel the symptoms

Remember that the transplant coordinator who is on call will not be in the office and will not have access to your chart. The coordinator will be receiving every emergency call that comes to our office, including the availability of donor organs for transplant.

Places to Eat In and Around Mount Sinai Medical Center

The Hospital's Plaza Cafeteria offers a wide selection of appetizing hot and cold dishes, including Kosher food. The Cafeteria is open from 6:30 AM - 7:30 PM, Monday through Friday, and some hours on the weekends as well. It is located on first floor of the Atrium of the Guggenheim Pavilion.

A Coffee Stand, serving Starbucks™ coffee and an assortment of breakfast rolls, is open on Monday - Friday, from 6:45 AM - 4:30 PM in the West Lobby of the Annenberg Building. There are vending machines located throughout the hospital's main corridor (MC level).

Places to eat near Mount Sinai Hospital

- Just Another Deli
Madison Avenue (98th Street)
- Hanratty's
1410 Madison Avenue (97th and 98th Streets)
(212) 369-3420
- Joanna's Restaurant
30 East 92nd Street off Madison Avenue
(212) 360-6313
- La Famiglia (Italian and Pizza)
Madison Avenue (97th Street)
- Middle Eastern Food
Madison Avenue (97th-98th Streets)
- One Fish, Two Fish
1399 Madison Avenue (97th Street)
(212) 369-5677
- Peter's Luncheonette
Madison Avenue (98th Street)
- Three Guys Luncheonette
Madison Avenue (96th Street)

Places to Stay Around Mount Sinai Hospital

Transplant Living Center (TLC)--RECOMMENDED

Provides a “home away from home” in NYC for liver transplant patients and their families. Its mission is to offer secure and affordable housing and strives to reduce the emotional and financial stress of a life-threatening illness by providing a network of support and comfort.

Located within walking distance of the hospital, this 10 bedroom, 8-bath facility has 2 full kitchens and large communal dining and living areas.

235 East 95th Street
New York, NY, 10128
(212) 348-3308

Mount Sinai Guest Residence

3 East 101st Street (Madison and Fifth Avenues)
(212) 828-3200

26-room Guest Residence for patients and their families. Rooms hold up to 4 people.

Standard Room

Hotel Wales

1295 Madison Avenue (between 92nd and 93rd Streets)
(212) 876-6000
Call for Rates

Resources

Recanati/Miller Transplantation Institute
One Gustave L. Levy Place Box 1104
New York, NY, 10029
1-212-241-8500
www.mssm.edu/rmti

American Association for the Study of Liver Disease
1729 King Street, Suite 200
Alexandria, VA, 22314
1-703-299-9766
www.aasld.org

American Liver Foundation
74 Maiden Lane
Suite 603
New York, NY 10038
1-800-GO.LIVER (465-4837)
1-888-4HEP.USA (443-7872)
www.liverfoundation.org

American Society of Transplantation
17000 Commerce Parkway
Suite C
Mt. Laurel, NJ 08054
1-856-439-9986
www.a-s-t.org

Coalition on Donation
700 North 4th Street
Richmond, VA 23219
1-804-782-4920
www.shareyourlife.org

Hep C Connection
1177 Grant St. Suite 200
Denver, CO 80203
1-800-522-HEPC
www.hepc-connection.org

Hepatitis Foundation International (HPI)
504 Blick Drive
Silver Spring, MD 20904-2901

1-800-891-0707

www.hepfi.org

Latino Organization for Liver Awareness (LOLA)

PO Box 842

Throggs Neck Station

Bronx, NY 10465

1-718-892-8697

1-800-367-LOLA

www.lola-national.org

New York Organ Donor Network

475 Riverside Drive

New York, NY 10115

1-212-870-2240

www.nyodn.org

www.transplantliving.org

Transplant Recipients International Organization, Inc. (TRIO)

2117 L Street, NW, #353

Washington, DC 20037

1-800-TRIO-386

www.trioweb.org

Transplant Support Organization (TSO)

1154 Webster Avenue

New Rochelle, NY 10804

United Network For Organ Sharing (UNOS)

PO Box 2484

Richmond, VA 23218

1-888-894-6361

www.unos.org

Contributors

Dorothy A. Robinson, RN, MA, ANP-C, CCTC
Leona Kim-Schluger, MD
Dara Lewis, RN, MSN, ANP-C
Margie Fernandez-Sloves, RN, MA, ANP-C, CCTC
Maria T. Carrera, RN, FNP-C
Judy Gang, RN, BSN
Marian O'Rourke, RN, CCTC
Ellen Silberman, BA
Cora Sarsar, M.S., R.D./CDN
Jodi Sternberg, LCSW
Kelli Kalimi, LMSW
Rosemary Gagliardi, c. EdD, MPH, CRA
Lindsay Arnott, RN, BS, CCTC
Michelle Crawford, Pharm. D., BCPS
George Tirlokhi, BS, MBA
Brent Peterson, RPAc

Reviewers

Thomas Schiano, MD
Sukru Emre, MD
Juan Del Rio Martin, MD

PATIENT EDUCATION MANUAL QUESTIONNAIRE

What is the cause of your liver disease?

How long ago, approximately, were you told you had cirrhosis?

How long ago, approximately, were you told that you may need a liver transplant?

How long did it take for you to review the material in this manual?

Do you feel that this manual provided:

Too much information: _____ Not enough information: _____ Just enough information: _____

Did you find this material helpful?

If **yes**, what parts were most helpful?

If **no**, what parts were not helpful?

What information would you like to see added?

Do you feel that this manual was?

Too long _____ Too short _____ Just right _____

Your age: _____ Your sex: Male: _____ Female: _____

Additional Comments: _____

PLEASE RETURN THIS TO THE ADULT LIVER TRANSPLANT OFFICE ON YOUR NEXT VISIT, BY FAX (TO 212-241-3100, ATTN: DOROTHY ROBINSON) OR BY MAIL TO:

**RECANATI/MILLER TRANSPLANT INSTITUTE
MT. SINAI HOSPITAL
ONE GUSTAVE L. LEVY PLACE, BOX 1104
NEW YORK, NEW YORK 10029
ATTN: DOROTHY ROBINSON, ANPC**