



TEXAS TRANSPLANT INSTITUTE

A member of the Methodist Healthcare System

www.TexasTransplant.org

Liver Pre-Transplant Education Manual

Phone: 210-575-4837

Liver Disease Clinic

Fax: 210-575-8480

Toll Free: 800-888-0402

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Introduction

The Methodist Health Care System is a well-respected health care provider in South Texas. The Methodist Specialty and Transplant Hospital is a part of this system and was created to specialize in the care of transplant patients. TTI partnered with MHS to provide our patients and their families with very individualized and efficient care before and after transplant.

The health and lifestyle changes brought about by End-Stage Liver Disease (ESLD) are devastating for patients and their families. We want to help you improve your health and quality of life. Our transplant hospital has experienced staff and focused resources for the mission of improving life through transplantation. Patients tell us that they choose Texas Transplant Institute because the staff works together as a team.

We encourage our patients and families to join the transplant team by taking an active part in their own health care. As a member of the transplant team, you will be responsible for learning as much as you can about your disease and the transplant process. The first step in your journey through transplantation is learning about the transplant evaluation and ways to optimize your health prior to transplant. You and your family should also understand how the transplant wait list works and how donors are identified. It will also be important to learn about surgery and post-operative care so that you can plan for the future.

This handbook will discuss:

- 1) Overview of liver transplantation
- 2) The roles of the members of the transplant team
- 3) The process of Liver Transplant Evaluation
- 4) Listing and waiting for transplant
- 5) Medications for transplant
- 6) Admission and discharge from the hospital
- 7) Long-term follow-up after transplant

Since we are a team, you will not go through this process alone. We are committed to quality patient care and being available for both patients and families. We encourage you to contact us with questions or concerns related to your healthcare needs.

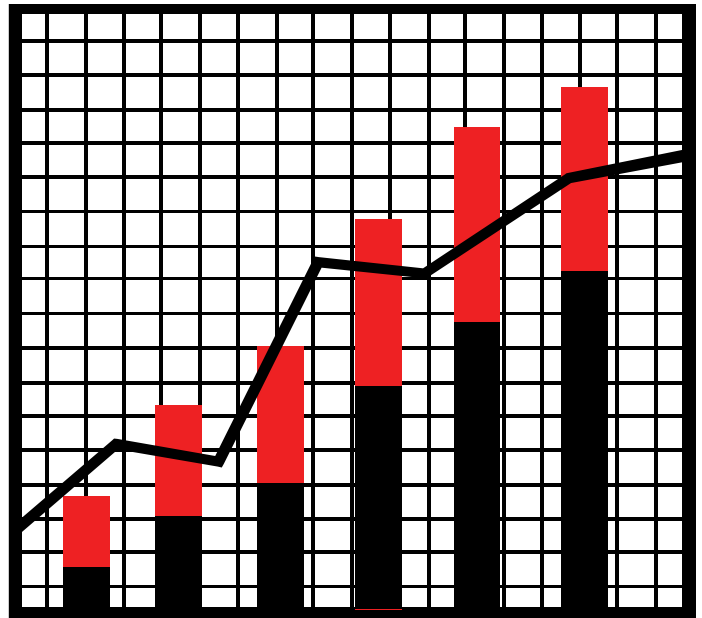


Liver Transplant Today

Advancement in surgical techniques, the development of better anti-rejection drugs, and improvements in organ preservation have led to great success in solid organ transplant. The overall patient survival rate after liver transplant is 85-90% nation wide. Even with these improved success rates, transplantation has risks that are discussed later in this brochure. It is important that you understand what transplant is about and always ask questions.

As of **May 14, 2004**, there are over **85,000** people on the national wait list for life-saving transplants. The number of people awaiting transplant has grown more than the number of donors each year. There have been many methods employed to increase organ donation and public awareness, but despite our best efforts the number of donors has still stayed relatively the same. Everyone involved in the transplant process must take on some responsibility to educate those around them regarding the positive effects of donation.

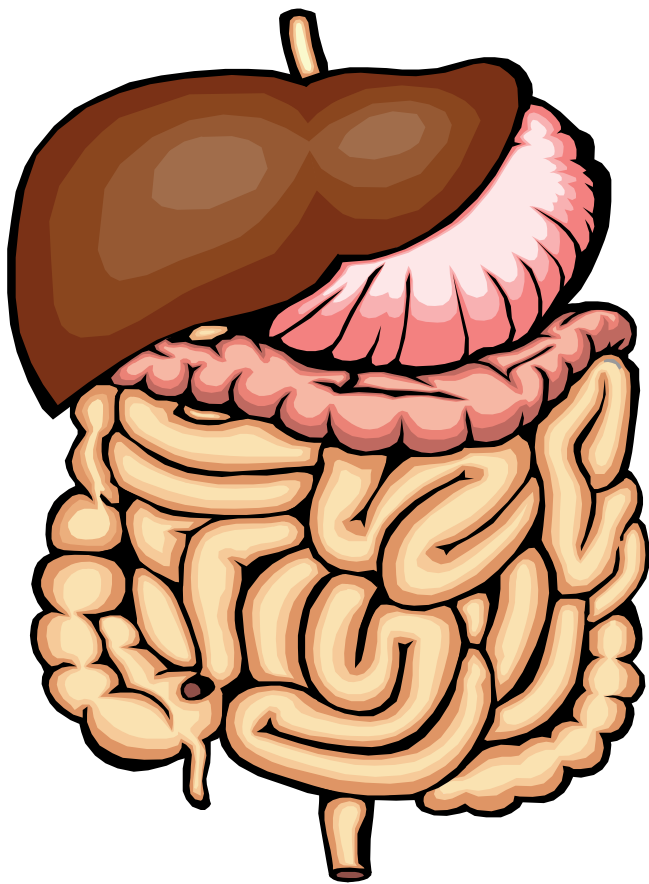
As a transplant institution, it is our responsibility to assist you to return to your desired level of wellness. We believe that with today's techniques and medications, you can enjoy a near normal lifestyle. Receiving a transplant is a big responsibility for you and your family. Compliance and willingness to be an active participant in your care is your responsibility.



The number of people waiting for transplant continues to grow at a rate faster than the number of available donors each year.

Understanding Liver Disease

The liver is the second largest organ in the body. It is located under the rib cage in the right upper part of the abdomen. It weighs almost three pounds in a healthy adult. The liver has two lobes. The right lobe is the largest and the left lobe which is smaller. The liver is made up of specialized cells called hepatocytes and it has blood vessels that feed it a large portion of the body's blood supply.



The liver has complicated functions that include:

- Secretion of bile necessary for the absorption of fats, vitamins and minerals

- Conversion of food into substances necessary for life and growth
- Excretion of waste products
- Manufacture of clotting factors

The liver has an amazing ability to grow and regenerate itself, but it can't do this if there has been massive and continuous tissue destruction due to disease. So despite a tremendous reserve capacity, liver disease can destroy the liver's ability to function. Some disease states destroy the liver rapidly like Fulminant Hepatic Failure while others like Hepatitis C can take years before symptoms of end stage disease occur.

Liver failure may occur rapidly or over several years, depending on the cause.

Some of the diseases of the liver include:

- 1) Hepatitis B and C
- 2) Alcoholic Cirrhosis
- 3) Fulminant Hepatic Failure
- 4) Primary Biliary Cirrhosis
- 5) Sclerosing Cholangitis
- 6) Auto-immune Hepatitis
- 7) Primary Hepatic Malignancy
- 8) Budd-Chiari Syndrome

**** Special note: Transplant does not remove the Hepatitis B or Hepatitis C virus from the body. It may recur and become a problem again after transplant.**

Symptoms of Liver Disease and Treatment

People with Liver Disease can have many symptoms that show that their liver is failing. Physicians around the world recognize a few symptoms as signaling the need for transplantation.

The following list includes the most common symptoms with recommended treatment strategies.



The liver is the second largest organ in the body.

JAUNDICE

Patient's eyes and skin turn yellow due to bilirubin elevation in the blood stream. Itching also occurs with the absorption of bile salts and can be without relief.

Treatment: Actigall is often used to "thin Bile" in a sense and make it easier to be excreted.

ENCEPHALOPHATHY

Mental changes including forgetfulness, lethargy and, in severe cases, coma. This occurs when high ammonia levels build up in the blood stream and start to effect the brain.

Treatment: Lactulose is used to assist your body in clearing ammonia.

ASCITES

This is a collection of fluid in the abdomen. The fluid can sometimes become infected and

the patient will need to be put on hold for transplant in order to be treated with antibiotics to clear the infection.

Treatment: Diuretics – water pills (Aldactone, Lasix)

UPPER GI BLEEDING

As the liver tissues become more diseased and shrunken, the blood that is coming from the small bowel and trying to return to the heart by passing through the liver is unable to push through. Think of a water hose that has a kink in it. This causes pressure to build up behind the obstruction. When another route is found, the pressure pushing the water along is very great. The same thing happens in the body. The liver is obstructing blood flow and blood backs up into the portal vein (i.e. Portal Hypertension) and into the spleen and small vessels that drain the esophagus. These vessels become engorged (varices develop) and the vessels can rupture resulting in a massive amount of blood loss.

Treatment: Prevention of bleeding with medications and procedures.

WEIGHT LOSS AND FATIGUE

These symptoms are a reflection of low protein levels.

Treatment: Proper diet and maintaining weight and strength, because weight loss has negative effects on post-transplant recovery.

The Liver Transplant Team

The following is a brief description of the members of the transplant team. Some of these professionals will see patients during the initial evaluation and others may not have contact with patients until the hospitalization for transplant.



Members of the Transplant Team:

Transplant Surgeons are involved in all aspects of a liver transplant patient's care. They evaluate patients pre-transplant, recover donor organs, perform transplant surgery, and are primary caretakers of the patient in the hospital following surgery. The surgeons also see patients in the pre and post-transplant clinic.

The Transplant Hepatologist is a physician who special specializes in taking care of patients with liver disease. He or she is very involved in the patient's pre-transplant evaluation and in the selection process for listing. These doctors often become primary caretakers for patients with End Stage Liver Disease. They also follow patients in post-transplant clinic after the initial post-operative period.

The Transplant Anesthesiologist performs anesthetic management for patients during the liver transplant surgery.

The Liver Transplant Team is a core group of physicians and medical professionals specializing in liver transplantation. They are joined by many other specialty areas and staff to provide optimal care throughout the transplant process.

The Advanced Practice Nurse is a registered nurse with advanced training in liver disease. He/she will see you in conjunction with the transplant physicians to provide medical care for you.

Consultant Physicians in many subspecialties are necessary for the comprehensive care of liver disease and transplant patients. Some of these physicians include Cardiologists, Psychiatrists, Infectious Disease Specialists, Pulmonologists, Hematologists/Oncologists, and Nephrologists

Residents are doctors in training to perform surgery and they rotate through the transplant service from numerous other medical training facilities. They are responsible for assisting the Transplant Surgeon and for carrying out the steps necessary to treat the patients in the hospital.

The Liver Transplant Team (continued)

Transplant Coordinators are nurses that organize all aspects of a transplant patient's care. Their specific duties include, but are not limited to organizing patient evaluations, setting-up for donor recoveries, arranging transplants, providing discharge plans and teaching for patient's post-operatively in the hospital and in clinic. They also handle patient phone calls, arrange for hospital admissions, and are in general "troubleshooters" for the liver transplant service.

The Nutritionist recommends diet plans for the patients before and after surgery. End stage liver disease patients can be very malnourished, so the nutritionist's help is crucial to a fast recovery after surgery.

Procurement Coordinators help the surgeons in recovery of organs and in the recipient transplant. They work 24 hours a day and 7 days per week to make sure a transplant can happen.



The Financial Coordinator is responsible for financial coordination of the transplant. They help with financial planning for patients and

families. They also talk with insurance companies and make sure the hospital can be paid for service and hospital stays. We plan ahead to prevent the patient and family from financial burden.

Social Workers are involved with the patients from initial evaluation and through post-operative follow-up. They help patients with psychosocial and financial issues. They also have periodic support groups.



Transplant Assistants are important to running a transplant practice. They serve patients and families in an extraordinary manner. They are responsible for scheduling and managing clinic visits; record keeping and data collection.

OR, ICU, and Floor nurses are essential for any successful transplant team. They are specially trained in caring of transplant recipients and their families.

Case Managers are nurses that coordinate services and help arrange for discharge needs. They also communicate with your insurance company to keep them updated on your condition.

Evaluation Process

When a referral is made to Texas Transplant Institute, the transplant coordinator will call you to conduct a brief survey over the telephone. This will determine if a liver transplant evaluation is appropriate at this time or if you need to see our Hepatologist. The referral is then sent to the financial department for insurance clearance and an appointment will be made with the Liver Clinic. We strongly suggest bringing a family member or someone close to you when you come for your visit.



On the day of the scheduled appointment, you will arrive at Methodist Specialty and Transplant Hospital and begin by registering with the Texas Transplant Institute Admitting Office on the ground floor. After registration, you and your family are sent to the Liver Disease Clinic on the second floor. At this point, you will be greeted by the Transplant Coordinator and given an overview and schedule of the day's events. You and your family are then interviewed and evaluated by the transplant team that includes the Liver Transplant Surgeon, Hepatologist, Transplant Coordinator, Social Worker, Financial Coordinator and

Nutritionist.

You will then begin a very thorough diagnostic testing procedure. These tests are described in detail on the following pages.

The initial visits include an extensive interview and evaluation process combined with diagnostic tests.

You may have some or all of these tests depending on your medical condition.

Also, if some of these tests have already been performed recently at other institutions, they will not be repeated.

The transplant team will work with you to try to complete your evaluation, selection committee review, and insurance approval within 30 days of your initial visit.

Laboratory Testing

As mentioned previously, included in the Transplant Evaluation are various laboratory and diagnostic tests. This section will give brief descriptions of some of the testing you may be required to have done prior to being listed for transplant.



Chemistries: A tube of blood will be drawn to measure electrolytes, glucose, and kidney function. These test help to determine your overall condition.

Blood Count: A tube of blood will be drawn to determine Hemoglobin and Hematocrit levels and white blood cell count. This test also helps to determine your overall condition.

Liver Enzymes: As a result of liver damage, by insult or disease, liver enzymes are released into the blood stream. This results in increased blood enzyme levels. Usually several liver enzyme tests are performed at the same time to confirm liver dysfunction, because some of the enzymes are released by other organs and tissues.

ALT (SGPT): Normal ranges 26-65. This is an enzyme found primarily in liver cells that is helpful in diagnosing liver disease.

AST (SGOT): Normal ranges 15-37. An enzyme also found in liver cells. Used in combination with ALT to diagnose liver disease.

GGT (GGTP): Normal ranges 5-55. A liver enzyme which is elevated with cirrhosis, alcoholism, liver cancer, and viral hepatitis.

Alkaline Phosphatase (ALP): Normal ranges 50-136. Enzyme found in liver, bone intestine and kidney. This result must be interpreted along with several other liver enzymes to diagnose liver disease.

Lactic Dehydrogenase (LDH): Normal ranges 100-200. Enzyme also found in organs and tissues other than the liver; however, when measured in conjunction with other enzymes is accurate in diagnosing liver.

Total Bilirubin: Normal ranges: 0.0-1.0. Bilirubin is formed from the breakdown of red blood cells. It is carried in the blood stream by albumin to the liver so it can be excreted in the bile. Bile from the liver is dumped into the bile ducts which lead to the small intestine. Bile in the intestines is needed to digest food. When there is an obstruction to flow of the bile from the liver to intestine, bilirubin is absorbed back into the blood stream. When the bilirubin level reaches about 3, patient's become jaundice. Skin and eyes turn yellow. Bile salts that are also in bile get absorbed into the blood stream. The bile salts deposited into skin

Laboratory Testing (continued)

tissue cause terrible itching that is hard to treat in end-stage liver disease.

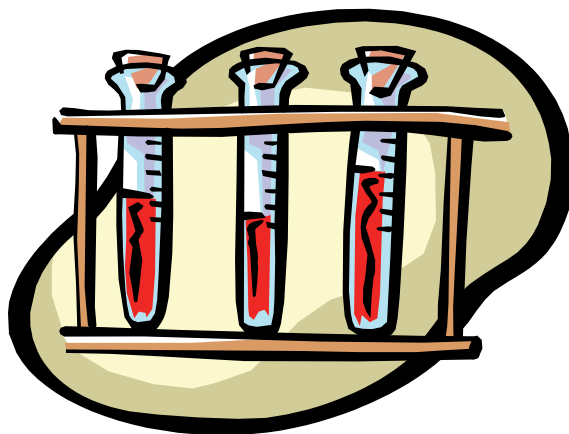
Albumin: Normal ranges: 3.4-5.0 Albumin is a protein produced by the liver. It is needed to maintain muscle mass and normal fluid balance in the body. The liver normally converts nutrients absorbed from the intestines into albumin. However, a liver that is not working properly can not manufacture enough albumin for the body's needs. The body then steals protein from muscles causing decreased strength and weight loss. A lack of albumin in the blood stream also causes fluid collection in the abdomen (Ascites) and lower legs (edema).

Ammonia: Normal ranges: 11-35. Ammonia is produced from protein breakdown. Protein can come from digested food like meat and chicken or from muscle breakdown in the body. Ammonia from protein breakdown is usually converted by the liver to urea, which is excreted by the kidneys. But, if the liver is not working properly, a high level of ammonia can build up in the blood stream. Ammonia causes bad effects on the brain. Ammonia can cause forgetfulness in low doses and coma or death when extremely high. You may hear the term "Hepatic Encephalopathy" used to describe the effects of high ammonia levels on the brain.

Platelet Count: Normal ranges: 150,000 to 400,000. As liver disease continues more liver tissue is destroyed. The healthy tissue is replaced by scar tissue. Blood flow through the liver is slowed. Often blood backs up into the portal vein and then into the spleen. The spleen becomes enlarged with the increased

blood flow. Normally the spleen breaks down used blood cells and platelets, but because it is receiving more blood than usual it destroys more blood cells and platelets. Platelets are needed for clotting and therefore a low platelet count can lead to bruising and/or bleeding.

Prothrombin Time (PT): Normal ranges: 11.7-14.7 seconds. The liver is responsible for making many clotting factors. The body needs both platelets and clotting factors to form a clot at the site of bleeding. Prothrombin is one clotting factor that the liver produces. A diseased liver can not make the amount of prothrombin that the body needs therefore a low level will cause prolonged bleeding.



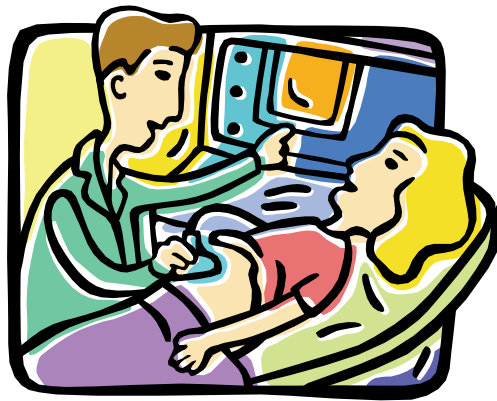
Alpha Feto Protein (AFP): Normal ranges: less than 6. This blood test is used to screen for liver tumors. Although it is not always accurate, it can be used to identify those people who needed additional tests to rule out cancer.

Serology Testing: Everyone will give blood to test for the following infectious

Diagnostic Testing

DOPPLER ULTRASOUND OF THE ABDOMEN

A special wand that emits sound waves is placed over your abdomen. The sound waves produce visual images of the organs and blood vessels in your abdomen on a video screen.



Purpose: To provide information necessary for the transplant surgery. Specifically, this test assesses liver size, portal vein size, vessel patency, direction of blood flow and any abdominal abnormalities including tumors.

Instructions: Do not eat or drink for 10 hours before the test. Medications can be taken with sips of water. You will lie flat on your back on the examining table. This procedure takes about 20 to 40 minutes.

COMPUTERIZED TOMOGRAPHY (CT) SCAN OF THE ABDOMEN AND/OR CHEST WITH/OUT CONTRAST

You will lie flat on your back and be positioned inside a large doughnut shaped machine. You may be asked to hold your breath at certain times to allow for taking a clear picture of your chest or abdomen. The scanner produces narrow x-ray beams that examine the body sections from many different angles.

The series of cross sectional images in sequence build up a three dimensional image of organs and other body structures. A CT scanner is about 100 times more sensitive than an X-ray machine. The scan can be performed with or without contrast dye. If contrast dye is used, it is either ingested by drinking it or it is injected through a small IV usually in your hand. The dye is absorbed by body tissues and creates better structure enhancement on the film.

Purpose: To visualize the organ and tissue structures of the abdomen and chest. The enhancement allows for detection of disease in the early stages and identification of small tumors.

Instructions: Please let the technician or nurse know if your are allergic to contrast dye, iodine and/or seafood. You should not eat or drink 8 hours prior to the test. You may take medications with sips of water. Diabetics need to stop taking glucophage 1 day prior to the test if it involves an IV contrast. An oral solution will be given to you 2 hour prior to the test. You will be asked to sign a consent form if dye is used. You will wear a hospital gown and all jewelry will need to be removed. The test takes about 2 hours and 20 minutes.



Diagnostic Testing (continued)

MRI (MAGNETIC RESONANCE IMAGING)

You will lie flat on your back and be placed in a cylinder like structure. This test provides images of body tissue through the use of a powerful magnet, radio waves, and a computer. Contrast dye called Gadolinium can be used and is injected through a small IV in your hand.

Purpose: MRI allows the physician the ability to inspect internal organ structure and tissue very carefully. This test is useful in detecting edema, hemorrhage, blood flow, infarcts, tumors, and infection.

Patients with metal pins, rods, plates, pacemakers, or defibrillators should not have an MRI.

Instructions: You will have to lie on your back and hold still for about an hour. The machine produces a banging noise that you should be prepared to hear (it can be loud). All jewelry must be removed and if anyone has metal pins, rods, plates, pacemakers or defibrillators implanted in their body this test can not be performed.

UPPER ENDOSCOPY

A flexible tube is passed through the mouth into the stomach as the physician visually inspects the esophagus, the stomach and the first portion of the small bowel. A sedative such as Versed is normally given to relax the patient.

Purpose: The physician is looking for varices, inflammation, and/or ulcers.

Instructions: A consent form must be signed. You must have nothing to eat or drink for 6 hours prior to the test. Dentures, jewelry, and clothing from the waist up must be removed.

COLONOSCOPY

A long scope is passed into the rectum and large intestine (colon). If polyps are identified, a biopsy can be performed.

Purpose: The physician can visually inspect the rectum and colon.

Instructions: A consent form must be signed. You must be on a liquid diet 48-hours before the test and no food after midnight. Iron medication must be stopped at least 4 days before the procedure. Medicines and/or enemas will be ordered to help clean out your bowels. You will be given specific instructions at the time you are scheduled for the test. The procedure usually takes 30 to 90 minutes. You should have someone accompany you who can drive you home after the test.

LIVER BIOPSY

Tissue is obtained from the liver. A liver biopsy can be performed 3 ways:

- 1) Percutaneous-a needle is inserted through the skin of the abdomen.
- 2) Transjugular-a catheter is inserted into a neck vein and threaded down into



Diagnostic Testing (continued)

the liver. This technique is often used to minimize bleeding or if the patient has ascites.

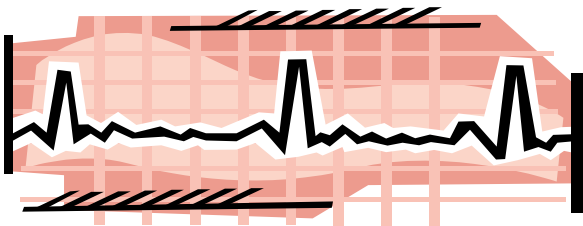
3) Surgically - tissue can be obtained during an abdominal surgical procedure. A local anesthetic is used for percutaneous and transjugular procedures.

Purpose: Obtaining liver tissue allows the physician to inspect liver cells under a microscope to determine the cause of liver dysfunction.

Instructions: A consent form must be signed. The procedure can take as little as 15 minutes; however, you are required to stay in bed for at least four hours after the percutaneous procedure to avoid bleeding.

CARDIOLOGY EVALUATION

Everyone will be required to have a basic EKG and Echocardiogram. Based upon your age and history of illness, you will be asked to have several examinations performed which will provide the physicians with information to establish the relevant cardiac risks for you



when undergoing the transplant operation.

ELECTROCARDIOGRAM (EKG)

Twelve monitoring patches are placed on the front of the chest, arms and legs. The test displays the pattern of electrical activity of your heart.

Purpose: This test can show irregularities in heart rhythm and whether or not the heart has sustained any damage from coronary artery disease.

Instructions: You will undress from the waist up and wear a hospital gown. Women may be able to keep their bra on. You will need to hold still during the test to help make the pattern tracing clear. Sometimes the technician may have to shave excess chest hair to get a good pattern tracing. The test takes 5-20 minutes.

ECHOCARDIOGRAM

An echocardiogram is an ultrasound of the heart and chest. The sound waves emitted from the transducer placed on the chest

An echocardiogram is a sonogram of the heart performed to evaluate the heart valves, determine the size of the heart, and the effectiveness of its pumping.

bounce off heart muscle and produce a picture of the heart on a video screen.

Purpose: This test will show heart size, shape, position, and movement of heart valves and pumping function.

Instructions: A consent form must be signed. You will undress from the waist up and wear a hospital gown. The test takes 15-30 minutes.

THALLIUM STRESS TEST

EKG patches will be placed on your chest to monitor the electrical activity of the heart while you exercise. You will be asked to walk on a treadmill in order to increase your heart rate. Exercise stresses the heart and

Diagnostic Testing (continued)

gives the doctor a better idea of how well your heart can function when put to work.

The test begins when Thallium (a safe chemical) is injected into your blood vessels through a small IV in your arm. The chemical will be

absorbed into your blood stream and by your heart muscle.

The tissue absorption produces a picture, which shows “hot” and “cold” spots on the heart. Hot spots are those areas of the heart that re-



ceive good blood flow and cold spots (or those areas where no thallium was absorbed) show areas of the heart that are ischemic or not getting good blood flow. Poor blood flow may be caused by blockages in the coronary arteries, which feed the heart blood and oxygen. An x-ray picture is taken shortly after the exercise and then again 2 hours later to see if there is a change when the heart is at rest.

Purpose: This test is used to detect coronary artery disease and damage to heart muscle.

Instructions: A consent form must be signed. You will have to wear comfortable shoes to walk on the treadmill. You should have nothing to eat or drink 8 hours prior to exam. The test can take between 4-6 hours depending on the time interval between x-rays.

CARDIAC CATHETERIZATION

During the procedure a catheter is inserted into the blood vessels in your wrist or groin area. A catheter is then threaded into the right and/or left side of your heart. Dye is injected into the catheter and X-ray pictures are taken to see the blood flow through the coronary arteries. You will be given some medicine to relax you. The procedure can take up to one hour. Your heart rate and blood pressure will be monitored continuously during the procedure.

Purpose: This test is used to detect heart disease just like the echocardiogram and stress tests. However, this test is used to directly visualize the coronary arteries that feed the heart blood and oxygen.

If these arteries are blocked or narrowed a patient runs the risk of having a heart attack. Liver transplant surgery is a big operation and the risk for heart attack or potential for heart problems needs to be deter-

Your heart will be evaluated to ensure you do not experience any problems during and after surgery.

mined.

Instructions: A consent form must be signed. You must have nothing to eat or drink 8-12 hours prior to the procedure. Patient must check with the doctor for instructions on how to take diabetic medications and/or blood thinners. Dentures and jewelry must be removed. The groin or wrist area may be shaved to insert the

Diagnostic Testing (continued)

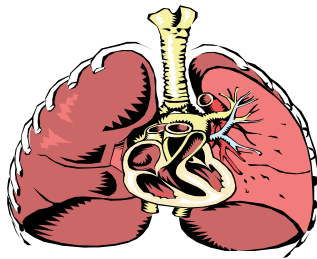
catheter in a sterile manner. After the test is complete, the catheter sheath in your wrist or groin will be removed and someone may apply pressure or place a sand bag over the site for 15-20 minutes. You will have to remain in bed for 6 hours after the procedure to prevent bleeding at the catheter insertion site.

PULMONARY EVALUATION

All patients will have pulmonary function tests (PFT's) and a blood gas analysis (ABG). If you are a smoker it is important that you take measures now to stop smoking. Patients with a history of smoking have more trouble with lung problems like pneumonia after a transplant. Sometimes it takes longer for smokers to get off the breathing machine (ventilator) and it prolongs the hospital stay.

PULMONARY FUNCTION TESTS (PFT'S)

You will be asked to sit in a special chamber and breath through a mouthpiece. A clip will be placed on your nose to prevent air exchange except through the mouth.



Smokers have more trouble with lung problems like pneumonia after transplant.

Purpose: This test demonstrates the capacity of your lungs to expand and exchange oxygen and carbon dioxide.

Instructions: Wear comfortable clothing. A light meal just prior to the test is usually okay. The test takes about 45 minutes.

ARTERIAL BLOOD GAS

A small catheter is inserted into an artery in your arm to get an arterial blood sample versus a normal blood draw which collects venous blood.

Purpose: To assess pH, oxygen, carbon dioxide, and bicarbonate levels in your blood.

Instructions: Alert the respiratory therapist if you are taking a blood thinner. Wear comfortable clothing. This test should take 10-15 minutes.

RENAL EVALUATION

It is important to determine whether or not there are any kidney problems prior to liver transplant. High blood pressure and diabetes are risk factors for kidney disease. Liver transplant surgery and the medication used after transplant can affect kidney function, therefore baseline renal status needs to be determined. In some cases patients are listed for a combined liver and kidney transplant. Any patient with abnormal kidney tests or a history of kidney problems will see a nephrologist prior to transplant.

24-HOUR CREATININE CLEARANCE

One of the kidney's main functions is getting rid of creatinine. Kidneys that are not functioning well will have low creatinine clearance over a 24-hour time period.

Purpose: To determine kidney function.

Instructions: You will be given a collection container from your doctor or hospital lab. You need to collect all your urine for a 24-hour time period. The container must be

Additional Evaluations

kept cool or on ice. On the first day when you wake up, urinate but do not collect this first morning urine. Collect the rest of your urine for the next 24-hours. When you wake the next morning, at the same time you did the day before, collect and save this urine as the last one. Take the urine sample to the lab. A blood sample may be drawn to calculate the urine results. You should eat and drink

DENTAL EVALUATION

Prior to your transplant, you will need to obtain a letter from your dentist stating that your mouth, teeth and gums are healthy and free of infection.



This may require dental work prior to surgery. Once you are on the transplant list, it is important that you have annual dental exams.

GYNECOLOGIC EVALUATION

Female patients need to see a gynecologist on a regular basis about once a year. Transplant candidates will need a letter from their gynecologist stating that they have completed several screening exams, including recent Pap Smear and Mammogram.

PAP SMEAR

This test should be performed every year.

Purpose: Detection of cervical cancer.

Instructions: Do not douche, insert vaginal medications or have sexual intercourse for at least 24 hours before the test.

MAMMOGRAM

X-ray examination of breasts. This test should be performed once a year in women 40 years of age (or older), or in those women with a family history of breast cancer.

Purpose: Early detection of breast cysts or tumors.

Instructions: Remove all clothing and jewelry from the waist up. Put on the hospital gown with the opening in the front. Each breast is examined by x-ray. The test takes about 30 minutes.

PSYCHOSOCIAL EVALUATION

As part of the liver transplant work-up, a psychosocial assessment will be conducted by a licensed, masters level social worker. The social worker will explore your level of support, your financial situation, your coping style, and assess your understanding of the transplant process. This work-up identifies strengths and potential problem areas that need to be addressed. If a substance abuse problem is identified, you will be referred to the substance abuse psychologist for therapy. These problems must be resolved before you can be approved for a transplant. It is the social worker's job to 1) help you understand the transplant from a realistic perspective, 2) identify possible barriers to transplants, and 3) when possible, to make recommendations to address identified problem areas. The transplant social worker is part of the Transplant team. Information you disclose will be shared with team members to determine your suitability for transplant.

Placement on the UNOS List

Every transplant program in the nation performs transplants with deceased donors with regulations from an organization called The United Network for Organ Sharing “UNOS”. UNOS is a non-profit and independent organization governed by medical professionals and the general public. It was awarded the contract to oversee the national transplant wait list by the Department of Health and the United States Government in 1984. UNOS assures equal access for all patients in need of organ transplants. The rules governing the wait list are the same throughout the country. Liver allocation is based on blood type, recipient/donor height and weight match, and severity of illness. All organs are offered locally first then regionally and then nationally. That means that a donor here in San Antonio will give organs to recipients here in South Texas first. If no match is found locally, then organs may be offered to patients regionally, for example to patients in Dallas or Houston. Finally, if no match is found regionally then the organs may be offered to very ill patients in other areas of the country.

When Do I Go on the List?

Once you have completed your work-up and all your testing, the Liver Transplant team will review your entire work-up and determine if you meet the criteria to be placed on the waiting list. If you do **not** qualify, the transplant physician will discuss other options and plan of care with you and your family. If you qualify, then your evaluation results will be submitted to the insurance company to receive approval. After the approval you will be placed on the waiting list.

A letter will be sent to notify you and your doctor when this happens.

How long do I wait for a donor?

Waiting time is based on blood type, weight range, and UNOS points assignment (MELD score). Points are assigned by UNOS from 6 to 40 that indicate the severity of the illness and the urgency to transplant. There is also a status 1 level assigned, if applicable. The average Status 1 patient is in the Intensive Care Unit and is expected to live less than 7 days unless transplanted. The average wait time for a liver transplant in South Texas is about two years. While more people are added to the wait list everyday, the number of donors stays the same. There are many people each year who have the potential to be organ donors, but either their families are not asked to donate or some families decline donation.

Listing Information

COMMUNICATION

Once you are on the wait list, your job is communication and compliance. Communication with the transplant team and compliance with your treatment are key to obtaining a transplant.

Liver disease can be very unpredictable. You can be seen in clinic one day and you may feel okay, but the next day you may become very sick. It is important that you keep your physicians and Transplant team up-to-date with what's happening to you. When your health status changes, we can modify treatment to make your symptoms improve or you may need to be hospitalized. Your standing on the national wait list is based upon severity of illness and length of time waiting. If your condition worsens, we may be able to upgrade your MELD score. However, if you are hospitalized or your condition worsens, and no one notifies us, we can't help you.

It is also very important to inform us as soon as possible about any changes such as a new address, or insurance and phone number changes. If you are going to travel, you must let us know where you can be reached during the time you are away.



Notify the transplant team immediately of changes in your health status.

COMPLIANCE

Compliance with prescribed treatment is important for your survival with liver disease. You must take your medications as prescribed and keep your scheduled visits. We will also be concerned about your compliance, because it is a predictor of how well you will take care of yourself after transplant.

AVAILABILITY

A donor can be available at anytime day or night. The Transplant Coordinator **must** be able to reach you. Do not leave your answering machine on during the night. Please make sure you answer your phone and if any phone numbers change please let us know immediately. Plan ahead for travel arrangements, driving route, and driver. If air transportation is necessary, have a list of commercial flights available in advance so no time is lost in last minute flight details. The Coordinator will review with you when to come in to the hospital, and ask you not to eat or drink anything. **Please bring your Insurance Cards and your Medications. Please leave all valuables at home.**

You may also be called in to the hospital and not get the transplant. This can happen when the donor team sees the donor liver and finds the liver to be damaged or not good enough for transplant. You may be sent home to await another liver. You may also come in as a “backup” for someone that has the possibility of not getting the liver meant for them. If everything is

Wait List Management

medically stable with the first patient, you may be sent home. The Transplant team will wait until you get a healthy liver, or it is your time to receive the liver.

STRESS MANAGEMENT

We recognize that it is very difficult to wait for a life-saving transplant and to keep a positive outlook. However, we are here to assist and support you and there are a number of important things to discuss about your wait for a transplant.

Many people who have received a liver transplant say that the waiting period can be the most difficult stage of the transplant process. This time period has been described as an “emotional roller coaster” with many different feelings being experienced. At times, you may feel optimistic and hopeful, while

at other times you may wonder how long you will wait or even wonder if an organ will ever be available for you. It is not uncommon to experience doubts about the prospects for ever receiving a liver. Many patients say that waiting for a



Waiting for transplant may bring about a variety of fears and feelings.

liver can easily become the focus of your life, and this can make the waiting period even more difficult.

There are some self-help measures you can take during this time to make the wait easier. The following suggestions have helped others in your situation.

Feelings and emotions

Waiting for a transplant may bring about a variety of fears and feelings. Fear of pain, fear of losing control, fear for your family’s well being, and fear of the future is common. Many people fear death as they contemplate the possibility that an organ may not be available in time. Although many feel that it is not best to admit to these fears, ignoring them may cause the fears to become greater. Experts suggest that an important step in conquering fear is to face it head on. Just as a splinter in your finger may become infected and painful if ignored, unspoken fears may result in anxiety, sleeplessness, irritability, depression, night terrors, and an overall decrease in the quality of your life.

Stay anchored in today and focus on the joys and pleasures of the moment.

There are several strategies useful in dealing with fear. One method that helps is to admit your fears and talk about them with your transplant social worker, a chaplain, minister, or even a close friend. Remember that family members and others who are close to you may be reluctant to discuss these fears as they are closely connected to you. For that reason, it is usually better to discuss areas of concerns with a more neutral, less involved individual, such as a professional. Another method that many have found helpful in facing fears, is to focus less on the future and more on the here and now.

Wait List Management (continued)

Staying anchored in today and focusing on the joys and pleasures of the moment help prevent you from focusing on the worse case scenario and the “what ifs” that are an inevitable part of the waiting process.

Fear is a natural, reasonable reaction to a threatening situation and it is normal to feel some fear during the waiting period. However, if you continue to feel anxiety or depression related to your fears and lifestyle changes after engaging in the self-help measure suggested below, discuss this with the transplant team. Medication, relaxation techniques, or a referral for counseling may be indicated.



Social Support

It is important to reach out to family and friends during this time. Many people find it helpful to talk to others when they are stressed, while others may benefit from engaging in activities that may take their mind off the waiting process. Most families and friends would welcome the opportunity to lend a hand, a good listening ear or to be available to help in any number of ways.

Many patients and families have found it helpful to “talk” to others who are in the same situation via the Internet. One helpful site is the Friends’ Health Connection at www.friendshealthconnection.org (or you can call 1-800-48-FRIEND). Several other helpful web sites are: www.transplant.org and www.stadtlanders.com.

In the words of one transplant patient, “*I think it always makes things easier if you have talked to someone who has ‘walked the walk’.*”

Support Group Meetings

You and your family members (or any significant other) are encouraged to attend the monthly support group meetings facilitated by the social worker. People at all stages of the transplant process attend these meetings along with their spouses, children, other family members and friends.

Find a hobby that you enjoy but will not leave you exhausted.

The group provides you with support and information, and gives you the opportunity to share feelings. This is an opportunity to learn what others have done to increase their coping abilities during the waiting period as well as to learn about the issues faced in the post-transplant period. An additional benefit is that you get to know other transplant patients, which helps in developing an expanded social support network.

Wait List Management (continued)

Options and Choices

As mentioned earlier, there are not enough available organ donations, and some people face death while they are on the waiting list. As their liver failure progresses, many patients begin to have mental changes that can cause confusion and the inability to make sound decisions. Not only is it important to make decisions, but it is also important to communicate your wishes to your family and to complete the necessary paperwork.

The hospital has a handbook for patients called, “Your Rights and Critical Choices as a Patient”. Most of the “choices” refer to your wishes about end of life issues. For example, in the event that you cannot make decisions, who would you want to appoint as your decision-maker for medical issues? In the event that your heart stops and your breathing stops, would you want to be resuscitated and connected to medical equipment that would support your bodily functions?

The handbook contains a lot of valuable information and it has the forms that need to be filled out and filed so that healthcare workers can honor your wishes. Since many of these topics are difficult to think about or to talk about, many patients and families need help to deal with these issues and to understand the necessary paperwork. Please ask for assistance if you want to discuss your options with a chaplain, nurse, or physician.

Additional tips for coping

As you know, liver disease causes a decrease in stamina and energy. Therefore, it is very important for you to decide how much you wish to expend the energy that you do have.



Decide how you want to spend your energy, and take steps to engage in the activities that you find fulfilling and pleasurable. For example, if spending quality time with your family is a priority, don't use all your energy cleaning the house.

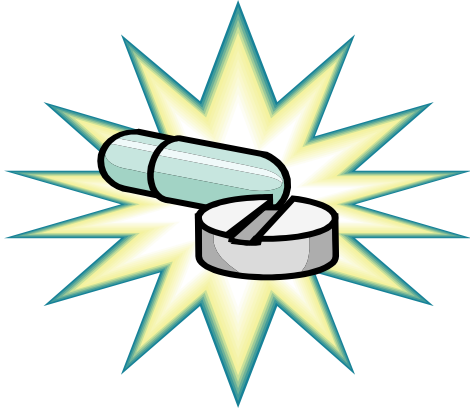
Enlist the help of the others in the tasks that you have trouble completing so that you have energy for the important events in your life.

Perhaps, the most important advice for anyone waiting for a transplant is to live life as normally as possible by not focusing on the wait. Continue to attempt to have some structure to your day, reach out and expand your social support system, engage in meaningful activities, and live life as fully as possible.

In the words of one transplant patient, *“Take one day at a time and savor that day. That's all you get even if you are very healthy”*.

The transplant team members are available to help you and your family during this waiting period. Please contact any member of the team if we can be of assistance.

Medications at the Time of Transplant



All patients who receive a transplant will be on immunosuppressive medication for the rest of their lives. These medications lower a person's ability to fight off foreign objects so that the body would be less likely to have a rejection episode. Each person reacts differently to the medications, so each person will have different medicines, doses, or combinations of these medicines.

IMMUNOSUPPRESSIVE MEDICATIONS

The recipient will not go home until he or she knows the name, dose, action, and side effects of all their medicines. The medications are the most important part of a transplant and you must know all about them in order to take care of yourself and your new liver. The following is a list of all the immunosuppressive medications that we give to patients. You will be on a combination of two to three of these medications. Please review them so that you are aware of what they are and what side effects they may have.

PROGRAF

REMEMBER: You will have to know all about the medicines before you can go home.

Purpose: Anti-rejection

Dose: Twice a day

Side Effects: Increased risk of infection, increased risk of cancer and tumors, increased creatinine, possible toxicity to the kidneys, high blood pressure, nausea, vomiting, diarrhea, elevation of blood tests of the liver, elevated blood sugars (can cause Diabetes and may require insulin to control sugars), headaches, rash, hand tremors, blurred vision, difficulty sleeping and/or nightmares, burning or tingling of hands or feet.

CELLCEPT

Purpose: Anti-rejection

Dose: Twice a day

Side Effects: Increased risk of infection, nausea, vomiting, diarrhea, anemia, overtiredness, mouth sores, and occasional hair loss.

RAPAMUNE

Purpose: Anti-rejection

Dose: Once a day

Side Effects: Increased risk of infection, high cholesterol / triglycerides, high blood pressure, rash, acne, anemia, overtiredness, joint pain, diarrhea, and low potassium.

NEORAL

Purpose: Anti-rejection

Dose: Twice a day

Side Effects: Increased risk of infection, increased risk of cancer or tumors, increased creatinine, possible toxicity to the kidneys, high blood pressure, increased hair

Hospital Admission

TRANSPLANT UNIT

Once you are called into the hospital, you will be sent to the transplant unit. The nurse will ask you several questions, take some blood and take your vital signs (temperature, pulse, blood pressure and respiratory rate). A physician will see you and complete a physical examination and review your past medical history.

You will also be provided with information regarding the risks and benefits of your impending surgery. You will then be asked to sign consent forms for the surgery and anesthesia. The form also has a section regarding blood transfusions.

SURGERY

After all consents are signed, nursing personnel will prepare you for your surgery and you will be brought down to the holding area.



The surgery usually lasts six to ten hours. Your family will be given updates of your progress during the surgery. We realize this is a stressful time, not only for you, but also for your family.

ICU AND TRANSPLANT UNIT

After surgery you will be brought to the Intensive Care Unit. Once the nurses have completed the transfer, your family will be able to see you in usually 1 hour. You will stay in the intensive care unit (ICU) four to five days,

then return to the transplant unit. The average length of stay in the hospital is ten to twelve days. After your surgery, you will continue your education and training by the transplant team. Your transplant coordinator, nutritionist, and social worker will make rounds with the transplant physicians. They will then review specific instructions on your medications, how to take care of yourself, how to eat, and how to take care of any social or financial needs. You will be a very important part of this team. A family member or someone who will help care for you must be a part of this education process. An individualized plan will be made for you to help you understand everything you need to know about how to take care of yourself.

COMPLICATIONS/RISKS

Complications after a transplant usually occur, but are not limited to the hospital stay. Most of the complications can be treated if caught early with your help.

They are: surgical complications, infections, rejection and death.

SURGICAL COMPLICATIONS

The surgery, as mentioned before, is long and you will have a large incision.



Important Phone Numbers and Names

**Texas Transplant Institute
on the campus of
Methodist Specialty and Transplant Hospital
8201 Ewing Halsell
San Antonio, Texas 78229**

Transplant Clinic—San Antonio Telephone: 210-575-8400
Fax: 210-575-8420

Transplant Clinic—McAllen Telephone: 956-688-6264
Fax: 956-688-6265

Transplant Clinic—Corpus Christi Telephone: 361-884-2809
Fax: 361-884-2781

Toll Free Phone Number 800-888-0402

My Transplant Surgeon: _____

My Hepatologist: _____

My Transplant Nurse Coordinator: _____

My Transplant Scheduler: _____

My Social Worker: _____

My Financial Coordinator: _____

My Home Health Nurse: _____

My Home Health Company: _____

My Pharmacy: _____