

Evaluation

Usually your gastroenterologist or primary care physician will make the transplant referral, but anyone, including you, can call to make the transplant appointment. Sometimes insurance companies will tell the policy holder which transplant centers are covered in their network. Our financial counselor can also check on this for you.

A transplant evaluation is the process by which you prepare for transplant. It includes a history and physical exam, psychosocial assessment, nutritional consultation, and financial evaluation. The first appointment will take approximately 1-2 hours. This is just the first step in the evaluation for many patients, as you will need additional tests and consultations with other physicians. Your Transplant Coordinator will be able to tell you what additional tests you may need before you leave after this first appointment, but sometimes we may not be able to tell you until after the whole team reviews your case. The formal liver transplant evaluation usually takes 2-3 days and is done on an outpatient basis unless an emergency situation exists.

The liver transplant nurse coordinator will be your guide through the entire process. You will be encouraged to communicate with your coordinator regularly and will be provided with his/her contact numbers. Your nurse coordinator will determine the testing required and the liver transplant scheduler will contact you regarding your availability.

What To Bring

You will need to bring your insurance, Medicare or Medicaid card for us to copy for our records. You also must present a picture ID so we can verify your identity. You also need to bring:

1. A list of your major medical problems and approximate years they developed.
2. A complete list of all the medications you are currently taking, including dosages, frequencies and the reasons in which they are taken.
3. A copy of your previous medical records from the last two years, including doctor's progress notes, lab results, radiology reports, biopsy reports, operative reports and any other results and/or consultation notes included in your file.
4. If you have had any imaging of your abdomen done, such as ultrasounds and/or CT scans, please obtain the actual films (or CD) or a copy. Although we may have the written report, it is optimal for our physician to be able to view the actual images.
5. If you have had a liver biopsy, you may be asked to obtain the actual slides from the facility where the biopsy took place so that our pathologist can

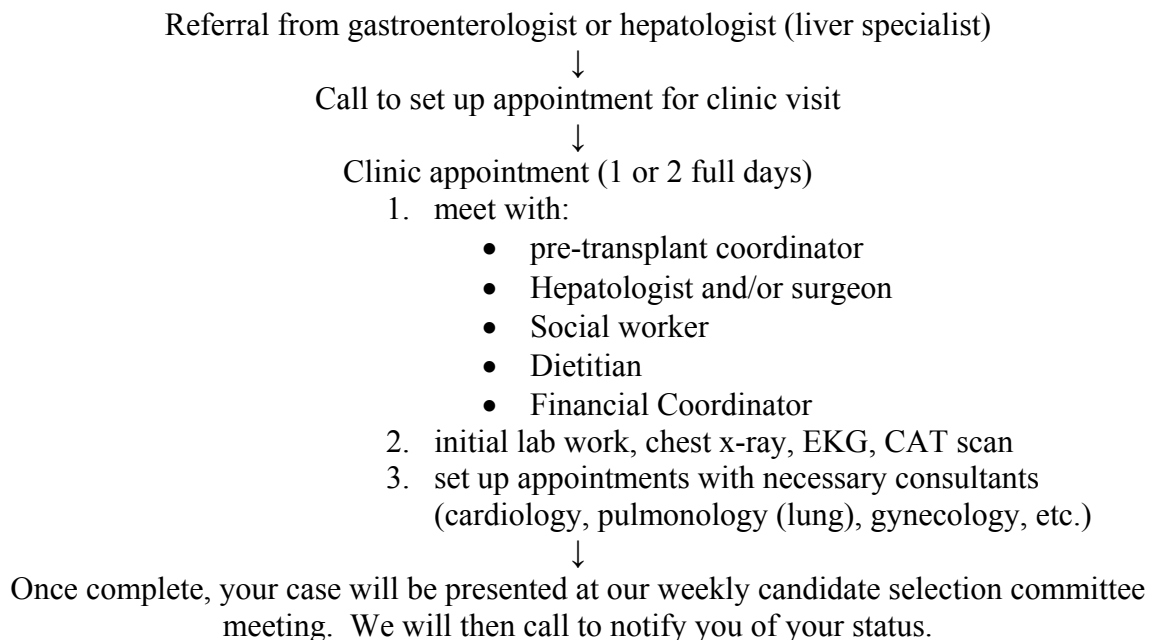
review them. If you can easily obtain them, please bring them to your appointment.

6. Most importantly, please bring a list of the questions you would like to ask us.

It will be easier for you if you have a family member who can come with you to this appointment – there will be a lot of information given to you during the evaluation. One of the important aspects of undergoing a liver transplant is having people around you to help you in your recovery. We need to meet these people so they too can be educated about what you will need. Our Social Worker will also want to meet with a family member or friend who is your close support.

Your Transplant Coordinator will call you after all your results have been received and have been reviewed by our team at our Candidate Selection Meeting. This is a meeting of the whole team to review your case and to make a decision about transplant for you. The liver transplant selection committee meets weekly. Within a week or two after we have received all the results of your tests, you can expect to hear from us. We will first get clearance from your insurance carrier before we place you on the waiting list. Once we do, you will get a letter in the mail telling you this. We will also send a letter to your referring physician and/or primary care physician. If you do not receive a letter from us, you should call us.

Schematic of the Evaluation



For referral, please call (504) 988-5344 or long distance (888) 988-5344. Our operator will direct you to the proper person.

Waiting List

As liver transplantation is a “life-saving” measure, livers are allotted by medical necessity to sustain life. The waiting time for a liver transplant varies depending on your blood type and your MELD score. MELD stands for “model for end-stage liver disease.” This is a numerical scale which ranges from 6-40. The score is derived by using various laboratory results that are calculated by a special formula using tests that evaluate your liver and kidney functions as well as your body’s blood clotting abilities. As a general rule, the lower the MELD score, the longer the wait for liver transplantation. Patients with higher MELD score are typically sicker and the risk of mortality is generally higher. These patients will be transplanted in shorter periods of time. Patients with hepatocellular carcinoma (liver cancer) may qualify for extra points which can place these patients at higher priority on the liver transplant list. Your nurse coordinator can further explain this process.

Depending on your results and medical situation, you may need to see us as little as once every 6 months or as frequently as monthly. Typically, we will see you approximately every 3 months. Depending on your MELD score at time of listing, you will be required to have blood work done at various intervals in order to maintain your place on the UNOS/OPTN national waiting list. The higher your MELD score, the more frequently your blood work will need to be done. Your nurse coordinator will advise you of your laboratory testing requirements and be able to assist with arrangements for the necessary blood work. Also, depending on your liver disease, we may choose to do other testing at specific intervals, at your physician’s discretion. Your Transplant Coordinator will be able to assist you with any questions or concerns that you may have.

Live Donor liver transplant

Living donor liver transplantation is possible because the liver - unlike any other organ in the body - has the ability to regenerate, or grow. In living donor liver transplantation, a portion of liver is surgically removed from a living person and transplanted into a recipient, immediately after the recipient's diseased liver has been entirely removed. Regeneration of the liver happens over a very short period - usually days to weeks. Certainly within 6-8 weeks the portion of liver has grown to almost normal size in both the donor and the recipient. More than a decade ago, surgeons around the world began to perform these procedures using adult donors for children who needed transplants.

The main advantage of living donation for recipients is that the waiting time is significantly decreased and the surgery can be performed on an elective basis. The donor's medical expenses related to the evaluation, surgery, hospitalization, and immediate postoperative care are covered by the recipient's insurance company. If any problems arise in the future directly related to the liver donor surgery, these are covered as well.

Being called in for transplant

Transplant nurses are on call 24 hours a day to accept offers of organs. You will be notified by telephone that a liver has become available for you. It is very important to make sure we can get in touch with you 24 hours a day, 7 days a week. If your telephone number changes, or if you will be staying with someone or will be out of town, be sure and notify your transplant coordinator of the telephone numbers where we can reach you. You should also call your coordinator every few months to check that all the phone numbers we have for you are up-to-date. You may list as many phone numbers as are necessary. You need to get to Tulane University Hospital as soon as possible. You should pack a suitcase to stay in the hospital for 1-2 weeks. Bring all medications you are currently taking and anything else you will need for a week in the hospital. Go to the Admitting Office or directly to the Abdominal Transplant Unit, whichever the coordinator tells you to go to.

Upon admission to the Abdominal Transplant Unit, you will be greeted by a nurse who will admit you into a hospital room. The nurse will get you settled into the room and will take several vials of blood. A physician will complete a history and physical to update your medical information to ensure that you do not have any new medical problems that will make the transplant operation unsafe. You may have more than one history and physical performed by various physicians. Depending on your individual situation, kidney specialists, diabetic specialists, heart specialists or other type of specialists will be consulted to ensure all aspects of your particular condition are addressed and you will be safe during surgery.

We won't know if we can proceed with transplant until we know the liver is usable. Sometimes this means patients wait in the hospital for many hours, without eating, and ultimately get sent home without a transplant if the liver is not good.

Liver Transplant Surgery

When it is time for surgery, you will receive anesthesia to make you sleep. Once you are asleep several large IV's will be placed in your arms, necks and groin. A tube will be placed into your nose to drain your stomach and also into your bladder to drain your urine. Once all the preparations are complete, the transplant surgeon will begin the operation. The incision is made under both ribs and up toward the breastbone. First, the surgeon removes the diseased liver. Patients can potentially lose a fair amount of blood during this part of the procedure and often will require several transfusions. Then, the new healthy donor liver is put in place. The blood vessels are sewn together and the final connection is made to the bile duct, a small tube that carries bile made in the liver to the intestines. Abdominal drains are placed around the new liver. Finally, the abdomen is closed and you are taken directly to the transplant unit where the staff will monitor your vital signs very closely. You will remain on the breathing machine for at least the first night. It may be at least an hour before your family will be able to see you after surgery.

Generally, liver transplant surgery takes between 4-8 hours, but each individual case varies based on the extent and complexity of liver disease and other health problems.

Hospital Stay

You will return to the transplant unit after surgery, and will probably be very groggy from the anesthesia. You may remain on the ventilator until you are awake enough to breathe safely on your own. During this time, fluids and medications will be given to you through an IV. You will also have a tube in your nose that goes down into your stomach to help drain the stomach juices until your bowels start to work on their own (usually 2-3 days after transplant). You will have one nurse devoted to taking care of you. These nurses are specially trained to care for transplant patients. He or she will be in your room frequently monitoring your progress. After you have been settled into your room, your family will be asked to join you.

Deep breathing and coughing are important exercises right after surgery. Once you are taken off of the ventilator and are breathing on your own, your nurse will give you a breathing device that is used to encourage deep breathing. Deep breathing and walking are the keys to a speedy recovery. Throughout your recovery after surgery, physical therapists will work with you to build your strength and help you to start walking again. Both deep breathing and walking will decrease the chance of developing pneumonia which is a common complication after surgery. Walking will also decrease the chance of developing a DVT (deep vein thrombosis). If you do not move and walk enough, there is a chance of blood clots getting stuck in the veins. This is called a DVT and can cause pain, swelling of the extremities, and decreased blood flow.

Most patients experience pain mainly over the incision site after liver transplant. You will be given IV pain medication that you can control. It is called a PCA (patient controlled analgesic). The pain medication is on a pump and you will have a button to push when you want the pump to deliver more medicine. The pump is set so that you cannot get too much medication, but just enough to keep you comfortable.

The usual length of stay following a liver transplant is 1-2 weeks. Of course, this depends on how well the new liver works and whether there are any complications. If you have a complication after surgery, you may need to stay longer. The transplant team will not keep you in the hospital any longer than necessary. Leaving the hospital as soon as you are ready will decrease the chance of getting an infection.

Before you leave the hospital you will be assigned to a transplant coordinator. Your coordinator will monitor your blood work and medications throughout the life of your transplant and will be available to you if you have any questions or concerns. A transplant coordinator is available even at night and on the weekends. You will always have someone to help you if you have any questions or concerns about your transplant.

After Your Transplant

Before you leave the hospital you will be assigned to a transplant coordinator. Your coordinator will monitor your blood work and medications throughout the life of your transplant and will be available to you if you have any questions or concerns. A transplant coordinator is available even at night and on the weekends. You will always have someone to help you if you have any questions or concerns about your transplant.

You will be sent home with a one month supply of the medications you will need and with orders for frequent blood tests. You should talk with your transplant coordinator about how you will get your medications filled, where you will have your blood work drawn, and how the results will be sent to your transplant coordinator. You will need to monitor and record your weight and blood pressure in your notebook when you get home. This information is important to your transplant coordinator and your transplant physician. You should bring it with you to your follow-up transplant appointments.

Even after your transplant you still need to be followed by your primary care physician. You should go to their clinics for regular check-ups and health maintenance. The transplant team will follow your transplant health; however your primary physicians need to be involved in your care as well.

It is your responsibility to take good care of your transplant by taking all medications when you should, getting your blood tested regularly, and by keeping in touch with the transplant team. Eating a healthy diet and staying active will help to keep your whole body healthy and give your transplant liver a good environment to work well. The transplant physicians, coordinators, dietitian, and social workers will work with you to help you to get the most out of your new organ.

Protocol

We pride ourselves at Tulane on our patients' success. We work as a team which requires that we all participate in patient care. On our end, we have developed a general protocol for patient follow-up that at times may seem rigorous, but is what we believe is safe and in your best interest. We expect our patients to respect their new organ by adhering to our required outpatient visits, medication regimen, and lab checks. Our basic protocol for uncomplicated patients in the first 3 months is as follows:

Discharge from the hospital (after inpatient teaching)



Lab checks 2-3 times each week until liver function is stable; by one year, lab draws are usually just once a month



Clinic visits every 2-3 weeks

- Remember, if taking Prograf or Neoral (cyclosporine), DO NOT take morning dose until after your blood draw

Bloodwork

Initially, you will have blood work done 2-3 times a week. These laboratory levels will be sent to your coordinator and he or she will contact you regarding these results. By 1 year after your transplant, you will have your blood work drawn only once a month, but if there are any problems, you may have to have blood drawn more often.

Your laboratory orders are based on the type of transplant you receive and the medications you are taking. Blood work may include: complete blood count (CBC), renal profile, Prograf level, Neoral level, urine analysis (UA), liver function test (LFT), and cholesterol level. Prograf and Neoral are two of the main anti-rejection medications and they need to be monitored very closely; the doses of these medications may be raised, lowered, or changed based on the results of your blood work.

Drug Levels

If you are taking Prograf, cyclosporine or rapamune as one of your immunosuppression medications, the level of this medication in your blood must be monitored. If the level is too low, you are at risk for rejecting the transplant, however, if it is too high, it could cause toxic side effects. The dose of your medication will be raised or lowered to maintain the level in a certain range.

Blood Counts

The CBC includes multiple blood levels. The main levels we check are the hemoglobin, hematocrit, and white blood cell count. A low hematocrit and hemoglobin is called anemia. Patients with kidney failure are usually anemic and may be taking iron pills or another medication to treat this problem. Anemia often gets better after transplant. We monitor your CBC to make sure your hematocrit and hemoglobin are within normal limits. Included in a CBC test is your white blood cell count. This number usually is slightly low when you are taking immunosuppression or anti-rejection medications. However, if it is too low, you may need to have the doses of your immunosuppression medications adjusted. Some types of infections may decrease the white blood cell count. In this case, the transplant team will want to check for infections in order to treat them as quickly as possible. It is very important to keep in contact with your transplant coordinator and to have your blood drawn as scheduled.

Chemistries

The kidneys and liver filter the blood and remove toxins. The renal and liver profile blood tests monitor how well your kidney and transplanted liver is filtering out toxins. The BUN (blood urea nitrogen) and creatinine levels reflect how well the kidneys are functioning. These numbers are monitored to ensure your transplant kidney is working properly. The renal profile blood test also monitors your electrolytes (such as potassium and phosphorus) as the kidney plays an important role in balancing the electrolytes. Most of your medications are broken down in the liver. Liver function tests are done to make sure your liver is healthy and able to break down these medications well.

Some of the anti-rejection medications may increase your cholesterol. If your cholesterol is too high, you may need to take a cholesterol lowering medication. High cholesterol levels are directly related to plaque formation in your arteries. This problem can occur in the brain (leading to a stroke), in the heart (leading to a heart attack), and in your new transplant.

Medications

In addition to your previous medications, you will be taking immunosuppression medication. Your immune system recognizes foreign bodies that are not its own and tries to fight to get rid of it, kill it or reject it. The immune system sends out white blood cells to combat what it sees as an intruder. The transplant liver is seen by the body as an intruder. To minimize the body's ability to reject your new organ, you will be given medication that will decrease the body's ability to make white blood cells. These medicines will also decrease your body's ability to fight infection. It is a delicate balance to give you enough medication to limit your body's ability to reject your new organ, and its own ability to fight viruses, bacteria and other things you come into contact with on a daily basis. Because of this delicate balance, your immunosuppressive medication doses will be increased or decreased based on blood levels and how your body reacts to the medication. You must take these medications every day for the rest of the life of your transplant organ. Your risk for rejection is much higher if you do not take your medications as prescribed.

Immunosuppression

There are a variety of different medications that can be used to suppress the immune system and prevent rejection. Most patients take at least 2 or 3 of these special medications. The Tulane Abdominal Transplant Institute has developed our own guidelines for immunosuppressive medications. We also tailor these guidelines to individual patient's needs when appropriate.

The main immunosuppressive medication is either Prograf (Tacrolimus) or cyclosporine (Neoral). These are the most important medications in the prevention of rejection. Sometimes Rapamycin (Sirolimus) is used in place of or along with Prograf or Neoral; this is usually done to help avoid side effects from the other immunosuppressants.

Steroids have always been used to prevent rejection in transplant patients. Gradually the dose of steroids you take is decreased (usually during the first 3 months after transplant). In some cases we consider early withdrawal from steroids or using no steroids at all in patients who have had bad side effects. In our experience, this small amount of steroids is an important part of preventing rejection and most patients have very few side effects at such small doses.

Another type of immunosuppressive medication that you take is called Cellcept or Myfortic. Research shows that patients who take this type of medication in addition to the other immunosuppressants will have transplanted organs that work better for longer.

This method of using a combination of medications helps to decrease the possible side effects from any 1 medication.

Other Meds

We prescribe other medications for our transplant patients that include antibiotics to prevent infection, blood pressure medications, and medications to prevent stomach ulcers that may be caused by the new medications.

Special Considerations

Rejection

Your body is able to recognize substances inside your body that are not yours. When your body recognizes that the transplant organ is not yours, your immune system will attack and try to destroy the transplant organ. This response is similar to what happens when your body fights off infection. Immunosuppressive medications decrease the body's ability to activate the immune system; they try to trick the body into thinking that the organ is actually yours. Rejection is most common in the first 6 months of transplant, however, may occur at any time. It is important to always take your immunosuppressive medications as directed; missing just one or two doses can put you at risk for rejection.

Having rejection does not always mean that you will lose your organ. Rejection is treatable, but only if it is found early. Call the transplant team if you have any of the warning signs of rejection.

Some signs of rejection include:

1. Fever over 100.5°
2. Flu-like symptoms: chills, aches, pains, fatigue, headaches, nausea, and vomiting
3. Fluid retention with weight gain, swelling, increased blood pressure
4. Pain, tenderness or fullness over the area of your transplant

These signs are much like the signs of infection. If you ever have any of these signs, you should notify your transplant coordinator immediately.

Rejection is often seen first on your routine blood work. This is one of the reasons why it is so important to always get your blood work done as prescribed. Rejection is best treated when it is found early.

If your transplant team suspects that you have rejection, you will be admitted to the hospital for further evaluation. Tests will be run including, blood work, an ultrasound of the transplant, and possibly a biopsy.

Rejection can be treated with a few days of high dose steroids, or another drug called Thymoglobulin which is a very strong immunosuppressant. Both drugs work to decrease

the body's ability to reject the transplant. You will stay in the hospital for 3 – 7 days while these medications are given.

Hepatitis C Virus (HCV) & Liver Transplant

Hepatitis C is the leading indication for liver transplant at Tulane as it is all across the country. At present, while we have options for treatment, none are ideal and once cirrhosis has developed it is nearly impossible to 'cure' hepatitis C. The patients and transplant professionals are faced with the difficult issues of recurrent disease.

Unfortunately up to 30% of the patients transplanted for HCV have cirrhosis again by 5 years after transplant. Much research is going on with newer types of medications to decrease this incidence. In the meantime, when patients have recurrent cirrhosis, the consideration for re-transplant is made on a case by case basis because the outcomes are so poor.

HIV & Liver Transplant

Advances in treatment for HIV have resulted in longer survival of infected patients and it is no longer considered a terminal disease. HIV positive, viral load negative patients with liver failure, often due to coinfection with HCV, are now potential candidates for transplant. Strict criteria, developed by the NIH, are used for selection of patients. Each patient is evaluated and considered on an individual basis. If you have any questions or would like to be evaluated for transplant, please call for more information.

Pediatric Liver Transplant

Our expertise in abdominal organ transplantation extends to our pediatric population. Here at the Tulane Abdominal Transplant Institute, we recognize that organ failure in your child can be a devastating diagnosis. Our multidisciplinary team evaluates each child to provide a comprehensive management plan. Should transplant be required, we are able to offer living donation for liver transplant recipients.. Deceased donor organs are also used. Currently our program is located at Tulane's Children Hospital but we are in partnership with Children's Hospital of New Orleans. Please see our webpage dedicated to transplant in the pediatric population.