History and Current Trends in Liver Transplantation

The first attempt at clinical liver transplant was made in 1963. Technical advances have improved operative success. By 1983 the expertise in liver transplantation finally reached a point where it was widely accepted as a suitable clinical option for patients. Since 1985 there has been a rapid increase in the number of centers performing liver transplants. Approximately 6,341 liver transplants were performed in the United States in 2011. As of December 31, 2011, there were 16,867 liver patients awaiting transplantation. The demand for liver transplants is expected to increase in the years to come. It is hoped that organ donation will increase to meet this need. Transplant centers across the nation are currently trying to maximize the donor pool by using living donors and donations after cardiac death.

What Does a Healthy Liver Do?

The liver is the largest internal organ in the body and plays a vital role in regulating many life processes. The liver weighs approximately 3-4 pounds and is roughly the size of a football. It is made up of a sponge-like mass of wedge-shaped sections called lobes. The liver is located in the right side of the abdomen and is protected by the ribcage.

The liver is a very complex organ that performs many functions that are essential for life. These functions include:

- Storing energy in the form of sugar
- Storing vitamins, iron and other minerals
- Making proteins, including blood-clotting factors, to keep the body healthy and growing
- Processing worn out blood cells
- Making bile, which is needed for food digestion
- Helping “clean” the blood by breaking down and removing many medicines and toxins, such as alcohol
- Regenerating its own damaged tissue
- Maintaining hormonal balance
- Aiding in digestion by helping in the absorption of fat and certain vitamins, including vitamins A, D, E and K
- Helping the body resist infection by producing immune factors and by removing bacteria from the bloodstream

A healthy liver also has a remarkable ability to regenerate (grow back), which no other organ in the body is able to do. There are illnesses, however, that can cause severe and irreversible damage to the liver.

The liver has two blood supplies, the hepatic artery supplies oxygen-rich blood to the liver (approximately 25% of the blood supply), and the portal vein, which supplies nutrient-rich blood to the liver (75% of the blood supply).

The gallbladder is attached to the liver and is a sac for storing bile. Bile is helpful in the digestion of food. The gallbladder is not essential for life. The liver is wrapped around the vena cava (the large blood vessel draining blood from the lower part of the body) and the blood leaving the liver drains directly into it. The liver is attached to the back wall of the abdomen, which complicates the operation and may cause significant bleeding during the transplant.
What Makes a Liver a “Diseased Liver?”

1. Sudden or acute failure from infection or drug
2. Chronic long-term failure due to:
   a) Ongoing infection
   b) Repeated injury due to persistent elevation of bilirubin
   c) Alcoholism
   d) Autoimmune disease
   e) Errors in Metabolism
3. A liver with cancer (primary liver cancer)

A liver normally has a great ability to heal itself and it can overcome most insults it encounters, such as heavy alcohol ingestion or viral infection. In fact, it is the only organ in the body, which has regenerative capabilities. Occasionally, the liver is so devastated by the insult that all of its cells are destroyed and there are not enough left to regenerate.

Some insults are chronic and can lead to scar formation replacing normal liver cells. Some scar formation on the liver can be tolerated but is not reversible. When all normal liver tissue is replaced by scar tissue, this is referred to as cirrhosis of the liver. Liver cirrhosis can occur from a variety of causes. Alcohol abuse or continued exposure to a virus can cause liver cirrhosis. High levels of bilirubin can occur in children with congenital absence of the bile ducts known as biliary atresia. In adults, primary biliary cirrhosis, sclerosing cholangitis or continual high levels of bilirubin can eventually lead to liver cirrhosis.

Two problems arise as a result of cirrhosis of the liver. First is a loss of biochemical function of the liver. This includes functions such as clearing waste products from the blood stream, making proteins necessary for growth, development and body maintenance. The abnormalities are a result of the liver’s inability to perform functions at the cellular level. This can result in any or all of the following conditions:

1. Encephalopathy, which is decreased mental functions ranging from fatigue to confusion or coma.
2. Coagulation defects, which result from inadequate supplies of proteins to produce clotting factors. This can lead to significant bleeding.
3. Malnutrition, weight loss, muscle wasting and chronic fatigue result from decreased ability to process nutrients appropriately.
4. The immune system may be impaired as a result of liver failure leading to potentially severe infections.

The second problem that arises is an increased resistance of the flow of portal vein blood through the liver as a result of the scar formation in the liver. This can lead to several potentially life-threatening conditions. The blood that bathes the intestines and absorbs nutrients as they are digested in the gut is the portal blood, which collects in the portal vein and then passes through the liver. This results in a high pressure developing in the portal vein system, causing enlargement of the blood vessels draining the intestines. These enlarged vessels, known as varices, are fragile. The vessels in the esophagus (food pipe) can become eroded and massive, and bleeding can occur. The high pressure in the veins in the abdomen also causes plasma to leak from the blood vessels into the abdominal cavity where it accumulates. The fluid is known as ascites. Both variceal bleeding and ascites are a result of a mechanical problem causing high pressure in the portal vein. If liver function is not too impaired, the pressure in the portal vein can be relieved with an operation. In this operation portal blood is diverted...
through a shunt from the portal vein directly to the vena cava without having to pass through the liver first. This decreases the pressure in the portal system. Ascites and varices are no longer a problem as long as the shunt stays open. However, in most patients with cirrhosis, liver function is too poor and diverting the portal blood from the liver deprives it of its nutrients leaning to further deterioration in liver function.

In children, the most common indication for liver transplant is biliary atresia (the congenital absence of bile ducts). Other types of liver cirrhosis can occur in children such as: inborn errors in metabolism, medication toxicity, or viral illnesses. For these diseases a liver transplant may be indicated.

In adult patients the most common indication for liver transplant is chronic active hepatitis with cirrhosis due to Hepatitis C. Other indications are cryptogenic cirrhosis (where the cause of the cirrhosis is unclear), primary biliary cirrhosis, fatty liver disease, sclerosing cholangitis, acute hepatitis with liver failure (viral, drug or alcohol induced), and chronic Hepatitis B.

Another common indication for liver transplant is cancer of the liver. Many liver cancers are managed by partial resection of the liver. When liver tumors are located in more than one lobe of the liver, are thought to be aggressive, or are located in an area that cannot be resected, a liver transplant may be recommended. Treatment of the tumors in the form of chemoembolization (local application of chemotherapy), or radio frequency ablation (RFA) is done while the patient is being evaluated for a transplant and during the waiting time for the organ.

Where Do Livers for Transplantation Come From?

Whole organ transplants come from a patient who is brain dead. Once the brain is no longer alive, the body can be maintained on life support machines. But, even with life support machines, the blood pressure will decline and the heart will stop. After brain death has been determined, the family is approached about the option of organ donation. Multiple organs may be recovered from one donor, making it possible for many lives to be saved.

Donation after cardiac death (DCD) is another option for organ procurement. In this circumstance, the potential donor is actually removed from life support. Once natural death has occurred, the donor is brought to the operating room for organ recovery. There are time restraints to this type of donation to ensure quality of organs. Donation after cardiac death is an effective way to meet the increasing need for organ donation.

Many transplant centers are also using Increase-Risk donor organs; these are organs from donors who have a history of behaviors that make them high risk for infections such as HIV and Hepatitis B. Before these organs are used they are tested, however there is still a small risk (less than 1%) to the recipient of contracting HIV, hepatitis or other viruses if the donor is infected but the infection is not detectable at the time of donation. Should your surgeon offer you an increase-risk organ, you will be informed that it is from an increase-risk donor, and you will be given information about the organ at that time. When these organs are offered, it is because your surgeon believes that the organ will function well and that you would benefit from accepting the organ.

Another type of donor is a direct donation donor. This is when a dying person’s family states that they want the liver to be donation directly to a specific person. In this case, the family of the potential donor notifies the doctor in the hospital where the person is dying that they are interested in a direct donation. The hospital notifies the organ transplant network.
In some cases it may be an option to utilize a split liver. Your surgeon would determine if this was a suitable option for you.

A thorough history of all potential donors is done to make sure the liver is healthy. A liver will not be accepted from an infected donor. The liver tests are evaluated and must be within normal range. The liver is inspected visually as well prior to the transplant operation. If the liver looks healthy and no abnormalities are found, it is prepared for implantation. The liver is kept in a preservation fluid and put on ice. By using this preservation technique, the liver can be maintained for up to 24 hours.

Living donation may be an option for some patients who are in need of a liver transplant. This surgery involves using a segment of the liver from a living person. Not all transplant candidates are eligible for this type of surgery. Persons interested in being a living donor to you, may call our transplant center once you are listed. Please discuss this option with the transplant team.

How is a Liver Found for Me?

After your evaluation is complete and if the team determines that liver transplant would benefit you, your name will be placed in a database with other patients waiting for liver transplants. When a donor becomes available, this information is entered into the database and the patient is chosen based on several different criteria. These include: severity of illness, blood type, height, weight, and time on the list. This is the most equitable system available to all patients. The most important matching criteria for liver transplant is the blood type. Height and weight of the donor and recipient must be similar as well. Infrequently a liver from a different blood group may be used in an urgent situation.

When a liver is found for you, we will call and ask that you come to the hospital as soon as possible. It is extremely important that we are able to reach you immediately. Please provide us with a list of phone numbers and names so that we will be able to get in touch with you when the time arrives. If you are activated on the transplant waiting list this means that you are ready and willing to accept a new liver. If you change your mind, become ill, or temporarily are unable to undergo liver transplant for any reason, you should notify the transplant office so that your name can be temporarily inactivated on the waitlist. A potential problem is that we may not be able to find a donor liver in time for you. There are some patients who die while waiting for a liver transplant simply because a suitable donor does not become available. In particular, this can sometimes be a problem in children. Finding a small enough liver for a child can be challenging. Sometimes we may elect to use part of an adult liver to transplant into a child. This is referred to as a segmental or split liver transplant. There are also times where the transplant team may recommend accepting a liver from an infected donor. When this option is offered it is because the team believes the risks of accepting an organ from an infected donor are lower than the risk of waiting for another donor organ.

Organ Donor Risk Factors

Donor organs undergo tissue typing and testing for transmissible diseases like HIV, Hepatitis and other viruses. The team considers the patient's social history, the age of the donor and the condition of the donor. Although all of these factors are taken into consideration there is always a small chance that the recipient will contract a transmissible disease from the donation if the donor is infected but the infection is not detectable at the time of transplant (less than 1% chance).

Multiple Waitlist Option

Recipients may be listed on more than one waitlist. In other words you may choose to be evaluated and listed at more than one transplant center.

UVA Physician Coverage Plan

The University of Virginia, as an academic medical center, meets all the national regulatory body requirements to provide appropriate medical staff coverage for all patient care needs. This coverage is
provided 365, 24/7 by dedicated transplant surgeons and physicians along with support from house staff, fellows, nurse practitioners, and nurse coordinators. All physicians are routinely available to cover their respective service on a rotational basis. This coverage is for all aspects of the transplant program activity including organ procurement and transplant surgery as well as patient management.

Should circumstances related to physician coverage change, patients will be notified via mail and/or any additional communication necessary.

Liver Transplant Evaluation

On the day of your initial transplant clinic appointment, you will meet with several members of the transplant team. Please bring all of your medications (including dosage) and any requested test results with you for the initial visit. During the initial visit, discussion regarding the transplant evaluation process, surgical procedure, complications, medications, and follow up care after transplant will occur. You will be required to attend an educational class prior to the appointment with your physician. This will be most informative and we require that you and your support persons attend this learning opportunity. In order to complete the evaluation process most efficiently we may ask that you stay in Charlottesville overnight or longer to attend the needed evaluation appointments and complete required testing.

During the evaluation you will meet with each individual on the multidisciplinary liver transplant team. These people are:

**Transplant Surgeon** – the Transplant Surgeon’s role is to assess your appropriateness for transplant based on the information obtained during your evaluation. The surgeon also discusses with you the significance of undertaking liver transplant, details about the procedure and the risks/possible complications associated with surgery.

**Transplant Hepatologist** – the Transplant Hepatologist meets with you to discuss many of the disease processes that have contributed to your liver failure. They review your medical history to determine medical tests that should be performed in addition to the standard evaluation tests required during the evaluation. They will discuss with you alternative treatments to transplant.

**Social Worker** – the Transplant Social Workers role is to evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan, both before and after transplantation. Patient and family/guardian commitment is necessary and the social worker will help you identify your support group.

**Financial Coordinator** – the Financial Coordinator will discuss with you the costs associated with transplant and with medications required post transplant. They will help you understand your insurance coverage and what costs may not be covered by insurance. They will ensure there is a solid financial plan in place prior to placing you on the transplant list.

**Nutritionist** – the Transplant Nutritionist will perform a nutritional assessment and provide nutrition education when necessary.

**Pharmacist** – the Transplant Pharmacist will review your current medications and identify concerns or possible complications with medications required post transplant.
The following is a list of examinations that may be completed prior to consideration for liver transplantation:

1. Complete history and physical
2. Blood work, urine tests
3. Chest X-Ray (Pulmonary Function Test if necessary)
4. Heart tests (age and history will determine the type of tests that will be ordered)
5. Social work evaluation
6. MRI of the liver, abdominal organs and vessels.
7. Colonoscopy
8. Endoscopy
9. Mammogram and Pap smear for women
10. Dental Examination
11. Testing for Tuberculosis (test for exposure to TB)
12. Evaluation by a Neuropsychologist
13. Nutrition Assessment
14. Pharmacy Assessment

Due to the known damage caused by alcohol and drugs, the expectation for all patients being considered for liver transplantation, is that they will not use these substances. Frequently, we will do blood and urine tests to determine if there is a presence of either alcohol or non-prescribed drugs. We do not transplant patients who are currently abusing alcohol or non-prescribed medications. Should there be evidence of alcohol or drug abuse, we may require documentation of six months of negative drug screens and substance abuse counseling. Receiving a new liver is a generous gift and will only be offered to those persons whom we believe will take very good care of themselves. We will not offer organs to persons who may place themselves at risk for a poor outcome. If required by your insurance or medical condition, you may be required to stop use of all cigarette and other tobacco products. It is highly recommended for all patients to stop all tobacco use.

You will meet with one of our Transplant Hepatologists (liver doctors) on the day of your appointment. This is the time for you to ask specific questions in relation to your medical problem. In some cases your current liver disease may recur in your new transplanted liver. The physician can discuss this aspect with you in more detail.

After your initial evaluation has taken place, we will schedule your required testing. This may necessitate more than one trip back to the University of Virginia, but we will make every effort to coordinate the appointments to minimize the number of visits. Once all testing is completed, your evaluation will be presented to the liver team to determine if you are an appropriate candidate for transplant. Once that decision has been made, you will be notified of the results in writing. It is important to remember that you can refuse transplant at any time.

What is Involved in a Liver Transplant Operation?

You will be notified by the transplant nurse coordinator that a liver has become available for you. We should have a number where you can be reached at all times. Be aware that when we call you, your caller identification may not let you know that we are calling from the University of Virginia. We may also call you from various cell phones, so please answer all of your phone calls so that we are always able to communicate with you. When you are contacted about coming in to the hospital for your surgery, you will be given detailed instructions about where you need to go for your surgery. Also at this time, the Blood Bank, the Inpatient Care Unit and the Operating Room are notified that a transplant is planned.

You will be admitted to the hospital before your surgery. You will have final pre-operative lab work, EKG and a chest X-ray completed. You will sign a surgical consent form after a discussion with the surgeon about the surgical risks. If all pre-operative test results are acceptable, you will be taken to the operating room.
During a liver transplant, anesthesiologists have the patient sleeping and place special IV lines to measure how the patient’s heart is functioning as well as different types of blood pressures. An incision is made under the patient’s ribs. The patient’s entire liver is removed as well as gallbladder (if not previously removed). The new liver, without donor gallbladder, is then connected and blood is allowed to flow through the new liver. The average liver transplant recipient requires 50-10 units of blood during the surgery. Following surgery, patients are transported to the ICU to make sure that the liver is working and bleeding from the surgery has stopped. The entire operation usually takes 4-6 hours, however can be longer or shorter.

The surgical risks related to liver transplant surgery are:

- Death, 1 in 100
- Bleeding requiring transfusions, 50 in 100
- Infection, 1 in 20
- Wound Infection, 1 in 20
- Pneumonia, 1 in 20
- Pain or discomfort usually lasting 1-8 weeks
- Blood clots (that are symptomatic) in legs, 1 in 33
- Damage to abdominal organs, including the spleen and intestines, 1 in 100
- Incisional hernia, 1 in 20
- Bowel obstruction (over lifetime), 1 in 20
- Primary Non-Function, 2 in 100
- Bile leak, 1 in 10
- Biliary Strictures, 1 in 10
- Hepatic Artery Thrombosis, 3 in 100
- Hepatic Artery Stenosis, 3 in 100
- Portal Vein Thrombosis, 2 in 100
- Re-operation for bleeding, 5 in 100
- Acute Re-transplant, 3 in 100
- Neuropraxia (arm pain/nerve compression due positioning in the OR), 1 in 5
- Arrhythmia, 1 in 100
- Cardiovascular Collapse, 1 in 100
- Multi-organ failure, 1 in 100
- Major anesthetic complication such as heart attack and/or stroke, 2 in 100
- Other risks (for example pleural effusion, pneumonia, allergic reactions to medications)

There is also the potential for psycho-social risks, such as:

- Depression
- Post Traumatic Stress Disorder (PTSD)
- Generalized anxiety
- Anxiety regarding dependence on others while recovering from the donation
- Possible feelings of guilt
What Can I Expect After the Operation?

After surgery, the liver transplant recipients are taken directly to the Surgical Intensive Care Unit. The typical length of stay in the Intensive Care Unit is 2–5 days. During this time, you will be monitored closely and will also have many tubes. In the first 2 postoperative days, many of the tubes will be removed. When your condition stabilizes, you will be transferred to the transplant floor.

Once on the floor, visiting hours are less restrictive. The typical hospital stay is 7–10 days after liver transplant. Patients who are more ill going into surgery can expect to have a longer recovery period and hospital stay. Maintaining activity and adequate nutrition while waiting for transplant is important for your recovery. While recovering, you will spend time learning how to care for yourself after transplant. You will receive a Transplant Notebook with all instructions for the post transplant phase of care.

Re-operations following liver transplants are common. Most are short operations. The most common indication for re-operation is bleeding and this usually occurs in the first 2–3 days after the transplant. Bile leaks and infections of the abdomen can also occur, usually about one week after the transplant. Some livers may fail to function properly and need to be replaced with another new liver. When repeat transplant is necessary, the operation is generally much shorter in length.

Two types of problems may develop in the early post-operative period. The first is ischemic injury, which can occur during the recovery and preservation of the donor liver. Signs of this usually develop in the first 7 days post-transplant. A more frequent occurrence is rejection. Rejection can occur at any time after transplant. Approximately 10–15% of patients who undergo organ transplant will develop some degree of rejection. Rejection can be diagnosed by review of lab results or by liver biopsy. Once rejection occurs, it can usually be reversed with adjustments in your medication. If the rejection is not reversed with steroids, other medications can be used. It is important to know that rejection happens frequently and that in most cases it can be reversed quickly.

What Can I Expect After I Go Home?

Following a liver transplant, you will need to be monitored closely. Enough immunosuppression is needed to keep the body from rejecting the liver, but too much immunosuppression can lead to serious infections. You are most at risk for rejection and infection in the first 90 days after transplant. Because you will require higher doses of immunosuppressive medications in the first 3 months, you are also at a higher risk for infection during that period of time. The amount of medication you take will be reduced gradually during the first year post-transplant. You will need to have lab work done twice weekly for the first 2 to 3 months. After 3 months, your lab schedule will be reduced so that at 1 year post-transplant you will need labs done monthly. Your labs can be done at a hospital or lab close to your home.

We will have you return to Transplant Clinic as needed after you are discharged from the hospital. We recommend that you stay locally for 1–2 weeks after discharge from the hospital so that your surgeon may see you in clinic often. Then we will ask that you return every 3 months for the first year. In some cases, you may be required to come more frequently. After the first year, your follow-up appointments need to be at least annually. We will also ask that you see your referring doctor within 2 weeks of your discharge from the hospital. He or she will remain very important in your follow-up care.
Transplant Medications

It will be necessary for you to take the immunosuppressive medicines for the rest of your life in order to maintain your transplanted liver. If you do not take your medications as prescribed you are at risk for REJECTION of your liver. The following is a list of anti-rejection drugs that are commonly used. The doctor will prescribe those medications which he feels will work best for you.

1. Cyclosporine
2. Tacrolimus
3. Mycophenolate
4. Imuran
5. Deltasone or Prednisone
6. Serolimus

These medications have side effects. Some of those include tremors, increased weight, mood changes, increased blood pressure, vision changes, increased risk of infection, increased blood sugar, and increased risk of cancer. You will not develop all of these side effects, however you will develop some. You are encouraged to report these to your transplant nurse.

You will need to take other medications in addition to anti-rejection medicines. Most patients are discharged from the hospital after transplant on an average of 13 different medicines. These medicines will be reduced over time. Other medications that will be prescribed for you are an anti-ulcer drug, an antibiotic, and an anti-fungal drug.

Finances

A financial counselor will meet with you to discuss how your transplant operation and post-transplant medications will be managed. If you do not have insurance or if your insurance will not pay for the transplant, other funding options may be explored. Prior to activation on the list or scheduling of a living donor surgery, patients must have a reasonable plan in place to obtain medications after transplant. All questions regarding the finances involved in liver transplantation should be directed to the Transplant Financial Counselor at the University of Virginia Medical Center. For individuals that qualify for Medicare 80% of immunosuppressive drugs are covered under Medicare Part B when transplants are performed in a Medicare approved center. If a recipient is transplanted in a center not approved by Medicare this may affect his/her ability to have their immunosuppressive drugs paid for. UVA is a Medicare approved center for Liver Transplantation. Also, after transplantation it is possible that health problems related to transplant surgery will not be covered by insurance. When a recipient loses their current insurance after transplant they may not be able to get health, disability or life insurance.

United Network for Organ Sharing

The United Network for Organ Sharing (UNOS) provides a toll-free services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll free number is 1.888.894.6361.
UVA Patient Rights and Responsibilities

What You Can Expect

UVA Health System provides quality health care while respecting the rights of our patients and their families. During your visit you can expect:

- Information you can understand about your illness and planned treatments.
- To take part in making care decisions including why you need a treatment and what will happen if you do not have it.
- To know the name of the doctors and all staff taking care of you.
- To have your family or doctor to be told when you are admitted to the hospital, if you wish.
- To receive care in a safe environment and to be free from any form of abuse or harassment.
- To have personal privacy and to have your health care information treated confidentially.
- To access information in your medical record.
- The chance to write down your wishes for future medical care (using an Advance Directives form). We will follow your expressed wishes.
- To have your pain assessed and managed.
- To be free from restraints unless needed to keep you or others safe.
- The option to agree to or refuse any research study or experiment.
- The chance to review your bills and have any questions answered.
- A timely reply to any concerns or complaints.

To provide you the best possible care, we ask that you and your family:

- Tell us correct and complete information about your health, wishes for your care, changes in your condition, and your concerns.
- Ask questions when anything is unclear.
- Follow your care plan or accept the risks if you make another choice.
- Show respect for all patients, visitors, staff as well as the hospital rules.
- Pay your bills promptly. If you are unable to pay for your care you may receive help. Ask us for information about our financial assistance program.

Please feel free to ask any questions or talk about any concerns with your health care team.

If you are not satisfied, please call our Patient Representative Department at 434.924.8315.

You have the right to contact an agency listed below:

Office of Licensure and Certification Virginia Department of Health Office of Quality Monitoring Phone: 800.955.1819 or 804.367.2106 Fax: 804.527.4503

The Joint Commission Office of Quality Monitoring Phone: 800.994.6610 | Fax: 630.792.5636
UVA Transplant Patient Rights & Responsibilities

Rights

Quality Care:
- Access to quality medical and psychosocial care regardless of ethnic background, national origin, religion, or age
- Access to transplant physicians, nurses, social workers, and other specialists as needed.
- To expect coordination of effort between my transplant team and primary care provider

Respect and Personal Dignity:
- To be treated with respect, dignity, courtesy, compassion, and cultural sensitivity
- To have privacy and confidential handling of all medical records and communication

A Voice in Decision-Making:
- To be consulted for my view of quality of life
- To participate as a full partner with my health-care team and to have my opinions heard and valued in the development of a plan of care
- To have treatment options, possible complications and self-care requirements explained in an understandable manner, with sufficient time to ask questions and have them answered
- To appeal decisions made by a physicians, hospital staff, managed care plan, or other health-care provider
- To obtain a second opinion and/or accept or refuse medical treatment
- To change physicians

Information:
- To have family members or significant others, I designate, be kept informed of my medical condition during hospitalizations
- To know the identity and profession of any individual providing a service to me
- To timely communication regarding lab work results, medical tests, and advice of my medical team, and to have access to all medical records
- To receive a complete explanation of the total bill for services rendered.

Emotional Support:
- To have feelings respected and, when appropriate, addressed by my health-care team
- To have a comprehensive psychosocial plan developed and updated by an appropriately trained mental health provider
- To have correspondence forwarded to the family of my donor, provided the donor family has expressed a willingness to receive communication from the recipient.

Responsibilities

Maintain Long-Term Health:
- To schedule appointments and tests at appropriate intervals with the transplant team
- To be prompt in attending appointments and when canceling, to give notice as early as possible of the need to reschedule
- To adhere to transplant medical instructions and to inform the transplant team when unable to do so
- To learn the names, dosages, and reasons for taking all prescribed medications and to report all adverse reactions to the transplant team
- To learn and identify signs and symptoms of rejection and infection and know when to report such signs and symptoms
- To maintain primary health care needs (dental, urology, dermatology, etc.) and to know when to report any abnormalities
- To ask questions and obtain clarification to ensure understanding of all communication from the transplant team

Provide Information:
- To inform the transplant team if my address, insurance or phone number change
- To inform the transplant team about any changes in my health condition including: desire to take new medication (including herbal, vitamins, alternative, or over-the-counter); any change in my daily activity (such as stopping or starting exercise regimen); or any other situation that may have an impact on my emotional or physical well-being
- To provide information from other treating physicians to the transplant center by giving written permission for records to be sent to the transplant office
- To provide the transplant team with the names and contact information of designated family or significant others who should receive updates on my medical and psychosocial condition
- To request results of my medical and lab tests if these are not provided in a timely fashion

Display Mutual Respect:
- To treat all health care professionals with respect and courtesy
- To cooperate and follow UVA Health System rules regarding patient conduct

Meet Financial Obligations:
- To understand that UVA will NOT pay for my medical care or medications needed after transplant
- To give UVA any information needed for insurance to pay for my transplant and to pay for my medical care and medications after transplant
- To apply, if needed, for financial help to pay for the cost of transplant and for medical care after transplant
- To submit any financial verification information required by assistance agencies (State or private)
- To understand if insurance and/or Medicare does not pay for the cost of my child’s transplant or for the drugs after transplant that I am responsible for paying for all of these costs
- To understand that changing health insurance may mean that a new insurance will not cover pre-existing conditions such as transplant medications, etc.
- To understand the limits of Medicare and/or other insurance (including deductibles and co-payments)
- To notify the transplant office of any insurance changes before or after transplant
- To accept responsibility for the cost of transplant surgery if insurance denies coverage due to my failure to notify UVA of insurance changes

Conclusion
Transplantation is one option for patients with liver disease. The Transplant Team at the University of Virginia will work closely with you and your referring doctor throughout the transplant process. Please contact us at 1.800.543.8814 if you are interested in more information.