

**Release Date** November 22, 2002  
**Revised** December 2006  
**Revised** March 2012

**Getting A New Liver**  
***Facts About Liver Transplants***



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## Getting a New Liver

### Facts About Liver Transplants

A liver transplant is a big step to take, but it can save your life. You will be able to take better care of your new transplant if you understand your illness and your treatment. You will need to reach certain goals in your recovery. It is very important that you understand what you must do to make your transplant work. You must take your medicines as told, keep your appointments, and stay in close touch with your doctors and nurses.

### Some Facts About the Liver

The liver does several things:

- It helps digest your food.
- It clears wastes from your blood.
- It makes proteins that help your blood to clot.
- It stores the sugars (glycogen) that are used for energy.
- It makes proteins that the body must have.
- It helps use and store vitamins.
- It makes chemicals that protect the body.
- It breaks down many toxins and drugs.

The liver also controls the way your body uses food and the way it works with your immune system.

When the liver is badly damaged, it cannot grow enough new liver tissue to heal itself. Severe liver damage with scarring is called cirrhosis. Cirrhosis can lead to several problems:

**Liver failure.** This happens when the liver cannot do what it is supposed to do.

**Portal hypertension.** This happens when scarring in the liver stops blood from flowing through it. This causes pressure to build up in the vein that feeds the liver (portal vein).

**Primary liver cancer (hepatocellular carcinoma).** Liver cancer can develop within a scarred liver.

The liver can take a lot of damage, but when most of it is damaged, it will start to fail. Once a person has signs of liver failure, it means there is not much of the liver left for the body to use during sickness and times of need. Signs of liver failure may include:

- Yellow skin and eyes (jaundice)
- Forgetfulness, confusion, or coma (encephalopathy)
- Feeling very tired
- Muscle loss (muscle wasting)
- Itching
- Poor blood clotting
- Swelling in the ankles or abdomen
- Bleeding from the esophagus, stomach or rectum

There is no treatment that can help the liver do everything it needs to do. So when a person reaches a certain stage of liver disease, a liver transplant may be the only way to prolong their life.

When you look at the inside of a liver, it can be hard to understand what you are seeing. Look at the drawing. It will help you understand some of the medical terms used by your liver transplant team. Ask your transplant team to explain what you do not understand.

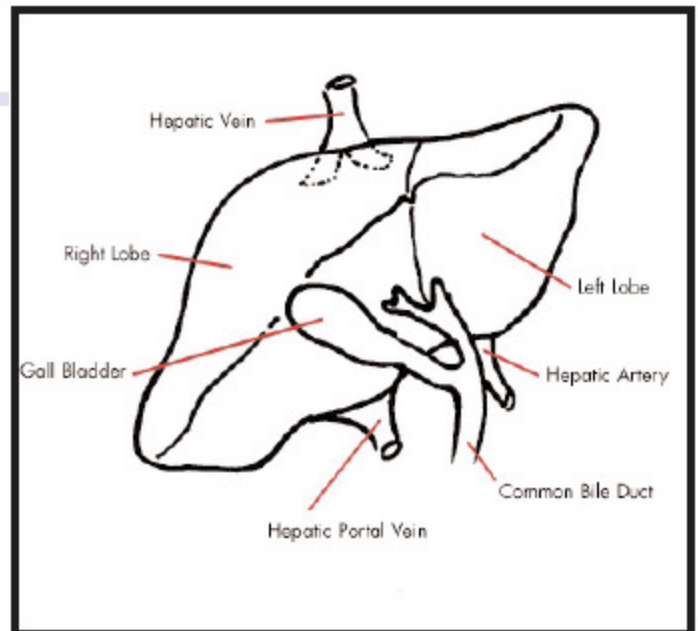


Figure 1

For more information about cirrhosis, visit:

[http://www.myast.org/sites/default/files/pdfs/what\\_makes\\_transplant\\_successful.pdf](http://www.myast.org/sites/default/files/pdfs/what_makes_transplant_successful.pdf).

## What Will Happen Before My Transplant?

### **First, your doctor will refer you to a transplant specialist.**

Your primary care provider or a gastroenterologist will refer you for liver transplantation when and if your liver disease begins to get worse and you show signs of liver failure or portal hypertension. This is a specialized operation, so you will need to go to a major medical center for a thorough assessment.

### **Your doctors will evaluate your health status.**

We call this evaluation the pretransplant evaluation. It is how your doctors decide if a liver transplant is right for you. During this time, you and your family will learn what you need to know about having a liver transplant. You will have many tests done. This process can take a few days or a few weeks. It depends on how many tests you need to have.

Some things that will happen during this evaluation:

- You will meet with a Hepatologist (a medical liver specialist), a transplant surgeon, and other doctors.
- The transplant nurse coordinator will schedule you for lab tests (blood work) and

- various scans and x-rays. Most patients do not need a liver biopsy.
- One of the lab tests will look for any infections you have had in the past.
  - You will be tested for tuberculosis (TB). The results of this test may show that you need special treatment or vaccines before your transplant.
  - You will receive the usual vaccines, like a flu shot.

#### Other tests to expect:

##### **X-rays and other imaging tests**

You will have regular x-rays taken, such as a chest x-ray. You will also have more specialized imaging tests, like a CT or MRI scan of your abdomen. These tests will give your doctors a detailed view of your liver, its blood supply, and other organs. The tests are also used to look for tumors in the liver. All these images will help the surgeon in outlining key pieces of information required for a liver transplant.

##### **Endoscopy and colonoscopy**

You may have an endoscopy (EGD) test done. During this test, the doctor will run a flexible tube with a tiny television camera on the end of it down your throat and into your stomach. With a colonoscopy, the doctor will run a tube through your rectum and into your large intestine. Both of these tests look for enlarged veins called varices. They are a sign of liver disease or problems with the lower intestine.

If you have large varices, the doctor may tie them off (ligate them) with rubber bands. This prevents them from bleeding. You will be given medicine to make you sleepy during your colonoscopy and endoscopy.

##### **Heart and stress tests**

Since a liver transplant is major surgery, it is important to know that your heart and lungs are healthy. Your doctors will do a detailed evaluation of your heart. They may do an electrocardiogram (EKG), echocardiogram, and a stress test. If you have been a smoker, your doctors may do some lung tests and a blood gas test. If you smoke, you need to quit before you have the transplant.

#### **Your emotional health will be evaluated.**

Your emotional health is as important to your transplant team as your physical health. For this reason, you will also be seen by a team of health professionals like a social worker, psychologist, addiction specialist, and chaplain. Your doctors will want to know how well you handle stress and can follow medical recommendations reliably. They also want to know that you have friends or family who can give you practical and emotional support. They will schedule a family meeting so everyone can meet the transplant team. At this meeting, members of the team will explain what a liver transplant involves, the responsibilities of a caregiver in being able to provide care and assistance while you recover from the operation, and answer any questions. These team members can connect you to hospital services and give you information on support groups.

### **Your nutritional needs will be evaluated.**

A dietician will talk to you about your nutritional needs, provide educational information and design an eating plan for you to follow. They will also support you in eating well to help your body heal after your transplant.

### **Your finances and insurance will be evaluated.**

A financial specialist will review your case. This team member can help you with financial concerns and work with your insurance company to obtain coverage for your transplant. In addition, they will evaluate your prescription drug benefits and coverage for office visits to make you aware of what resources you will need for a successful transplant.

### **Your results will be reviewed by the Liver Committee.**

Once your evaluation is complete, a Liver Transplant Selection Committee will review your test results and decide if a transplant is right for you. This committee is made up of the hepatologists, surgeons, transplant nurse coordinators, financial counselor, and the psychosocial team.

If the committee decides a transplant is right for you, it will recommend you be placed on the waiting list for a liver transplant. The process of evaluation and listing may take a few hours or several weeks depending on what tests you require and whether your insurance company requires additional information prior to approval for the operation. There are times when a patient is too healthy for a transplant. If this happens, the patient is usually monitored over time for signs of liver failure. If their liver gets worse, they will be re-evaluated. Sometimes, a patient is too ill to survive the transplant. In this case, the committee will recommend against liver transplant as the risks are likely to outweigh the benefits.

## **The Waiting List**

When placed on the waiting list, you will be given a score based on the results of your blood work. This is called the MELD score, which means Model of End-stage Liver Disease. (For children, it is the PELD score, which means Pediatric End-stage Liver Disease.)

A computer calculates this score. The score is calculated using results from two liver blood tests and one kidney blood test. A higher score means you are sicker, and you will be put higher on the list to get a liver. This system is a fair one since it gives livers to the sickest people on the waiting list.

The score, and when you get a liver, has nothing to do with who you are, who you know, how long you have waited on the list, or the hospital where you will have your operation. The rules on how organs are given out may change. Talk with your doctor. You can also log on to [www.unos.org](http://www.unos.org) to learn more.

While you are waiting for your liver, it is important to see your doctor on a regular basis and stay in as good health as possible. You will need to have blood work done regularly to update

your MELD or PELD score. Be sure to notify your transplant center of any change in your medical condition.

When a donor is found for you, the transplant team must be able to contact you quickly. Your coordinators will need a current list of names and phone numbers of people who will know where to reach you.

To help with the stress of waiting, we suggest you and your family go to support group meetings. Members of the group are patients who have either had their transplants, or are waiting for transplants. Family members also go to the meetings.

## The Transplant

There are two types of liver transplant: Deceased donor and living donor.

**Deceased donor.** Usually, a liver transplant is done with a liver from a brain-dead person called a deceased donor. The liver is removed from the body. It is kept on ice until it is ready for transplant. The donor is matched to you based on medical condition, size, and blood group.

**Living donor.** These transplants are less common. Doctors remove a piece of liver from someone who is living. In adults, usually the right half of a liver is removed from the adult donor and used for the transplant. In a child, a smaller part of the adult liver (part of the left side) is removed and used for the transplant.

Would you like more information about living donor transplants? Ask us. We can give you a brochure.

### When a Liver is Found for You

When a liver has been found for you, the transplant center will call you right away so you can get to the hospital. Some things you need to know:

- Do not eat or drink anything after you are called.
- Sometimes the liver may not be good enough to transplant, so your operation will be canceled. This does not happen very often, however.
- Once you are in the operating room and put to sleep, intravenous (IV) and other types of lines will be put in your body so you receive medicines and fluids. Doctors will also monitor your heart and blood pressure.
- Surgeons will make a cut that goes along both sides of your ribs. There are four blood vessels that connect the liver to the rest of the body. When your liver is removed, these vessels are cut and clamped shut. The surgeon will connect the new liver to these vessels. The bile duct on the donor liver is then connected to your bile duct. The bile duct is a tube that carries bile from the liver to the gallbladder and then to the small intestine. The bile duct may drain into your body, or it may drain through a tube to the outside of your body.

- In some cases, a small piece of the intestine is connected to the new donor bile duct. This connection is called a Roux-en-Y.
- It will take about two hours to prepare you for the operation. The operation itself will take six to eight hours.

### **After Your Operation**

You will wake up from your operation in an area such as an intensive care unit (ICU) where you can be closely monitored. You may have a tube in your throat to help you breathe. It will be removed when you are fully awake and strong enough to breathe on your own. You may have other tubes as well. These tubes will be removed as you recover.

### **When You Get Out of the ICU**

When the doctors feel you are ready, you will be transferred from the intensive care setting to another part of the hospital where you will be cared for by nurses who specialize in transplant patients. They will help you start walking and eating. You may also get some physical therapy, because being active will help you recover. You will have blood tests every day. You will have x-rays if and when you need them. A liver biopsy may be done if your doctors think your body is rejecting the new liver. Rejection is common and does not mean you are losing your liver. You may not even feel your body begin to reject your liver. If it does, you will receive medicines to treat it.

If you have bleeding, an infection, poor liver function (called primary non-function), or clots in the blood vessels in the liver, you may need to go back to the ICU or the operating room.

### **When You Leave the Hospital**

You will be in the hospital for about eight to 14 days. Before you go home, you will learn the signs of infection and rejection, how to change your dressings, how to take your medicines, and what you need to know about taking care of yourself.

Infection can be a real danger because you are taking drugs that block your body's immune system. The greatest time of risk for getting infections, such as colds and the flu, is in the first three months after your transplant. For this reason, follow these rules when you get home:

#### **Rules for going home**

1. Stay away from people who are sick.
2. Tell your doctors if you are exposed to any disease.
3. Wash your hands often.
4. Always tell your doctors if you get a cold sore, rash, or small water blisters on your body.
5. Tell your doctors about any spots that show up in the back of your throat, or a white coating on your tongue. This coating is known as thrush. It is a fungal or yeast infection. Women can also get a vaginal yeast infection.
6. Stay away from crowds and rooms with poor circulation. Make sure vents in your home are cleaned often by professionals.

7. Learn the signs of infection.
8. Stay away from houseplants or garden soil during the high-risk period.
9. Do not swim in any lakes or community pools during the high-risk period.
10. Make sure your meat is cooked well, and remember to wash your hands after handling raw meat.
11. Be sure to follow your nutrition plan. What you eat and how well you eat after your transplant will affect how well you recover.

For more on what to eat after your transplant, visit:

[http://www.myast.org/sites/default/files/pdfs/what\\_makes\\_transplant\\_successful.pdf](http://www.myast.org/sites/default/files/pdfs/what_makes_transplant_successful.pdf).

For more information about health guidelines after transplant, visit:

[http://www.myast.org/sites/default/files/pdfs/what\\_makes\\_transplant\\_successful.pdf](http://www.myast.org/sites/default/files/pdfs/what_makes_transplant_successful.pdf).

#### **Rules for taking your medicines**

1. Never doctor yourself. This means you should take all of your medicines just as your doctor says. Do not skip doses. Do not change the dose or the time of your dose. Do not take any other medicines (including vitamins, herbs, or over-the-counter medicines) without first checking with your transplant doctor or coordinator. Notify your coordinator immediately if another doctor prescribes a medicine that is new.
2. Store all drugs at room temperature, unless it says something else on the medicine bottle or package.
3. Make taking your medicine part of your daily routine, just like eating and sleeping.
4. Call the pharmacist or the transplant coordinator before you start any new medicine.
5. If you are vomiting or have diarrhea, your body will not absorb your medicines as well. Call your doctor, transplant doctor, or transplant coordinator to let them know you are sick.

## **Complications**

You will need more tests after leaving the hospital. These tests will help your doctors keep track of how you and your new liver are doing. You will have blood tests, ultrasounds, or x-rays. Your doctors will monitor you closely to help prevent and treat these conditions:

**Acute rejection.** Most rejection happens while you are still in the hospital, but it can happen at any time. Rejection can be treated with drugs. You may need a liver biopsy to confirm the presence of rejection and/or to monitor your response to treatment.

**Your liver disease comes back.** The diseases that damaged your liver in the first place may come back in the new liver. They can damage your liver a little bit or a lot. The disease can often be treated easily, but sometimes a second transplant is needed.

**Cancer.** People who have organ transplants are at a higher risk for some cancers, especially skin cancer. These cancers may spread faster than they do in people without transplants. Because of this, you will need to get screened for cancer.



**Other medical complications.** Transplant patients can get infections, high blood pressure, diabetes, high cholesterol, thinning of the bones, and become obese.

## **Making Sure Your Liver Transplant is a Success**

A liver transplant gives you the chance to have good health and a normal lifestyle. However, you must respect this gift of life and take good care of your new liver. It is important to live a healthy lifestyle, get good medical care, and keep in close contact with your doctors and nurses. This helps reduce the risk of problems later on (see complications above). You will need to follow up with your medical team for the rest of your life. However, your visits will be less often after a couple of years. So make sure you stay in touch with your transplant team and follow their advice. Ask for counseling when you have any problems.

## **Pediatric Liver Transplant**

A transplant is one of the best treatments for fatal liver disease in children. New drugs and new surgery techniques have improved the one-year patient survival rate. There are two main concerns about liver transplant for children. They are the cause of the liver failure in the first place, and if there are enough livers for children who need transplants.

## **What Causes Liver Disease in Children?**

There are several reasons a child might need a liver transplant:

**Biliary atresia.** This is a disease that destroys a child's bile ducts within the first few months of life. It is the most common reason for liver transplants in children.

**Problems digesting and using food.** Children can be born with diseases called "inborn errors of metabolism." They include:

- Alpha-1-antitrypsin deficiency, tyrosinemia, and Wilson's disease.
- Lipid storage diseases (Gaucher's disease, Niemann-Pick disease, Wolman's disease, cholesterol ester storage disease)
- Carbohydrate storage diseases (galactosemia and glycogen storage diseases)

**Liver cancers.** Some liver cancers (hepatoblastoma) are found only in children.

**Acute liver failure.** This is a sudden liver failure that can cause death. Acute liver failure can come from many causes like toxins, too much medication, drugs or viruses. In this kind of liver failure, a liver transplant can cure the problem if it is done early.

## **What are the Donor Organ Options for Children?**

**Reduced-size liver graft.** A piece of a liver is taken from a brain-dead person (deceased donor).

**Split-liver transplant.** A liver from a deceased donor is cut in two. A small piece is used for transplant in a child and a larger piece is used for transplant in an adult.

**Living-donor transplant.** A piece of a liver comes from an adult living donor and is used as a transplant for a child. Over the past 10 years, nearly 1,000 of these transplants have been done in the world. They have been just as successful as transplants of whole organs. There are some risks of adult donation for transplant to a child. These risks seem to be much smaller than the risks of a living donor transplant to an adult.

### **Is it Difficult to do a Transplant on a Child?**

Yes, for several reasons. First, the blood vessels in children are very small. Transplants on children under one year of age may be even harder to do. And, the care after surgery must be done in ICUs that can handle small children.

### **Do Children Get the Same Anti-rejection Drugs as Adults?**

In general, children get the same type of drugs that adults get, but children may have different side effects. For this reason, doctors who specialize in this field should do the follow-up care.

### **What makes a transplant successful?**

Three things help make a transplant successful.

- Good medical care
- Doing exactly what the doctors tell you to do
- Good communication between the patient, family, and medical teams

Children who get liver transplants will need to take drugs as prescribed and see their doctors often. They may need more tests and evaluation of their growth and development than children who have not had a transplant. Children can have long, healthy lives after transplant. As a parent, make sure you stay in touch with your child's transplant team, and follow their advice. Ask for counseling when you have any problems.