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GETTING A

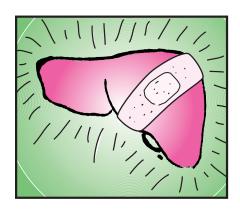
Facts About Liver Transplants





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What makes a transplant successful?

INTRODUCTION

A liver transplant is not a simple step to take, but it can save your life. You will do better with a new transplant if you understand your illness, the many steps you must take in your treatment, and the goals you need to reach at each step. You should try very hard to understand what you must do to make your transplant work. You must take your medications as prescribed, keep your appointments, and stay in close touch with your doctors and nurses.

FACTS ABOUT THE LIVER

The liver has many jobs to do:

- It helps digest your food.
- It clears some wastes from your blood.
- It makes proteins that help your blood to clot.
- It stores the food that is used for energy (glycogen).
- 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 poisons and drugs.

The liver also helps control the way your body uses food and it works with the body's defense system.

When the liver is badly damaged, it cannot grow enough new liver tissue to heal itself. Severe liver damage is called "cirrhosis." Cirrhosis often means that the liver has two main problems:

- 1. It cannot do the work it is supposed to do.
- 2. The liver is so damaged that the blood cannot flow freely. High blood pressure builds up in the vein that feeds the liver.

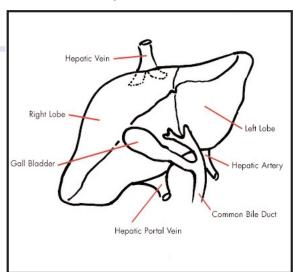
The liver can hold up under a lot of damage. It only starts to fail when more than half of it is damaged. Once a person shows signs of liver failure, it means there is not much of the liver left for the body to rely on during sickness and times of need.

Signs of liver failure may include the following:

- Yellow skin and eyes (jaundice)
- Forgetfulness, confusion, or even coma (encephalopathy)
- Feeling very tired (fatigue)
- Muscle wasting
- Itching
- Poor clotting of the blood

Other signs of liver disease include a buildup of fluid in the stomach (ascites), infections, and bleeding in the stomach. There is no treatment that can help the liver do all of its jobs. Therefore, when a person reaches a certain stage of liver disease, a liver transplant may be the only way to prolong his or her life. For more discussion on cirrhosis click here: compcir.doc

The inside of a liver may look confusing. Look at the drawing. It may help you to understand some of the medical terms used by the liver team members. Go back and look at this drawing often, and ask any questions you may have.



PRETRANSPLANT EVALUATION

Can you be considered for a liver transplant?

To get a liver transplant, you must go through many tests. First, you must meet with the liver specialist, the transplant surgeon, and other doctors. The coordinator will schedule you for laboratory tests ("blood work"), consultations, and x-rays. This will help doctors decide whether a liver transplant is needed and if it is the best choice for you.

An Interview With Doctors About Infections

As a result of the medicines you will need for your body to accept the new liver, your defense system will be less able to fight off infections. You will be screened to see what infections you have had in the past. You will also have blood tests, a skin test for tuberculosis (TB), and routine adult immunizations such as the flu shot.



X-RAY FILM STUDIES

1. COMPUTED TOMOGRAPHY(CAT or CT) Scan

This x-ray film is used to look at the size of your liver and any other problems that would make it hard for you to have a liver transplant. Cirrhosis can lead to liver cancer. A CAT scan will help screen for this.

2. MAGNETIC RESONANCE IMAGE (MRI) of the LIVER

This study is similar to the CAT scan, but it is another way of looking at the size and shape of the liver. As with the CAT scan there is no pain during an MRI.

3. ULTRASOUND

This test uses sound waves from a microphone that is passed across your skin. It will give a picture of your liver, bile ducts, and the blood supply to and from the vessels to the liver.

4. ROUTINE CHEST X-RAY

This study gives a black-and-white picture of your lungs, ribs, heart, and diaphragm muscle.

ENDOSCOPY

In this test a flexible tube is passed down your throat and into your stomach. It will look for enlarged veins or ulcers that are caused by liver disease. You will be given medicine to help you relax and make you sleepy during this test.

Sclerotherapy and Rubber-Band Ligation

Some patients may have life-threatening bleeding from enlarged veins in the throat or stomach caused by liver disease. These are treated with injections or small rubber bands. The injection of chemicals clot and harden the veins. This is called *sclerotherapy*. Some doctors prefer to put rubber bands on the enlarged veins that will make them shrink. This is done to prevent or stop bleeding.

PRETRANSPLANT EVALUATION (CONTINUED)

Transjugular Intrahepatic Portosystemic Shunt (TIPS)

The TIPS test controls most of the bleeding caused by enlarged veins and are not controlled by injections or rubber bands. TIPS is done by a doctor in the x-ray department. You will be given medicine to make you sleep as well as a small injection in your neck. A small valve or shunt is put into a vein in the neck, and from there it is passed into the liver. This will relieve the blood pressure in the vein that feeds your liver. TIPS is done in the hospital. You will need to stay overnight to be closely watched.



CREATININE CLEARANCE

This is a test used to check your kidney. Often it means you must collect your urine for 12 or 24 hours. You will also have a blood test. This test helps the doctor check the dose of transplant drugs that will have to go through your kidneys.

CARDIAC TESTING

1. ECHOCARDIOGRAM

This test looks at sound waves from a microphone that is lightly moved across your skin. It shows how well your heart is pumping. This may also check the blood pressure in parts of the heart. Doctors will then know if you need more tests or treatments for your heart.

2. ELECTROCARDIOGRAM (EKG or ECG)

An EKG is a record of the electrical action of your heart. It gives a record of your heartbeat and is used to find heart disease.

PULMONARY FUNCTION TEST

This test measures how well your lungs work when you breathe in and when you breathe out.

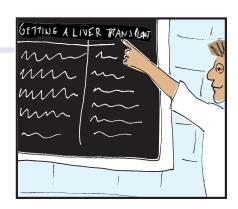
LIVER BIOPSY

A liver biopsy is a test of a tiny piece of the liver. The tissue is taken out with a small needle. Very few patients need a liver biopsy before transplant. If it is needed, it will help to show what type of liver disease you have.

PRETRANSPLANT EVALUATION (CONTINUED)

PSYCHOSOCIAL EVALUATION

Your emotional state is as important as your physical health to your transplant team. For this reason, you will also be checked by a team, which may include a social worker, psychologist, addiction specialist, and chaplain. This will help your doctors find out how well you handle stress and who will be your source of support. The members of this team can also help you with financial worries, connect you to hospital services, and give information on support groups. A family meeting is scheduled for each patient. This will help your family understand what a liver transplant involves and will let them meet the transplant team.



NUTRITIONAL EVALUATION

The dietitian will look at your nutritional needs and will then help design an eating plan for you. He or she will find ways to help you follow your new diet.

PROCESS COMPLETION

Once they are completed, your test results are reviewed and given to the Liver Transplant Selection Committee. This committee is made up of doctors, the transplant coordinators, and the psychosocial team. Once in a while, patients are found to be too healthy for a transplant. These patients may then be followed closely for signs of more liver failure. If their liver gets worse, they will be retested. Other patients are too ill to survive the transplant. In these cases, the committee will not approve a liver transplant. If the patient is found to be right for a transplant, the committee will approve a transplant. Once you are approved, you will be placed on the waiting list for a liver transplant.

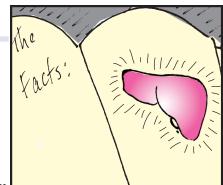
TWO TYPES OF LIVER TRANSPLANT

Mostly, a liver transplant is done with a liver from a brain-dead person called a *cadaver donor*. The liver is removed from a brain-dead donor. It is kept sterile until it is ready for transplant. The donor is chosen based on medical condition, size, and blood-group match. Recently, **living-donor** liver transplants have become more common. For an adult who needs a liver, the right half of a liver is removed from a living adult donor and used for the transplant. For a child who needs a liver, a smaller part of the liver (left side) is removed from a living adult donor for the transplant. Questions about living donor liver transplants are discussed later.

THE WAITING PERIOD

THE WAITING LIST

When placed on the waiting list, you will be given a score based on the results of your blood work. A higher score means you are sicker and you will be put higher on the list to get a liver. This is a process that is done by computer. Waiting time is used as tiebreaker when two people on the waiting list have the same score. The rules on how organs are given out may change. Talk with your doctor. You could also log on to www.unos.org to learn more.



There are many problems that can come up during the waiting period. You may need to be seen by a doctor. You should have your blood tested and your medicines changed as needed to keep you in the best possible shape for a transplant. It is very important that you keep all your appointments.

When a donor is found for you, the transplant team must be able to contact you. Your coordinators will need a list of the names and telephone numbers of people who will know where to reach you. You may be given a free pager. When you get your pager, please be sure to call the coordinator's office and give us the pager number.

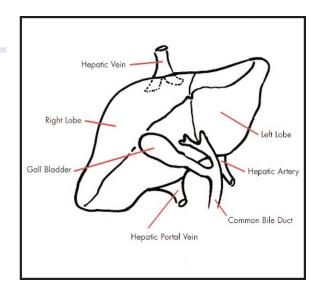
To help with the stress of waiting, we suggest that you and your family go to support group meetings. Members of the group are patients who have had their transplants and those who are waiting for transplants and their families.

THE TRANSPLANT ADMISSION

TRANSPLANT OPERATION

Once an organ has been found for you, the transplant service will contact you to come to the hospital at once. Don't eat or drink anything from the moment you are called. Sometimes the liver may not be good enough to transplant and your operation may be canceled. This does not happen often. It is impossible to tell when it might happen.

Once you are in the operating room and put to sleep, more lines will be put in your body to watch your heart and blood pressure. The operation is done through a long cut that goes along both sides of your ribs. Sometimes, there is also a cut that goes up making the whole cut look like the Mercedes-Benz sign.



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 transplant surgeon, after getting the donor liver ready, connects these vessels to the donor vessels. The bile duct on the donor liver, the tube that drains the bile from the liver, is then connected to your bile duct. The bile duct may drain into your body or through a tube that will be passed through the skin to the outside of your body.

In some cases, depending on the person, a small piece of the intestine is connected to the new donor bile duct. This connection is called *Roux-en-Y*.

Most often the operation itself will take 6 to 8 hours with another 2 hours to prepare for surgery. Therefore, you will be in the operating room for 8 to 10 hours.

SURGICAL INTENSIVE CARE UNIT

You will wake up from your operation in the surgical intensive care unit (SICU). During the wake-up period, you will have a tube in your windpipe 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.

TRANSPLANT GENERAL CARE UNIT

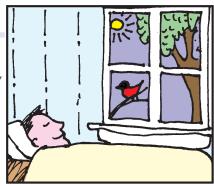
When it is safe to leave the SICU, you will be transferred to the transplant floor. Focus will shift to get you walking and eating. You may also get some physical therapy, because being active will help you recover. When you begin to feel hungry and your bowels are working, you will be able to eat regular food that is low in salt. Blood tests will be done every day. X-rays will be ordered if you need them. A liver biopsy may be done if there is any thought that the new liver is being rejected. Rejection is common and does not mean you are losing your liver. You may not even feel it. Medications are given to treat it.

THE TRANSPLANT ADMISSION (CONTINUED)

DISCHARGE

You should expect to spend 10 to 14 days in the hospital. For some, the stay may be shorter or longer. Before you go home, you will be taught how to take the new medicines, know the signs of infection or rejection, change the small dressings you will have, and understand general health guidelines.

Besides rejection, infection can be a real danger because you are taking drugs that block your body's defense system. The greatest time of risk for getting infections, such as colds and the flu, is in the first 3 months after your transplant. For this reason:



- 1. Stay away from people who are ill.
- 2. Tell your doctors if you are exposed to any disease.
- 3. Wash your hands frequently.
- 4. Always tell your doctors if you get a cold sore, a rash, or small water blisters on your body.
- 5. Report any spots that may 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 could also get a vaginal yeast infection.
- 6. Stay away from crowds and rooms with poor circulation. Make sure that any ventilation systems in your home are cleaned often by professionals.
- 7. Learn to report early the signs and symptoms of infection.
- 8. Stay away from soil, either from houseplants or gardens, during the high-risk period.
- 9. Do not swim in any lakes or community pools during the high-risk period.
- 10. Eat well-cooked meat, and remember to wash your hands after handling raw meat.

For more on health guidelines after transplant click here: <u>health.doc</u>.

You should also follow these general rules about your medicines:

- 1. Never "doctor" yourself for anything.
- 2. Store all drugs at room temperature, unless it says something else on the medicine bottle or package.
- 3. You must take your medicine as part of your daily routine, just like eating and sleeping.
- 4. It is your job to call the pharmacist or the transplant coordinator before you start any new medicine.
- 5. If you have vomiting or diarrhea, it can keep you from getting the medicines you need into your body. Call your doctor, transplant doctor, or transplant coordinator.

THE TRANSPLANT ADMISSION (CONTINUED)

COMPLICATIONS

Your doctors will be checking you and your liver with blood tests, ultrasound and x-rays to make sure you are doing well. Some of the things that may happen that will need treatment:

- Acute rejection: This can be treated with drugs. You may need a liver biopsy.
- Surgical problems: There may be bleeding after surgery. The bile duct or blood vessels of the liver could become too narrow. These may be solved by surgery but sometimes can be treated without surgery.
- Primary graft nonfunction: Sometimes, because of how it is preserved, a new liver transplant may not work as it should. This is critical. It means going on the transplant list again and getting a new liver within days.
- Recurrence of disease: The diseases that damaged your liver may come back in the new organ. They can cause a little damage or a lot. Sometimes a second transplant is needed.
- Cancer: People who have organ transplants are at a higher risk of some cancers, especially skin cancer. These
 cancers may spread faster than they do in other people. Therefore, close follow-up and cancer screening are
 needed.
- Other medical complications: Transplant patients can get infections, high blood pressure, diabetes, high cholesterol, thinning of the bones, and become obese. Close medical care can help prevent and treat these conditions.

Nutrition and what you eat after your transplant plays an important role how well you recover. For more on what to eat after your transplant, click here: <u>nutrition.doc</u>.

Enhancing the Success of Your Liver Transplant

As you can see, once you get a liver transplant, many things can go wrong. You must get good medical care and make every effort to keep in touch with your doctors and nurses. To make sure the transplant works and to have a long and healthy life, you must prevent and treat complications. As long as you have a liver transplant you need follow-up but less often as time goes by. So make sure you stay in touch with your transplant team, and follow their advice. Ask for counseling when you have any problems.

LIVING-DONOR TRANSPLANTATION

WHAT IS A LIVING-DONOR LIVER TRANSPLANT?

A living-donor transplant is when someone who is alive gives a part of his or her liver to a person who needs a transplant. Family members, such as parents, sisters, brothers, adult children, or someone close, such as a spouse, may offer to give part of his or her healthy liver. This can be done because healthy liver can grow new tissue. After the transplant, the liver parts of both the donor and person in need will grow and form complete organs.

What Are the Benefits of Living-donor Liver Transplantation?

The best reason for a living-donor transplant is that it shortens the waiting time for a liver. The timing of the surgery can be planned. The chance for a successful transplant is increased. In the United States, more than 18,000 people wait for liver transplants. But there are fewer than 5000 cadaver organs that can be used each year. A living-donor transplant gives those in need an early transplant: before their liver failure gets worse and their lives are in danger.

How Did Living-donor Liver Transplantation Begin, and How Prevalent is It?

Living-donor transplants were first done in children because of the long waiting times for cadaver organs and a high death rate on the list. It was done in children in the 1980s and is now being done in adults. The first concern in adults was that a large piece of liver was needed from the donor, which was thought to be too risky for the donor. In medical centers that do a lot of transplants, taking large sections of the donor's liver for adults can be avoided.

It is thought that living-donor transplants are done on half the children who need new livers. In some medical centers, up to 25% of all adults get living-donor transplants. The use of a living-donor transplant is increasing at a rapid rate. More than 500 of these transplants have been done in the last 3 years in the United States.

LIVING-DONOR TRANSPLANTATION (CONTINUED)

Who Can Become a Donor?

People who want to be liver donors are carefully checked to choose those who can safely give a part of their liver and to make sure that their liver is healthy. The first concern is the safety of the donor as well as being sure that the graft will work for the person in need. The risk of death is real. Discuss this with your doctor, and ask for the statistics. In general, those who can be liver donors must:

- Be in good general health
- Have a blood type that is a close match to the blood of the person in need
- Not have a selfish motive for donating

There should be no pressure of any kind on a person to donate part of his liver nor should there be any money given or received. Federal law does not allow the sale of organs.

WHAT ARE THE MAJOR RISKS IN DONATING?

Risks to the donor include bleeding, infection, leaking bile, and possible death. A donor might also need a liver transplant if his piece of the liver is damaged. This is rare. Many donors have minor problems after surgery. Most have full recoveries and are alive and well. As with major surgery, there will be pain from the incision, but it will get better with time.

What Is Involved in the Donor-evaluation Process?

A person who wants to donate part of his or her liver must go through a total check-up. This check-up could include the following:

- **Blood tests.** The first test will find out if the donor's blood type is a close match with that of the person in need. Blood tests are done to test the donor's liver, kidneys, and thyroid. Others are done to check for viruses such as hepatitis and HIV (the virus that causes AIDS).
- **Physical examination.** If donor and recipient blood types are a close match, the donor will get a physical examination.
- Ultrasound. An ultrasound is done of the liver, other organs, and blood vessels.
- Consultations with a social worker and/or psychiatrist are scheduled.
- Other tests, such as MRI and CAT scans, help to give a complete view of the donor's organs.
- Tests of the lungs and heart may also be done.

It takes 2 to 4 weeks for a donor to go through these tests. In an emergency situation, it can be done in as little as 48 hours.

LIVING-DONOR TRANSPLANTATION (CONTINUED)

What Happens During Donor Surgery?

Depending on which part of the donor's liver is removed, the incision is either straight up and down or in the shape of an upside-down "T." The gallbladder is almost always removed too. The donor's liver is split into two parts. One part is removed for the transplant. The surgeon then closes the wound with sutures or staples. These are later removed at a follow-up visit to the surgeon's office. The liver begins to heal and grow new tissue. It takes about 6 to 8 weeks for the liver to grow back to its normal size.

How Long Does the Donor Remain Hospitalized?

Donors stay in the hospital from 4 to 7 days after surgery. They may spend their first night after surgery in the SICU. The next day, they often go to the general surgical floor where the nurses have experience in caring for liver donors. Donors are encouraged to get out of bed and sit in a chair the day after surgery and to get up and walk as soon as they are able.

How Long Before the Liver Donor Is Fully Recovered?

For the most part, it takes about 4 weeks to recover from surgery. In the month after leaving the hospital, donors return to the clinic regularly to be checked. Donors often get back to work within 3 to 6 weeks, but this will differ from person to person. The medical staff will say when it is safe to return to normal life.

Federal employees can get a special leave for being organ donors. Other employers have such programs. You should ask if there is such a program in your company.

What Are a Donor's Health-care Costs?

The health insurance of the person who gets the transplant covers the donor's health-care costs. This includes the costs of the check-up, doctors' fees, hospital costs, and follow-up visits after surgery.

PEDIATRIC LIVER TRANSPLANTATION

A transplant is now one of the best treatments for fatal liver disease in children. New drugs and ways of doing surgery have greatly improved the 1-year patient survival rate. In liver transplants for children, there are two main issues:

- 1. What caused the liver failure in the first place?
- 2. What is the gap between the supply of livers and the number of children who need transplants?

Why Do Children Need Liver Transplants?

- **Biliary atresia:** This is a disease in which a child is born with no bile duct. It is the most common reason for liver transplants.
- **Problems in digesting and using food:** There are many diseases that children can be born with called "inborn errors of metabolism" including the following conditions:
 - Alpha-l-antitrypsin deficiency, tyrosinemia, and Wilson's disease.
 - Lipid storage (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 are found only in children.
- Sudden liver failure: This is a sudden liver failure that can cause death. It can have many causes. Mostly it comes from too much acetaminophen or other drugs. In this kind of liver failure, a liver transplant can cure the problem if it is done early.

What Are the Donor Organ Options That Are Used for transplantation in Children?

- **Reduced-size liver graft:** A piece of a liver is taken from a brain-dead person (cadaver donor).
- **Split-liver transplant:** A liver from a cadaver donor is cut in two. A small piece is used to transplant a child and a larger piece is used to transplant 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 1000 of these transplants have been done throughout 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.

Are There Technical Problems in Doing a Transplant on a Child?

Yes. It is much more difficult because the blood vessels are very small. Transplants for small children, under the age of 1 year, may be very hard to do. Also, the care after surgery must be done in ICUs that can handle such small children.

DO CHILDREN GET THE SAME ANTIREJECTION DRUGS AS ADULTS?

In general, children get the same type of drugs that adults get. However, children may have different side effects. Therefore, only doctors who specialize in this field should handle the follow-up of children after transplants.

PEDIATRIC LIVER TRANSPLANTATION (CONTINUED)

WHAT MAKES A TRANSPLANT SUCCESSFUL?

First, you must have good medical care. Then, families and patients should make every effort to keep in touch with their medical teams. Children who get liver transplants will need to take drugs on schedule, see their doctors often, and may need more procedures. All this will help to make transplants successful and will help to give long and healthy lives to the children. So make sure you stay in touch with your transplant team, and follow their advice. Ask for counseling when you have any problems.

