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Getting A New Liver: Facts About Liver Transplants

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Before the Evaluation: Understanding Liver Disease

FACTS ABOUT THE LIVER

The liver has many important functions that maintain your overall health. It controls the way your body uses food. It also takes up harmful substances and converts them into harmless substances or makes sure they are released from the body.

The liver does several things.

- Helps digest your food.
- Clears wastes from your blood.
- Makes proteins that help your blood to clot.
- Stores the sugars (glycogen) that are used for energy.
- Makes proteins that the body must have.
- Helps use and store vitamins.
- Makes chemicals that protect the body.
- Breaks down many toxins and drugs.

WHAT IS CIRRHOSIS

When liver cells die, scar tissue is formed. This scar tissue damages the liver and makes it not work as well as it should.

When the liver is badly damaged, it cannot heal itself. Severe liver damage with scarring is called cirrhosis.

Cirrhosis can lead to several problems.

- **Liver failure**
This means the liver is not able to do the normal functions that are needed to keep you alive.
- **High blood pressure in the portal vein**
This happens when scarring in the liver stops blood from flowing through it normally. This causes pressure to build up in the vein that feeds the liver (portal vein).
- **Liver cancer (hepatocellular carcinoma)**
Liver cancer can develop within a scarred liver.

WHEN THE LIVER FAILS

The liver can recover from a lot of damage, but when too much of it is damaged, it will start to fail. Once a person has signs of liver failure, it means that the liver is barely working as it should to help 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 (fatigue)
- Muscle loss (muscle wasting)
- Itching (pruritis)
- Poor blood clotting
- Swelling in the legs (edema) or abdomen (ascites)
- Bleeding from the esophagus, stomach or rectum

There is no treatment that can help the liver do everything it needs to do. There is no "dialysis" for the liver. So when liver disease reaches a certain stage, getting a liver from someone else, referred to as a liver transplant, may be the only way to prolong a person's life.

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 liver 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.

For more information about cirrhosis, visit:

http://www.myast.org/sites/default/files/pdfs/what_makes_transplant_successful.pdf

The Transplant Evaluation

FIRST, YOUR DOCTOR WILL REFER YOU TO A TRANSPLANT SPECIALIST.

When your liver disease begins to get worse and you show signs of liver failure or portal hypertension your primary care doctor or a specialist who treats stomach problems (gastroenterologist) will refer you for a transplant evaluation. Since a liver transplant is a specialized operation, you will need to go to a major medical center for a thorough assessment.

YOUR DOCTORS WILL EVALUATE YOUR HEALTH STATUS.

This thorough assessment is referred to as the pretransplant evaluation. This 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. The doctors will do many tests. 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 include:

- You will meet with a doctor who specializes in treating people with liver problems (hepatologist), 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.
- Doctors will perform tests to 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 include:

- X-rays and other imaging tests.
- 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 upper endoscopy (EGD) test done. During this test, the doctor will put a flexible tube with a tiny camera on the end of it down your throat and into your stomach. This test is to look for enlarged veins in your throat and stomach, called varices. These are at risk of bleeding, but can be treated. If you have large varices, the doctor may tie them with rubber bands to prevent them from bleeding.

To do a colonoscopy, the doctor will put a flexible tube with a camera through your rectum and into your colon. This can look for growths, colon cancer and enlarged veins in the rectum.

You will be given medicine to make you sleepy and so that you did not feel any pain 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. Some patients may need a heart cath (cardiac catheterization), which looks at the blood vessels in the heart. 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 a 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 how well you can follow medical recommendations. They also want to know that you have friends or family who can give you practical and emotional support. They will schedule a meeting with your family so that 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 the foods your body needs, provide information and create an eating plan for you to follow. The dietician will also be available to help you 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, the financial specialist will evaluate what medicines your insurance will pay for. The financial specialist will also tell you what your insurance will pay for office visits. The advisor will help you find other ways to pay for your transplant and care.

YOUR RESULTS WILL BE REVIEWED BY THE LIVER TRANSPLANT COMMITTEE.

Once your evaluation is complete, a Liver Transplant Selection Committee will review the results of the evaluations from the committee members. Based upon these evaluations, the committee will decide if a transplant is right for you. This committee is made up of the liver specialists, 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 days or several weeks.

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 the liver gets worse, the patient will be re-evaluated.

Sometimes, a patient is too ill to survive the transplant. In this case, the committee will recommend against liver transplant because the risks are likely to outweigh the benefits.

The Waiting List

UNDERSTANDING THE MELD SCORE

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-Na score, which means Model of End-stage Liver Disease-sodium score. For children, it is the PELD score, which means Pediatric End-stage Liver Disease. The score is calculated using results from three blood tests. 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 the sickest people on the waiting list are given the highest priority to receive a liver.

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.

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.

KEEPING CONTACTS UPDATED IS CRITICAL

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

THERE ARE TWO TYPES OF LIVER DONORS

There are two types of liver transplant, deceased donor and living donors. 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.

Living donor 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.

If you want information about living donor transplants, ask us. We can give you a brochure.

The Transplant

WHEN A LIVER IS FOUND FOR YOU

When a liver has been found for you, the transplant center will call you and ask you to come to the hospital right away.

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.

IN THE OPERATING ROOM

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 can receive medicines and fluids. The doctors will also monitor your heart and blood pressure.

The 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 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 usually takes 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 when you need them. A liver biopsy may be done if your doctors think your body is rejecting the new liver. Rejection is common. About 10-20% of patients will have at least one rejection.¹

If you have a rejection, remember it does not mean:

- you will lose your new liver
- your new liver is failing

You may not even feel your body begin to reject your new 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.

After the Transplant

WHEN YOU LEAVE THE HOSPITAL

You will be in the hospital for about 7 to 14 days. Before you go home, you will learn what to look for that may indicate an infection or rejection. You will also learn how to change your dressings, how to take your medicines, and what you need to know about taking care of yourself.

Infection is a real danger because you are taking drugs that block your body's immune system. The time of greatest 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.

1. Stay away from people who are sick.
2. Tell your doctors if you were near anyone who was sick.
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.

1 <http://columbiasurgery.org/kidney-transplant/organ-rejection-after-renal-transplant>

For more information about health guidelines after transplant, visit http://www.myast.org/sites/default/files/pdfs/what_makes_transplant_successful.pdf.

Below are five rules to follow about 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 indicated differently 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 is less able to absorb your medicines. Call your doctor or transplant coordinator if you are sick.

COMPLICATIONS

You will need more tests after you leave the hospital. These tests will help your doctors keep track of how you and your new liver are doing. 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 test to confirm the presence of rejection and/or to monitor your response to treatment.

- **Recurrence of your liver disease**

The diseases that damaged your liver in the first place may come back in the new liver. The damage can be 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 tested to see if you have cancer.

- **Other medical complications**

Transplant patients are at risk for medical complications, including infections, high blood pressure, diabetes, high cholesterol, thinning of the bones, and obesity.

MAKING SURE YOUR LIVER TRANSPLANT IS A SUCCESS

A liver transplant increases your chances 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. Refer to the section above for more information about complications.

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. Make sure you stay in touch with your transplant team and follow their advice. Ask for counseling when you have any problems.

Enjoy your life!