



New Horizons Liver

A patient's guide to pre-transplantation



You Need a Liver Transplant...

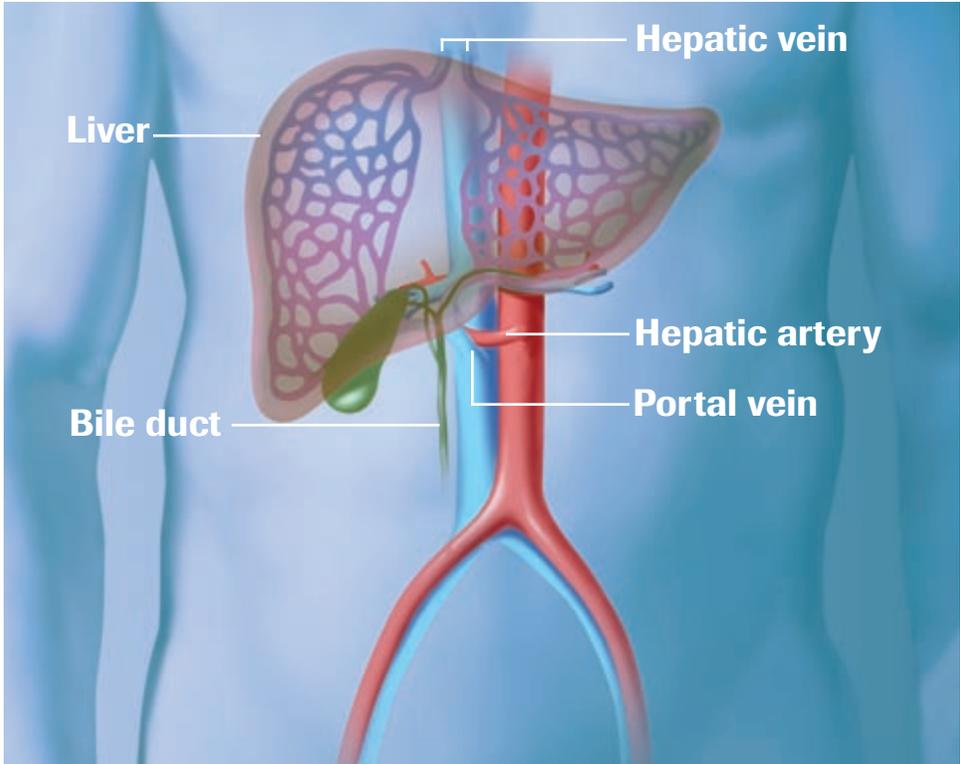
Now What?

If you are anticipating or considering a liver transplant, you probably have a lot of decisions to make and many new things to think about. Hopefully, this booklet will answer some of your questions, and it may prompt others that you should ask your transplant team. Your healthcare professionals want you to know as much as you can about the transplant process, so that you can be an active partner in your own care. The more informed you become, the more in control you will feel.

Important Facts About the Liver and Its Functions

The liver is one of the largest organs in the body, consisting of 2 main sections, or lobes. The left lobe makes up about 40% of the liver mass and the right about 60%. The liver receives a double supply of blood—blood rich in oxygen comes from the heart through

the hepatic artery; blood with newly absorbed nutrients comes from the stomach and intestines through the portal vein. In total, there are 8 sections in the liver. Each section functions like a little liver, with each one doing the same job.



What does your liver do?

The liver plays an important role in many vital life processes, including:

- Breaking down food into the chemicals our bodies need
- Producing bile (necessary for digestion)
- Controlling blood glucose levels
- Storing vitamins, minerals and sugars
- Maintaining hormonal balance
- Removing toxins from the bloodstream

A special feature of the liver is its ability to regenerate—that is, to make new liver tissue. Although the liver can usually repair and restore itself, this function may be defeated by repeated or extensive damage to the organ that causes permanent scarring. If damage is extensive and the liver fails to perform its function, transplant surgery may be required.

What happens when the liver is not working the way it should?

If the doctor has determined that there is a problem with your liver, it is probably because a disease is affecting the way your liver is supposed to be doing its job. This may mean that your body is not:

- Making the necessary proteins to control blood clotting
- Filtering poisons you eat, drink or absorb
- Storing vitamins, minerals and sugars that give you energy and protect you from infection
- Removing waste products properly
- Producing bile to help you digest food

When is a liver transplant necessary?

There are many diseases that can injure the liver to the point that it may threaten your life. This is when a liver transplant must be considered. In fact, some of these diseases are potentially treatable with liver transplantation. Diseases of the liver include:

- Hepatitis (A, B* and C*)
- Cirrhosis (alcoholic and of unknown cause)
- Primary biliary cirrhosis
- Primary sclerosing cholangitis
- Autoimmune liver disease
- Acute liver failure

Types of liver transplant surgery

Currently, the national 1-year survival rate for liver transplant patients is as high as 88%. So as you can see, liver transplantation can be a successful treatment for liver disease. There are several possible liver transplant procedures you and your healthcare team may consider, such as:

- Live donor liver transplant
- Deceased donor liver transplant
- Split-liver transplant

Whichever option is right for you, it is important to know that you must not have used alcohol or any illicit substances for 6 months prior to your liver transplantation, as these can further damage a diseased liver. Because of this, all patients will undergo random screening, and if you test positive for alcohol or illicit substance use, you will not be considered for a liver transplant evaluation until you are “clean” for 6 months.

*Please note: Hepatitis B and hepatitis C are not eliminated from the body when a liver transplant takes place. It is very possible that these viruses may come back and act up once again even with a new liver.



Live donor liver transplant

The constant shortage of organs available for liver transplantation from deceased donors has led to innovative measures to increase the supply. One such alternative is a surgical procedure in which a portion of a healthy liver is removed from a living donor and immediately transplanted into the body of a waiting recipient. Although this procedure has become more common since the mid-1990s, it is not yet widely available.

A live donor liver transplant, however, may be an option that you may want to discuss with your transplant team.

Because the liver is able to regenerate, part of a donor's healthy liver can be removed and implanted into another person's body. In the recipient, the transplanted liver segment grows to the size needed to support life. The remaining part of the donor's liver also grows to eventually compensate for the portion that was removed.

Who can be considered a live donor candidate? Those who are related to you make the most successful donors because their blood and tissues are usually similar to yours. Living donors can be parents, siblings, aunts and uncles, children who are at least 18 years old and cousins. There is also a possibility that an altruistic (“Good Samaritan”) nonrelated donor may be found, but this is not yet widely accepted.

If a live donor liver transplant is a possibility, your transplant center will have a long list of requirements for the potential donor, which may include:

- Over 18 years of age and in good physical condition (some centers require the donor to be at least 21 years old)

- Passes all physical and psychological testing
- Compatible blood type (listed in the table below) and normal liver and kidney function
- Liver volume and structure verified by CT scan
- Willing and prepared to handle the physical, emotional and financial challenges of major surgery, with full awareness of the risks involved

Not everyone who needs a liver transplant is a candidate for a living donor transplant. A patient may be too sick for part of a donated healthy liver to support their stage of disease. In this case, the patient would require a whole liver to survive, which would have to come from a deceased donor.

Compatible Blood Types

Recipient's Blood Type	Donor's Blood Type
O	O
A	A or O
B	B or O
AB	A, B, AB or O



Deceased donor liver transplant

Deceased donors are people who have died and donated their organs for transplantation. The donated recovered liver may then be transplanted in whole or in part to 1 or 2 recipients. This procedure is known as a split-liver transplant (see page 10). Split-liver transplants are not yet available at all centers, but they are gaining acceptance as a way to increase the supply of organs for transplantation.

“The list”—waiting for a deceased donor liver. There is a designation system in place to ensure that those patients most in need of a liver transplant are given the highest priority. This is managed by an organization called the United Network for Organ Sharing (UNOS).

To determine how the livers are allocated, a special formula was created to find out how sick each patient is and the severity of their disease. It was discovered that if the results of certain blood tests

were put into a mathematical equation, a patient's risk of death without a transplant could be established. The blood tests, which tell how the diseased liver is functioning, are performed every few days, and this is what helps UNOS know which patients are the sickest and most in need of a new liver. The formula is called the Model for End-Stage Liver Disease, or MELD. You will most likely hear about this at some time during the transplantation process.

Your transplant team and the UNOS Web site, www.unos.org, will have the most current information.

You are only on “the list” when your transplant nurse coordinator or doctor confirms that you are on the list. Some patients mistakenly think they are automatically listed once they have been referred to a transplant center, or after they have completed testing. If you are not absolutely sure that you are on the list, talk to your transplant coordinator.

As you never know when a donor will be available for you, it is important that you stay in constant contact with your coordinator. If you move or change any of your phone numbers, please be sure to give this information to the transplant center, so you can be contacted immediately when it is your turn to receive a donor liver.

Split-liver transplant

A deceased donor liver can sometimes be divided into 2 parts and transplanted into 2 recipients: 1 receives the left lobe, while the other receives the right lobe. This procedure is similar to live donor liver transplantation, and it, too, is possible because the liver has the unique ability to regenerate. Split-liver transplant is an option that increases the donor pool, helping to improve the availability of potential organs.

What are the possible complications of surgery?

As with any surgical procedure, there is always a possibility of complications. After a liver transplant, there may be a risk of:

- Infection
- Rejection of the new liver
- Bleeding
- Clotted veins, arteries or lymphatic vessels
- Narrowing or leaking of bile ducts
- Liver not working properly
- Discomfort (possibly for up to 6 months)
- Death





Pre-transplant screenings

Every patient who is being considered for a transplant will undergo a number of tests that are repeated several times. These evaluations reveal your overall health and help your healthcare team determine if transplantation is right for you. Some or all of the following tests—and possibly more—may be required by your transplant team.

Blood tests are performed to rule out certain infectious diseases and provide information regarding:

- Various blood cell counts, such as white cells, red cells and platelets
- Blood typing (O, A, B or AB), which will help determine your compatibility with a potential donor
- Blood chemistries, including those that measure glucose and electrolytes
- Kidney and liver function
- The presence of viruses and/or antibodies to viruses. Exposure to some common viruses will not rule out liver transplantation but will be taken into account when monitoring your condition after surgery. In some cases, vaccination prior to transplantation may be required

Common Pre-transplant Blood Tests (Liver)

Test type	What it measures
Albumin	A protein produced by the liver and released into the bloodstream
Alkaline phosphatase (ALP)	An enzyme produced in the liver, bone and placenta and released into the bloodstream
Alanine transaminase (ALT)	An enzyme produced in the liver and released into the bloodstream when liver cells are injured
Aspartate transaminase (AST)	An enzyme released into the bloodstream when the liver is injured
Bilirubin	A component of bile, a product of the liver
International normalized ratio (INR)	The ability of the liver to make prothrombin, a protein that is important for blood clotting
Lactic acid dehydrogenase (LDH)	An enzyme found in body tissues, including the heart, liver and kidney; most often measured to evaluate tissue damage

An increase may mean

- Recovering from a serious illness
- Inflammation of the bile ducts inside the liver

- Liver cell injury
- Hepatitis
- Noncancerous tumor
- Use of medications that are toxic to the liver
- A rejection episode
- Excessive use of alcohol
- Severe infection

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- Liver cell injury
- Hepatitis
- Change in the bile duct structure
- A rejection episode
- Use of medications that are toxic to the liver
- A narrowing of the common bile duct
- Gallstones

- Liver damage
- Use of a blood-thinning medication

- Stroke or heart attack
- Low blood pressure
- Liver diseases such as hepatitis
- Pancreatic disease

A decrease may mean

- Ascites (excess fluid in the abdomen)
- Kidney disease
- Hepatitis
- Cirrhosis
- Body not absorbing nutrients from food
- Malnutrition

Does not apply

Chest x-ray will help determine the health of your lungs.

Imaging scans can show the size and shape of the liver and major blood vessels. Some imaging scans that may be performed include:

- Abdominal ultrasound
- Computerized axial tomography (CAT/CT)
- Magnetic resonance imaging (MRI), when more detailed information is needed

Electrocardiogram (EKG) shows heart function and reveals any past damage. Additional heart tests may be required if you have a history of

heart or vascular disease, or have significant risk factors for hidden, silent (occult) heart disease.

Urinalysis can detect and measure cells and substances that may indicate disease or infection.

Pulmonary function tests—breathing forcefully into a tube—measure how well your lungs are working and the ability of your blood to carry oxygen.

Interviews with a transplant social worker, a psychiatrist and a transplant nurse coordinator may be required to confirm your eligibility for transplant.



Keep a record of all the tests you may need

You and your transplant team may use the following table to keep track of the pre-transplant tests you may be required to have. Your nurse can check off those that are necessary for you in the “required” column, or add any additional tests required by your center. Carry this booklet with you, so you always have a record of what needs to happen, when it needs to happen and when it is done.

Pre-transplant tests and evaluations			
Test	Required	Date Scheduled	Completed
Blood/Urine			
Alpha fetoprotein (AFP)			
Arterial blood gas			
Blood typing			
Coagulation profile			
Complete biochemical and liver profile			
Complete blood count (CBC)			
Drug and alcohol screening			
Hepatitis serologies			
Renal function			
Urinalysis			
Virology studies			

Test	Required	Date Scheduled	Completed
Cancer Screening			
Colonoscopy			
Mammogram			
Pap smear			
Upper endoscopy (EGD)			
Prostate specific antigen (PSA)			
Imaging/Function			
Cardiac catheterization			
Cardiac (thallium) stress test			
Chest x-ray			
CT/CAT scan			
Echocardiogram (ECHO)			
Electrocardiogram (EKG)			
MRI			
Nuclear bone scan			
Pulmonary function test			
Ultrasound of abdomen			
Other			
Dental examination			
Liver biopsy			

What does all this testing mean?

Most of the tests and interviews you will undergo are performed to help your transplant team decide how best to increase your chances of achieving the most successful results from your liver transplant. These tests and discussions will determine if:

- Your disease can be treated effectively with a liver transplant
- There are any problems, such as blocked or closed blood vessels, that could interfere with successful surgery
- Your heart, lungs and kidneys are able to withstand transplant surgery
- There are emotional, psychological or family issues that must be addressed

Is everyone a candidate for liver transplantation?

Not everyone is a candidate for liver transplantation. The following may prevent a person from receiving a transplant*:

- Severe kidney, heart or lung disease
- Advanced liver cancer (hepatocellular carcinoma)
- Active use of alcohol or illicit substances
- Advanced HIV disease (AIDS)
- Proven history of not following medical directions (noncompliance)

*Each transplant center has its own criteria for potential transplant candidates. Be sure to check with your center about the particular factors that might exclude you from being considered for an organ transplant.



Who are the members of your transplant team and what do they do?

It is important for you to know the medical professionals who will be taking care of you and exactly what they do. Each of these experts is a specialist in his or her field with a very distinct job. Following is a description of the typical team members involved in liver transplantation, but your team may be slightly different. You can use this information as a guide to understand your available resources.

The transplant surgeon evaluates whether you qualify for a liver transplant and will perform the actual surgery. After surgery, he or she looks for possible surgical complications. This is the physician who can answer many of the questions you may have about the surgery and its risks.

The transplant hepatologist is a liver specialist who usually monitors all nonsurgical aspects of your care, such as liver function, rejection episodes and post-transplant medications. You will see this doctor often—feel free to ask as many questions as you want.



The consultant physicians may include cardiologists, infectious disease specialists, hematologists/oncologists, anesthesiologists, psychiatrists, psychologists, pulmonologists and nephrologists. With transplant care, many medical specialties are involved to make sure you have the complete care you need.

The transplant nurse coordinator is a licensed, registered nurse who is responsible for many duties, some of which include organizing your patient evaluations, monitoring

laboratory results, educating you post-operatively, providing discharge instructions and serving as the keeper of all your medical information. Think of him or her as the center of the wheel of professionals around you—someone who will keep track of how you are doing throughout the entire transplant process.

The physical therapist will create an exercise plan to help you prevent muscle deterioration, control your weight and maintain a normal level of activity after your surgery.

The dietitian/nutritionist is a licensed professional trained in the science of diet and nutrition. This team member will design healthy meal plans for you both before and after your transplant. He or she will also develop special diets for patients with medical issues. Be sure to ask about any food or fluid restrictions.

The financial planner/coordinator is specially trained to help patients and their families deal with the financial burdens of an organ transplant. This professional will explain what your insurance will and will not cover; help you determine if you qualify for coverage from Medicare, Medicaid or private insurance and direct you to available financial resources.

The social worker can help you and your family cope with the nonmedical aspects of the transplant. By working closely with you, the social worker can identify emotional or family issues that need attention, and link you to community services, such as support groups, you might find useful.

The pharmacist can help oversee and coordinate the many medications you will be taking after the transplant, as well as explain any side effects you may experience.

Other team members may include physician assistants, operating room and intensive care nurses, nurse practitioners, medical residents, procurement coordinators, case managers and transplant assistants.

You play an important role in the transplant process and are one of the most essential members of the team. Help yourself by being an active participant in your own care. Share your feelings, ask questions, talk about issues that are important to you—open communication is how the rest of your team will know how you are doing and what you are thinking.

Stay healthy prior to transplantation

Physically

- Stay as active as you can, and take care to keep your muscles toned within your physical limitations
- Eat healthy, well-balanced meals. If you have a protein restriction, you can get information about a protein-restricted eating plan from your transplant center, or meet with your dietitian to customize a plan that accommodates your tastes, health and habits
- Do not drink alcohol or use illicit substances. If you smoke and have had difficulty quitting, ask your team to direct you to the help you need
- Lose weight, if necessary, to reduce the risk of complications during and after your transplant and, most importantly, to protect your overall health
- Get treatment for other healthcare problems, including high cholesterol, high blood pressure and diabetes



Emotionally

- It is very important to be as mentally and emotionally healthy as possible. If you are having trouble coping, there are relaxation techniques you can try or counseling might be a consideration. This can help you have a more positive transplantation experience
- Depression is not uncommon among people awaiting transplantation. Your transplant team wants to know how you're handling the stress of your situation. They can advise you about all of your options from support groups to antidepressant medications
- Join a support group through your transplant center. This forum for learning and sharing can be very valuable to you and your family
- Keep connected—even though you may often be very tired—make every effort to stay in touch with the people you care about; your support group is very important at every stage in the transplant process
- Try to let people help you when they offer. Learn to say “yes,” even if accepting help is hard to do. Those who offer usually really want to help but don't know what would be most useful to you. Allow them to pick up groceries, run errands, cook a meal or two—whatever will save you time and energy

Be prepared

Be prepared financially. Be proactive in finding out what your options are through private insurance and Medicare/Medicaid, and what supplemental coverage you may need. Rest assured that there is someone at your transplant center who is eager to help you make the financial plans that will minimize your stress and prepare for your future. Ask your team.

Be proactive

Arrange for someone to:

- Transport you to the center when the call comes
- Prepare food and care for you following surgery
- Accompany you to the center for your follow-up visits and help keep track of your medications
- Clean, do laundry and straighten up for you when you're not able to "do for yourself"

Surgery and recovery timeline

Surgery

Liver transplantation can be a long operation. Families should be aware that it could take anywhere from 4 to 12 hours. It is hard to predict how long the operation will take, but your surgeon will update your family while surgery is in progress.

Recovery

Prior to transplant, your surgeon will discuss the actual procedure and possible risks with you in detail. Many patients want to know how long the recovery time following transplantation will be. Your condition prior to the surgery often affects your recovery time.

Generally, without complications, there is a 5- to 14-day hospital stay. You may anticipate a 2- to 6-month disability period, or even longer if your physical condition dictates.



Your muscles will have been deprived of protein due to liver disease, and they will need time to recover and rebuild. Physical therapy may be needed to help build up your strength. After a transplant, most patients feel better and stronger as each day passes, with their new liver doing the job it's supposed to do.

After everything you will go through together, your transplant team will seem like family. They will closely monitor your progress post-transplant. You'll receive clear instructions and encouragement about taking your medications, monitoring your health and making the most of your second chance at life.

Liver Dictionary

The following is a list of terms you may hear your healthcare team use during the transplant process.

Alcoholic cirrhosis (sir-O-sis).

A chronic inflammation of the liver caused by excessive alcohol intake. People who quit drinking can significantly improve their liver function in as little as 6 months.

Ascites (ah-SIE-teez). Excess fluid in the abdomen.

Autoimmune hepatitis

(aw-to-i-MUNE hep-ah-TIE-tis).

Liver disease caused when the body's immune system destroys liver cells for no known reason.

Biliary atresia

(BIL-ee-a-ree ah-TREE-zha).

A disease of young children that prevents proper development of the main bile ducts connecting the liver to the intestinal tract. This results in obstruction and cirrhosis of the liver, usually within the first year of life.

Cholestasis (koe-le-STAY-sis).

A blockage of bile in the liver or bile ducts.

Cirrhosis (sir-O-sis). An irreversible scarring from chronic inflammation that causes the liver to be unable to regenerate. Chronic inflammation can be caused by many factors. Cirrhosis is a response to injury that damages the blood flow through the liver.

Deceased donor. Someone who has died and has donated his or her organs for transplantation.

Encephalopathy

(en-sef-ah-LOP-ah-thee).

Damage to the brain and central nervous system caused by toxins not filtered from the blood by the liver.

Hepatitis (hep-ah-TIE-tis).

An inflammation of the liver, which can be caused by many things, among them viruses and alcohol.



Hepatitis A (hep-ah-TIE-tis ay).

A virus that causes inflammation of the liver. As the virus is shed in the stool, the most common means of transmission is through contaminated food or water. It rarely causes lasting liver damage.

Hepatitis B (hep-ah-TIE-tis bee).

A virus that causes inflammation of the liver. Most people are able to get rid of the virus and develop antibodies that protect them from further infection. People who do

not get rid of the virus can develop chronic inflammation and cirrhosis.

Hepatitis C (hep-ah-TIE-tis sea).

The most common blood-borne virus in the country, hepatitis C can lead to cirrhosis of the liver within 15 to 20 years. Often, there are no symptoms; and the virus is usually discovered when signs of cirrhosis begin to develop. Hepatitis C is responsible for about 50% of the liver transplants performed in the US.

Jaundice (JAUN-dis). A yellow color of the body tissues, most noticeable in the skin and eyes, caused by the liver's inability to remove bilirubin from the blood.

Metabolic liver disease. Liver enzyme deficiencies that prevent carbohydrate, fat, protein and vitamin metabolism, which can lead to cirrhosis or result in serious diseases in other organs and tissues.

Model for end-stage liver disease (MELD). This is a mathematical formula used to determine which patients are the sickest and most in need of a new liver. It uses blood tests to identify the severity of each patient's disease, for prioritizing the distribution of deceased donor livers.

Nonalcoholic steatohepatitis (ste-A-toe-hep-ah-TIE-tis) (**NASH**). Fat in the liver, along with inflammation and damage.

Portal hypertension. Increased blood pressure in the portal vein (which carries blood from the digestive organs to the liver).

Primary biliary cirrhosis (BIL-ee-a-ree sir-O-sis) (**PBC**). Progressive damage and destruction of the bile ducts due to an unknown cause.

Primary sclerosing cholangitis (skle-ROE-sing koe-lan-JIE-tis) (**PSC**). Chronic inflammation of the bile ducts, causing them to become narrow and close.

United Network for Organ Sharing (UNOS). A national organization that makes sure all patients have a fair chance to receive the organ they need. UNOS matches donors with recipients and manages the list of those people waiting for a transplant.

Important Resources

The following is a partial list of where you can turn for support, information and education.

American Liver Foundation

1-800-465-4837/1-888-443-7872
www.liverfoundation.org

American Transplant Association (ATA)

1-800-494-4527
www.americantransplant.org

Children's Liver Alliance

www.liverkids.org.au

Children's Organ Transplant Association (COTA)

1-800-366-2682
www.cota.org

National Foundation for Transplants (NFT)

1-800-489-3863
www.transplants.org

Transplant Living

1-888-894-6361
www.transplantliving.org

Transplant Recipients International Organization (TRIO)

1-800-874-6386
www.trioweb.org

TransWeb

1-734-998-7314
www.transweb.org

United Network for Organ Sharing (UNOS)

1-888-894-6361
www.unos.org

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