#### Liver Transplantation









#### What is a liver transplant?

Liver transplantation is a surgical procedure performed to remove a diseased or injured liver and replace it with a whole or a portion of a healthy liver from another person, called the donor. Since the liver is the only organ in the body able to regenerate, a transplanted segment of a liver can grow to normal size within weeks.

### When is a liver transplant recommended?

A liver transplant is recommended when a person's liver no longer functions adequately enough to keep them alive. A successful liver transplant is a life-saving procedure for people with liver failure.

Liver failure can happen suddenly – called acute liver failure – as a result of infection or complications from certain medications, for example. Liver failure resulting from a long-term problem – called chronic liver failure – progresses over months, years or decades. Chronic liver failure is usually the result of cirrhosis, a condition in which healthy liver tissue has been replaced with scar tissue making the liver unable to carry out its normal functions.

# What are the common conditions that cause someone to need a liver transplant?

Among adults in the U.S., the most common reason for a liver transplant is cirrhosis

caused by chronic hepatitis C, followed by cirrhosis caused by long-term alcohol abuse. Many other diseases cause cirrhosis, including the following:



- Other forms of chronic hepatitis, including hepatitis B and autoimmune hepatitis.
- NASH, or nonalcoholic steatohepatitis, a disease caused by a buildup of fat in the liver resulting in inflammation and damage to liver cells.
- Some genetic conditions, including Wilson disease where dangerous levels of copper build up in the liver, and hemochromatosis where iron builds up in the liver.
- Diseases of the bile ducts. Bile ducts are tubes that transport bile, a digestive liquid made in the liver, to the small intestine. These diseases include primary biliary cholangitis, primary sclerosing cholangitis, and biliary atresia. Biliary atresia, a disease of absent or malformed bile ducts usually identified shortly after birth, is the most common cause of liver failure and transplant in children.

Other reasons for liver transplantation include primary liver cancer, meaning

cancers that originate in the liver, such as hepatocellular carcinoma.

# How are candidates for liver transplant selected?



Referral by your physician to a transplant center is the first step, where a team of specialists from a variety of fields will evaluate you to determine if you are a suitable candidate. The transplant team usually consists of the following members:

- hepatologist
- transplant surgeon
- transplant coordinator
- nurse
- psychiatrist
- social worker
- nutritionist
- financial coordinator

Evaluation will include assessment of your:

- liver disease and other conditions you may have;
- mental and emotional health;

- support system;
- ability to adhere to the complex medical regimen required after transplant; and
- likelihood of surviving the transplant operation.

Pre-transplant evaluation appointments often last four to five hours. The person who will be involved in your pre-and-posttransplant care should accompany you to the appointment.

### What tests are required for evaluation?

Extensive testing is required before someone can be placed on the transplant list. This usually includes:

- physical exam
- detailed medical history
- psychological and social evaluation
- diagnostic tests to evaluate the status of your heart, lung and other organs
- imaging studies, such as CT scans and ultrasound, to assess your liver and blood flow through various vessels
- multiple blood tests to determine your blood type, kidney function and liver function, and check for other infectious, immune, and inherited diseases
- HIV, hepatitis, drug and alcohol screening



If you have a history of drug and/or alcohol abuse, documented sobriety from a treatment facility may be required. Your transplant center's policy on drug and alcohol use should be discussed at the first visit.

#### Where do donated livers come from?

We will now discuss transplantation in two categories: deceased donor transplantation and living donor transplantation.

Livers for transplantation come from either a deceased or living donor. Most donated livers come from deceased donors, often victims of severe, accident-related head injury. Either they have arranged in advance to be an organ donor or their family grants permission for organ donation when the victim is declared brain dead.

#### **Deceased Donor Transplantation**

#### How does the transplant waiting list work?

Once you complete all required testing, the transplant selection committee will review your case. If the committee determines you are a suitable candidate, your name will be placed on the national transplant waiting list. This list is maintained by the United Network for Organ Sharing (UNOS), which administers the Organ Procurement and Transplantation Network (OPTN), responsible for transplant organ distribution in the U.S.

When people are put on the waiting list they're assigned a priority score indicating how urgently they need a transplant. The score is calculated by your healthcare provider based on a specific formula. The two scoring systems are the MELD (Model for End-stage Liver Disease) used for adults, and the PELD (Pediatric End-stage Liver Disease), used for children less than 12 years of age.

MELD scores range from 6 to 40 and are based on whether or not you're currently on dialysis and the results of the following four blood tests:

- INR (internal normalized ration), which reflects whether your liver is making the proteins necessary for your blood to clot
- creatinine, an indicator of kidney function

- bilirubin, an indicator of liver health
- sodium, an indicator of your body's ability to regulate fluid balance

PELD scores range from negative numbers to 99 and are based on the:

- child's age
- child's degree of growth failure
- results of the following blood tests: INR, bilirubin, and albumin – a protein made by the liver which is usually below normal levels in people with liver disease

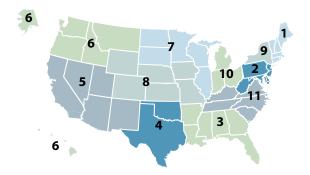
A higher MELD or PELD score indicates a more urgent need for a liver transplant. While you're on the waiting list, your score may go up if your condition worsens or down if it improves.

A small group of people who are critically ill with acute liver failure and likely to die within a week have the highest priority on the waiting list. More information about these scoring systems is available from UNOS at unos.org.

# How long does it take to get a new liver?

It's impossible to predict how long you'll have to wait for a new liver. Sometimes people wait only a few days or weeks before receiving a donor organ. It may take months or years before a suitable donor organ becomes available. Blood type, body size, severity of illness, and availability of donor organs in your geographic region will all affect waiting time.

To facilitate transplantation, OPTN divides the U.S. into 11 geographic regions.



The states comprising each region are as follows:

- **Region 1:** Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Eastern Vermont
- **Region 2:** Delaware, District of Columbia, Maryland, New Jersey, Pennsylvania, West Virginia, Northern Virginia
- **Region 3:** Alabama, Arkansas, Florida, Georgia, Louisiana, Mississippi, Puerto Rico
- Region 4: Oklahoma, Texas
- Region 5: Arizona, California, Nevada, New Mexico, Utah
- **Region 6:** Alaska, Hawaii, Idaho, Montana, Oregon, Washington
- Region 7: Illinois, Minnesota, North Dakota, South Dakota, Wisconsin
- Region 8: Colorado, Iowa, Kansas, Missouri, Nebraska, Wyoming
- Region 9: New York, Western Vermont

- Region 10: Indiana, Michigan, Ohio
- Region 11: Kentucky, North Carolina, South Carolina, Tennessee, Virginia

Every region has a different supply and demand for livers. Some regions may have shorter wait times due to a higher rate of liver donation. To find detailed information about how these regions compare, visit the OPTN website at optn.transplant.hrsa.gov.

### Can I list in more than one transplant center and region?

Yes, OPTN policy allows multiple listing; however, it's up to the individual center to decide whether or not to accept you as a candidate. You probably would **not** benefit from listing at multiple centers in the same region because priority is first calculated among candidates within the local donation area, not for each hospital individually.

If you're considering multiple listing, you should contact staff of the transplant program where you are listed or want to be listed. They will have the most specific information about how they handle requests for multiple listing. For more information, you can find a brochure entitled "Q &A for Transplant Candidates about Multiple Listing and Waiting Time Transfer" by visiting www. unos.org and searching "multiple listing."

# What happens when a donor liver becomes available?

Each transplant center has its own specific procedure, but in most cases the transplant

coordinator will notify you by phone or pager that a liver is available. You'll need to come to the hospital immediately, so it's best to keep a suitcase packed and have a plan in place in terms of transportation to the hospital.

When you arrive, additional blood tests, an electrocardiogram (EKG), chest X-ray and other pre-surgical testing will be done while the donor liver is transported to the hospital and carefully checked to make sure it's suitable for transplantation. If the donor liver is acceptable, you'll proceed to transplant. If not, you'll be sent home to continue waiting. As such, you may come to the hospital more than once.

# What happens during transplant surgery?

Liver transplant surgery is complex and generally takes between six and 12 hours. During the operation, surgeons will remove the entire injured or diseased liver and replace it with the donor liver.

Several tubes will be placed in your body to help it carry out certain functions during the operation and for a few days afterward. These include a breathing tube, intravenous lines to provide fluids and medications, a catheter to drain urine from your bladder, and other tubes to drain fluid and blood from your abdomen. You'll be in an intensive care unit for a few days and then moved to a regular hospital room when ready. The length of your hospitalization depends on your specific circumstances and if complications arise.

### What complications are associated with liver transplantation?

The two main risks following liver transplant are infection and rejection of the new liver by your body's immune system. Your immune system attacks unwanted foreign substances – like bacteria and viruses – that invade your body. But the immune system can't distinguish between the transplanted liver and unwanted invaders, so it may try to attack – or reject – your new liver.

To prevent rejection, all transplant patients must take anti-rejection medications, called immunosuppressants. These drugs are given to suppress your immune system in an effort to ward off rejection of the new liver. However, by suppressing your immune system you become more susceptible to infections. Fortunately, this problem usually lessens as time passes and most infections can be treated successfully with other drugs.

The other thing to be aware of is that liver disease can recur in the transplanted liver. One of the primary problems with hepatitis C patients was universal recurrence of the virus after transplantation. However, with the advent of newer, more effective treatments, hepatitis C can be cured before or after liver transplantation. Patients with advanced liver disease from hepatitis B require lifelong medication to suppress the virus both before and after transplantation. Autoimmune diseases such as primary biliary cholangitis (PBC) and primary sclerosing cholangitis (PSC) may also recur.



# What are the signs and symptoms of rejection?

Rejection does not always cause noticeable symptoms. In fact, sometimes the only way rejection is detected is from routine blood tests. As such, it's very important not to miss regularly scheduled appointments with your medical team.

If there are symptoms, each individual may experience them differently. Some of the more common signs and symptoms of rejection include:

- fever
- headache
- fatigue
- nausea
- loss of appetite
- itchy skin (pruritus)
- dark-colored urine
- jaundice (a yellowing of the skin and whites of the eyes)
- abdominal tenderness or swelling

# How is transplant rejection treated?

Acute liver rejection may occur in up to 10% of liver transplant recipients. It's most common within the first three months after transplantation, but can occur at anytime. To prevent rejection, you must take immunosuppressive medications for the rest of your life. These may include:

- Prednisone
- Tacrolimus (Prograf)

- Cyclosporine (Sandimmune, Neoral)
- Sirolimus (Rapamune)
- Mycophenolate mofetil (CellCept)
- Azathioprine (Imuran)

The dose of these medications may change frequently, depending on your response. Generally, you can expect to take more medications the first few months following transplantation after which time some may be discontinued or the doses lowered. The goal is to maintain a balance between preventing rejection and making you susceptible to infection and other side effects associated with the long-term use of immunosuppressants.

### What is the long-term outlook after a liver transplant?

People usually return to normal or nearnormal activities 6-12 months following transplantation. Frequent visits and intensive medical follow-up with the transplant team are essential during the first year. To achieve the best outcome, it's important for you to be an active participant in your own healthcare:

- Keep all medical appointments.
- Take medications exactly as prescribed.
- Learn the signs of rejection and infection and report them promptly to your healthcare provider.
- Avoid people who have a contagious illness (colds, flu, etc.).
- Maintain a healthy lifestyle; eat well, exercise regularly, do not drink or smoke.

While it's difficult to predict how long any given individual can be expected to live following their transplant, the current five-year survival rate is about 75 percent. The good news is that results from liver transplantation in the U.S. continually improve. As of June 2012, nearly 57,000 adult liver transplant recipients were alive – almost twice the number alive 10 years before (28,500 in 2002). Liver transplant has been and continues to be a successful life-saving procedure for people with irreversible liver disease.

### What can people do to help those who need liver transplants?

Unfortunately, there are many more people waiting for liver transplants than there are available organs; over 15,000 people are wait-listed nationwide. The most important thing you can do is register to be an organ donor. People of all ages and medical histories should consider themselves potential donors. Your medical condition at the time of death will determine what can be donated. To obtain an organ donor card, contact the American Liver Foundation or visit Donate Life America at donatelife.net.

#### **Living Donor Transplantation**

#### Where do donated livers come from?

The person will go through extensive medical and psychological testing to evaluate their appropriateness for donation.

# How are matches for living donation made?

Blood type and body size are critical factors in determining who is an appropriate donor. In living donor transplantation, a portion of the health person's liver is used for transplantation.

# Does the portion of the liver regenerate?

Yes. The liver is the only organ which can regenerate healthy tissue and will regrow to fit the suitable size of the person so the donor's liver will regenerate, and the portion transplanted into the recipient will grow to fit the patient.

### How does the transplant waiting list work for living donation?

Recipients with living donors are evaluated as candidates the same way in which deceased donor transplantation recipients are. The criteria for becoming listed are also the same except recipients with living donors do not have to wait for an organ to become available. Transplant can take place before the recipient is critically ill, which can result in a better outcome.

The transplant team separates its care for the donor and recipient to make sure both parties are being evaluated and taken care of properly. There is often a "cooling off" period when a matching donor is allowed time to reflect upon their upcoming donation and see whether they would like to move forward with surgery.



The length of time for transplantation can vary based on finding a suitable match for the recipient. For those with donor matches, transplant surgery can be scheduled in a matter of weeks whereas individuals waiting for a deceased donor may wait years for a suitable match to become possible.

Since these surgeries are planned, you should begin to think about the following necessities you may need:

- Planning for adequate time off work
- Facilitating pet or childcare, if needed
- Coordinating transportation to and from the hospital
- Packing a bag with necessary health records and insurance information
- Arranging for necessary postsurgery care

# What happens when a living donor becomes available?

Your transplant team should notify you to make you aware of a match. Surgery will be scheduled weeks in advance.

# What happens during living donor transplant surgery?

Living donor transplant surgery time is typically less than those of deceased donor transplant. The operation lasts five to eight hours. Both the recipient and donor undergo surgery at the same time with their own individual transplant teams.

The size of the portion and specific part of the liver that is donated depends on the needs of the recipient. Sometimes the needs of the individual can vary greatly and it also impact the decision on which lobe should be taken for living donation.

The procedure itself involves an incision on the side of the chest. Special instruments are used to gain access to the donor's liver called a retractor. Sometimes vessels are needed from other parts of the body (such as leg) to be used to connect the donated liver.

### What happens after a living donor transplant surgery?

During the first few days your transplant team may keep you in an intensive care unit (ICU) recovery room. Your team will monitor your health and vitals over the span of a few days. Each person's recovery can vary but it is possible both the recipient and the donor could return home in as little as 2-3 days. You will return back to the transplant hospital for follow ups and bloodwork. During the initial recuperation period there may be limits on mobility and diet so it's best to communicate with your team and make sure you understand your discharge plan.

### Where can I find more information about finding a living donor?

More information about living donation can be found on UNOS' website. Please visit the following links to find informative educational pieces:

Finding a Living Donor https://optn.transplant.hrsa.gov/ media/2267/find a living donor.pdf

#### Living Donation Information You Need to Know https://unos.org/wp-content/uploads/ unos/Living\_Donation.pdf

### Where can I find more information about becoming a living donor?

If interested in becoming a living donor, contact your local transplant center to begin the evaluation process.

More information about becoming a living donor can be found on UNOS' website. Please visit the following link to find an informative educational piece: <u>https://transplantliving.org/livingdonation/being-a-living-donor/</u>

#### Facts-at-a-Glance

- A liver transplant is recommended when a person's liver no longer functions adequately enough – from either disease or injury – to keep them alive.
- Liver failure due to cirrhosis caused by hepatitis C is the most common reason for liver transplantation in the United States
- Most donated livers come from deceased donors; some come from living donors who donate a portion of their liver, usually to a relative or friend.
- Over 6,000 liver transplants are performed each year in the United States.
- The five-year survival rate for liver transplant patients is about 75 percent.
- Over 15,000 Americans are on a waiting list for a liver transplant.

#### **Related Organizations**

#### American Transplant Foundation 303-757-0959 americantransplantfoundation.org

**Children's Organ Transplant Association** 

(COTA) 800-366-2682 cota.org

#### **Donate Life America**

804-377-3580 donatelife.net

#### HelpHopeLive

800-642-8399 helphopelive.org

#### National Foundation for Transplants (NFT)

800-489-3863 transplants.org

#### **National Living Donor Assistance Center**

888-870-5002 livingdonorassistance.org

#### Organ Procurement and Transplantation Network (OPTN)

optn.transplant.hrsa.gov

#### Transplant Recipients International Organization (TRIO)

800-874-6386 trioweb.org

#### United Network for Organ Sharing (UNOS)

802-782-4800 unos.org

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#### American Liver Foundation LiverFoundation.org **1-800-GO-LIVER** (1-800-465-4837)

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