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Considering a Liver Transplant



From a Veteran's Point-of-View



By The Hepatitis C Resource Centers

The Basics

“What is a liver transplant?”

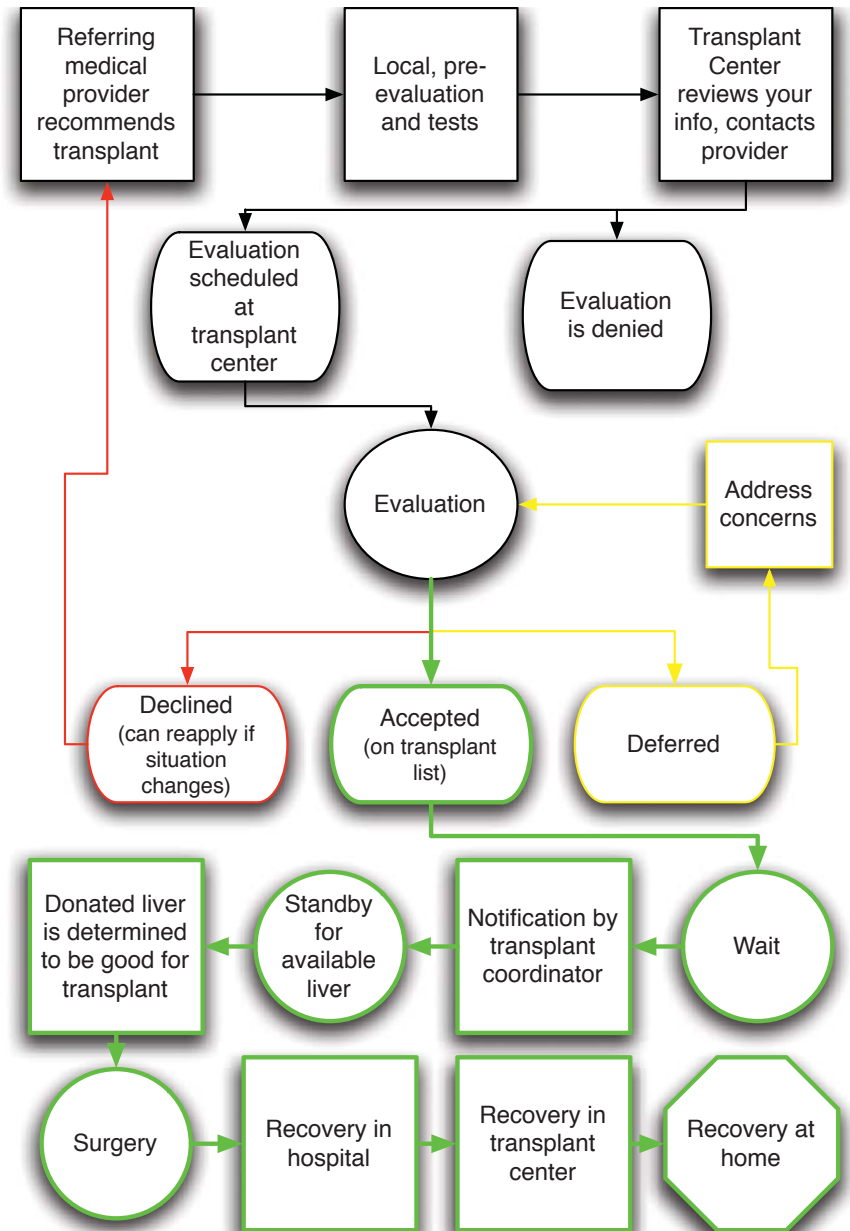
A liver transplant is a surgical procedure that may be recommended by your health care provider if you have a high risk of dying from liver disease. As you will read, getting evaluated for a liver transplant, getting a liver transplant, and recovering from the procedure takes a lot of time and medical attention; it is not a simple task. Several people are involved in the process, not just your health care provider. If your health care provider has suggested that you get a liver transplant, you may be afraid that you will die right away; however, this is usually not the case. It typically takes a long time to go through the entire process, so your health care provider may recommend far in advance that you have a transplant to allow time for all of the necessary steps. This brochure is for people who want general information about liver transplant.

Definitions

A liver transplant replaces a sick liver with a healthy one from someone else. Most of the time, a liver is donated from someone who has died. This was once called a *cadaveric donor* but is now known as a *deceased donor*. When an organ donor dies, the liver is removed by a surgeon and sent to the transplant recipient as quickly as possible. There are a few considerations for finding a good match, which include blood type and size.

In rare cases, a living person (called a *living donor*) donates a portion of their liver. The portion of the donated liver and portion of the sick liver regenerates and grows to normal size. At this time, the VA does not provide living donor transplants. Living donations is a relatively new procedure for adults and have yet to be researched more thoroughly.

Liver Transplant Flow Chart



Resources

Terms

Ascites – Fluid in your belly.

Bilirubin – A pigment detected by blood tests; abnormal levels *may mean the liver is not working well*.

Creatinine – A protein found in the blood; abnormal levels mean the kidneys are not working well.

Deceased donor – A person who donates organs after they are brain dead. Previously called cadaveric donor.

Edema – Having too much fluid in your legs or arms.

Encephalopathy – This is a general term to describe problems with thinking, which may range from confusion to coma. It is caused by the build up of toxins in the brain.

Hepatocellular Carcinoma – Liver cancer.

Immunosuppressants – Drugs that prevent your body from rejecting your new liver.

INR (International Normalized Ratio) – A measure of how your blood is clotting.

Jaundice – The yellowing of your skin or whites of eyes.

Psychosocial support – People, places, things and processes that help you with your functioning.

More information

American Liver Foundation – 800-465-4837 or

www.liverfoundation.org

The Coalition on Donation – 800-330-8620 or

www.shareyourlife.org

National Transplant Assistance Fund – 800-642-8399 or

www.transplantfund.org

Organ Procurement and Transplantation Network – (888) TX-

INFO-1 or www.optn.org

Transplant Patient Partnering Program – 800-893-1995 or

www.tppp.net

Transplant Recipients International Organization (TRIO) – 800-

874-6386 or www.trioweb.org

TransWeb – www.transweb.org

United Network of Organ Sharing (UNOS) – 888-894-6361 or

www.unos.org

Consider this:

You or your loved one may have strong religious, spiritual or moral beliefs about transplants. For some, the idea of having another person's body part in their own body can be uncomfortable. Having a part of one's body removed is a loss that can lead to a variety of emotions. You may wish to discuss these feelings with friends, family, or chaplain.

Statistics

According to the United Network for Organ Sharing (UNOS), nationwide from 1988 to 2006:

- About 5,000 liver transplants occur per year.
- The most common age for liver transplantation is 50 to 64 years.
- The least common age group for liver transplantation is under one year.
- Transplant recipients who have hepatitis C have slightly lowered rates of survival than the average after 3 years.

According to the Organ Procurement and Transplantation Network for transplants performed between 1996 and 2001

- Survival rate for transplants after 1 year is 85.7%
- Survival rate for transplants after 3 years is 77.7%
- Survival rate for transplants after 5 years is 72.1 %
- Because the first liver transplant occurred fairly recently (1984), long-term survival rates are hard to provide at this time.
- As of July 2006, there were 17,148 people nationwide waiting for a liver transplant. Priority is given to the sickest individuals.

Consider this:

You or your loved one may have thoughts and feelings that come up around survival rates. You may feel overwhelmed by the long waiting list. You may have feelings about going through such an extensive process without guarantees. Make sure to voice these concerns to your medical or mental health provider.

When is a liver transplant considered?

A liver transplant is considered when you *might* die from liver disease. In some situations, very severe liver disease may exclude you from receiving a liver transplant if you are too sick to tolerate the surgery and recovery. You may also be excluded if other parts of your body are too sick or have cancer. If cancer originates in the liver (called *hepatocellular carcinoma*) and is detected early enough, a transplant can stop the cancer from spreading.

Before your health care provider recommends a transplant, you will be evaluated by a hepatologist (or another medical professional who specializes in the care of the liver). Other treatments will be considered with the hope that your liver disease can be managed without a transplant. Being told you need a liver transplant does not mean that you are in danger of dying right away.

Your health care provider may think you need a liver transplant if you have symptoms or signs of severe liver disease, which may include:

- Yellowing of skin or whites of eyes (called *jaundice*)
- Fluid in your legs (called *edema*) or in your belly (called *ascites*)

Words from a transplant recipient and a donor's family member

"I was diagnosed with hepatitis C in 1996. I had no idea what the disease was or what its treatment was all about. At the time, there were no support groups and very little in the way of education for veterans; I didn't really know how to take care of myself (or my liver). After a long battle to get help failed, I ended up in liver failure and had to be transplanted. Though the process of evaluation for transplant was trying and at times, overwhelming, my faith and desire to live helped me persevere. My transplant was successful and I'm grateful to be alive. While I am limited in certain respects, I am able to live a very prosperous life. I have found educating and assisting others who struggle with liver disease to be very fulfilling."

Gene Mask, Longview WA
Veteran
Transplanted in 2000

"The best job I've ever had was being Amy's mom. Becoming a donor mom was the result of a tragic accident. Amy gave so much in her short, almost 18 years and now her legacy continues. I am so proud of my daughter and equally as honored to be able to speak passionately about the importance of organ and tissue donation. In a world so full of turmoil, I live in peace and comfort knowing that lives have been saved, families spared the pain of loss, sight restored and bodies mended. So much good out of one very special young lady. Of course, I miss her terribly, but I get to brag about her and all the wonderful good she has done. How cool is that!"

Terry Hegerle, Vancouver WA
Donor Mom
Terry's daughter Amy passed away in 2000

Other Considerations

- You will need to carefully plan travel and consider how you will have quick access to medical care if needed. You may want to avoid traveling to places with high incidence of diseases that could be spread through water, food or bug bites.
- You will have many medical appointments.
- You will still have hepatitis C (if you had it before the transplant).
- You will have a compromised immune system because of the medications you'll take to stop your body from rejecting your liver. This means that your body will be less resistant to fighting off other sickness.
- You will be discouraged from participating in activities that pose a high risk to your health.
- You will need to take medications for your lifetime and may experience unpleasant side effects from them.
- If you are considering having a child, definitely discuss this with the transplant team prior to conceiving.

- Thinning of your muscles, especially in your face, neck, and arms
- Easy bruising or bleeding
- Vomiting blood or passing blood in your stool
- Times when you can't concentrate or become easily confused (called *encephalopathy*)
- Changes in your liver tests that suggest your liver is not healthy

Remember that some of these symptoms may be present in people who DO NOT have severe liver disease. If you are having any of these symptoms, you should contact your health care provider.

Consider this:

You may feel confused about when a transplant is and isn't considered. You may wonder if you need one. You are encouraged to research your important questions on the Internet, library or discuss it with your health care provider.

Cost

The actual liver transplant (surgery) and seven day stay in the hospital usually costs between \$150,000 and \$250,000. The cost of medications following transplant is well over \$12,000 per year. The VA covers the cost of evaluation and transplant for eligible veterans. Some patients whose income level exceeds the threshold may be billed a co-pay for medications and/or services (This will depend on your eligibility).

The Process

“What happens after my health care provider tells me that I need a liver transplant?”

The following information is based on guidelines specific to the transplant center in Portland, Oregon. Recovery and follow-up guidelines are center-specific and may be different from Portland. Remember, this booklet is only a general guide. If your health care provider refers you for a transplant evaluation, you will be given more detailed information to help you through this process.

First steps

Getting evaluated for a liver transplant, getting a liver transplant, and recovering from the procedure takes a lot of time and medical attention; it is not a simple task.

Many health care providers are involved in the process, not just one.

Your referring medical provider (usually a hepatologist, but not always) will order tests to evaluate your liver disease. If he or she believes you would benefit from a transplant, you will need further tests and evaluations. This is called the “pre-transplant evaluation” or “workup,” and may include a mental health and/or substance use assessment. It occurs at your home VA medical center, and it can take several months.

If you decide to use your VA health care benefits, the first step toward a liver transplant is getting approval from the National VA Transplant Office in Washington, DC, for an in-person evaluation at one of the VA transplant centers. This is done by having your “transplant packet” forwarded to a panel of physicians across the

The Pay Off

“A longer and healthier life”.

Usually, you will feel better immediately after surgery and continue to improve as time progresses. Recovery takes between six and twelve months. After the first year you should be “back to normal”; however, your lifestyle will likely change. You will notice physical changes and likely, mental, emotional and spiritual changes as well.

Consider this:

You will experience changes which may be positive, negative or both.

- Liver transplant recipients may feel healthier physically because they have a new liver that functions properly, however they may feel sick from medication side effects or have discomfort from the surgery. There may be other medical conditions that continue or develop.
- Depending on the severity of their condition before the transplant, some may experience more mental clarity.
- Emotions will vary and may include feeling happy and ecstatic about having another chance at life, some may feel depressed considering that their donor may have died to help another person, some may feel guilty because they don't believe they deserve a second chance.
- Some liver transplants recipients may feel closer to God or feel they've been given a spiritual gift of life. While some may feel more spiritual, others will not have any spiritual reaction.

center provides your care and how you are recovering.

Your transplant team will let you know when you can return to work. Remember, the goal of the transplant is for you to return to a normal and active lifestyle.

country for review. If they decide that your condition warrants going further, they will contact a transplant center. There are two primary VA transplant centers: Portland, Oregon, and Pittsburgh, Pennsylvania. There are two other hospitals that the VA contracts with for transplants in Richmond, Virginia, and Nashville, Tennessee. The transplant center will then contact your referring health care provider and tell them when and where your evaluation will be. Your evaluation and transplant may take place in a city or state different from where you live.

If you are using VA benefits, the VA will pay for you and your support person's travel and lodging at a VA transplant center. A social worker or transplant coordinator from the transplant center will call you and schedule the evaluation at the transplant center.

Evaluation

The evaluation will take approximately one week, but it can take longer, so you and your support person (see next paragraph) will need to pack accordingly. You will meet members of the transplant team: the transplant surgeon, hepatologist, transplant coordinators and other staff. You may be given many of the same tests you have already taken in order to have the most recent information on your current health. Your mental and physical health will be evaluated, and your home and personal life will be assessed. You will be asked to complete an advanced directive, which is a written document that tells what you want or do not want if you become unable to make your wishes about health care treatments known.

One of the major concerns for both the evaluation and the transplant is having *psychosocial* (psychological and social) support available. Psychosocial support can be a spouse, family member or a close friend who is able to provide you with support for both the physical and mental aspects of

the evaluation, the transplant, and the recovery. You may additionally be referred to a psychiatrist or mental health therapist for professional support if needed. Your personal support person will need to be available at all times from the time you are evaluated until you are stable and independent as determined by the transplant team. They will need to live with you in the transplant lodging unit after your surgery and provide assistance with all of your needs. This help is crucial for your evaluation, transplantation and your recovery. Some people may have more than one personal support person, so they can share the responsibilities. However, there must be one consistent support person for the first few weeks after surgery. Without adequate support, you will not qualify for a transplant.

Another important aspect of the evaluation will be an assessment of your substance use, including alcohol, illicit drugs, medical marijuana, and tobacco. All of these substances can harm your body and make your transplant less likely to succeed. Prescribed methadone may be acceptable.

The evaluation process is very extensive because there are so many people in need of a liver transplant with far fewer donated livers available.

Accepted, Deferred or Declined

After your evaluation, you will be notified whether you have been:

Accepted – You have met all of the medical, psychological and social criteria and are ready to be placed on a waiting list when any pending tests are completed.

Deferred – You have not been rejected completely but you are not accepted for transplant until your medical or psychosocial issues are taken care of (for example, having a tooth infection or

your health care as your health care providers are. You are part of your own treatment team!

Consider this:

Ultimately, it is up to you to follow all of these recovery recommendations. One of the reasons for extensive screening is to rule out people who may not take care of their new liver. Ideally, someone who is approved is someone who is willing to follow these aftercare guidelines and in doing so, will benefit from the transplant. Those who do not follow medical recommendations run a greater risk of getting sick or dying. Remember that there are a limited amount of donors.

Changes

You will take daily medications that compromise your immune system. These medicines will stop your body from rejecting your new liver.

In the beginning you will see your health care provider frequently. Medical appointments will be less frequent with time (as long as your health remains stable). You will feel better physically because your sick liver has been replaced with a healthier one. If you had hepatitis C prior to transplant, symptoms of hepatitis C that impacted your life may be greatly reduced. You will still have hepatitis C and may need treatment later. The need for this will be monitored.

For the first 3 months after your transplant, your blood will be checked twice a week. From 3-6 months, your blood will be checked once a week. From 6-12 months, your blood will be checked every other week. After one year, your blood will be checked monthly for your lifetime. One of the purposes of this is to watch for any changes in the condition of your transplanted liver. These guidelines will vary depending on which transplant

- Routine tests and labs will be done daily to monitor your progress.

Interim recovery (while at transplant center lodging – usually lasts up to three months)

- Your health care provider will probably see you once a week, but this can vary as your recovery progresses.
- For the first three months you will get your blood tested twice a week, but if there is a need for more, your transplant coordinator will notify you. Your blood tests will indicate to your health care provider if medication adjustments are needed. They also show how your body is responding to your new liver (even before you notice how your body is responding).
- Following a liver transplant, some people develop conditions such as diabetes or irregular chemical levels. They need to receive treatments to address these problems. All liver transplant recipients will be treated with medication called *immunosuppressants* that stops the body from rejecting its new liver.
- Exercise is a major factor in your recovery. Prior to the transplant, your body may have been extremely sick, emaciated and out of shape. You will begin physical therapy, which will assist you in regaining your strength for quicker recovery and teach you how best to exercise in life after surgery.

Recovery at home

- Instructions are given from the liver transplant team to you, your personal support person and your primary medical care provider. They include which lab tests to complete and how often. You will receive recommendations about your visits with your primary medical care provider. You and your support person must have a solid understanding of the medications you'll need to take. In fact, you may feel like a medication expert because you will be just as responsible for

not having adequate social support). Being deferred means that you need to address the concerns raised in the evaluation before your case will be reconsidered.

Declined – You have been turned down for transplant. You may have some medical or social support issues that disqualify you from being on the waiting list. These may include continuous use of drugs, alcohol, or tobacco or other potentially fatal illnesses, such as cancer outside of the liver, or heart disease. If you are a current alcohol and/or drug user, you will be declined. You may need to demonstrate longer abstinence from alcohol and drugs and may be asked to complete an alcohol and drug treatment program to be considered for transplant.

Consider this:

You may be wondering how you will cope if you are deferred or declined a chance to have a transplant. It may be important to consider the factors that could disqualify you. Is this information an incentive to have medical and dental problems addressed now; to become more involved in social relationships; to quit using drugs or alcohol?

Waiting

It is hard to say how long you will have to wait for a transplant once you are on the list. It could be 5 hours to 5 years.

While you wait, continue to take your medications as prescribed. Keep all health care appointments. Make sure your health care provider and the transplant center know of any health changes. Exercise, walk and try to keep up some social activities. Though you may feel too sick to be active, you will have to push yourself to keep active; even short walks will help. If you have concerns about your physical limitations and exercise, discuss it with your health care provider. If you become sicker you need to let your

health care provider know immediately. Also, make sure the transplant center is aware of these changes.

MELD Score

The method for determining who gets an organ that becomes available is complicated. As part of this process, the Organ and Procurement Transplant Network (OPTN) and the United Network for Organ Sharing (UNOS) have developed a system for prioritizing patients waiting for liver transplant. This system, called the *MELD Score* (Model for End Stage Liver Disease), is based on statistical formulas that are very accurate for predicting which individuals are most likely to die soon from liver disease. The number is calculated by a formula using three routine lab tests (*bilirubin*, *INR* and *creatinine*). Generally those with the sickest livers will receive a transplant first.

When your name has come to the top of the waiting list, a transplant coordinator will notify you by phone. Once you are at or near the top of the list, you may need to reside nearby the transplant center. You will need to pack a bag, arrange housing for yourself and your family (VA will assist you) and arrange coverage for finances and aftercare. If you don't live nearby, the VA may provide housing for you and your family. Be prepared to stay for a while. Even though you have been notified that you are at the top of the list you still have to wait for a liver to become available. The wait at the transplant center can be anywhere from 1 day to a year and your stay after transplant is usually 3 months but this can be longer. Make sure you have made arrangements for your mail, and any other services you need to change.

Consider this:

Once you are approved for transplant, all of the conditions that contributed to the approval will continue to be monitored. In other words, just because you have been approved, doesn't mean you can start or resume drinking alcohol, eating poorly or missing health care appointments, etc.

Surgery

When you arrive at the hospital – Many tests will be done the day of the surgery. Although you are at the hospital, ready for surgery, the transplant is not guaranteed until after the hospital has seen the donated liver and the surgeon has determined that it is safe to proceed.

Surgery prep – Occurs the same day of surgery and includes blood draws, consenting and IV.

The surgery – Will last anywhere from 7 to 12 hours (average) after which time you will be moved to surgical intensive care. When you have recovered sufficiently, you will be transferred out of intensive care.

Recovery

Recovery in the hospital

- Typically, you will be in the hospital 7 to 10 days but this could be longer. The transplant staff will want to be certain that you understand your medications and aftercare plan and that your new liver is functioning properly.
- Expect some restrictions (walking, food, weight, visitors), which will be carefully reviewed with your health care provider.