
National Liver Transplant Guide





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Your provider has determined that your liver disease is severe enough that a referral for consideration of liver transplantation is appropriate.

Your transplant guide is designed to be a reference and to help answer some of the questions about the evaluation, transplantation, and post-transplant period. There is space for notes and pockets to hold information. You may want to bring this with you to your clinic visits during the work-up for transplant and during follow-up, while you wait for your transplant evaluation. Your providers may want to use this to teach you about your care. Remember, you are the most important part of the transplant team.

For those who are accepted for continued evaluation at the transplant center, some of this same information will be given to you at that visit. The goal

of this booklet is to help you understand the process (it is complicated!) before you arrive at the transplant center for the final stages of the evaluation. We hope it will provide you and your support person(s) with an overview of the entire process from evaluation to the surgery and aftercare and alert you to some of the issues unique to transplantation that may arise. We also hope it will help you make sure that the possibility of a transplant is the right decision for you (and your family/support person).

There are a great many acknowledgements that need to be made with regard to this book – most importantly, however, it was reviewed and edited by a number of patients (from the Seattle Liver Transplant Support Group) whose suggestions were invaluable. It is a book written for you by knowledgeable providers and others who have actually gone through the process. The result is a book that they felt would have better prepared them for what lay ahead. We hope you, too, find it a valuable resource. While some

of the language in this book may seem “too technical”, most of us (including the post-transplant individuals who reviewed this) felt that the language was necessary since transplantation is a big responsibility requiring knowledge of specific terms and concepts. “Better to start now,” they all said, so here it is.



Transplant Team

Your care as a transplant patient is approached as a team. You are an important part of the team. Other members of the team include the transplant surgeons, hepatologists, house staff, advanced practice nurses, transplant coordinators, social workers, dietitians, pharmacists, psychiatrists, psychologists, research coordinators, and pastoral counselors. While you await your transplant, your Hepatology provider (or in some cases, your Primary Care Provider) and others at your local VA are the team members you will work with until you go to your designated transplant center. These are the people who can answer your concerns and questions during the transplant evaluation and later when you are awaiting your transplant.

Team Members

As part of the transplant process, you

will have a team of specialists and support working with you. This team may include some or all of the following people:

- Transplant surgeon – this is the specialist who will perform your transplant operation. He or she is trained specifically in transplant surgery. The surgery team will follow you daily after your transplantation.
- Hepatologist – this is a specialist trained in the study of liver disease; he or she is also trained in the medical aspects of transplantation and often follows you after surgery along with the surgeons.
- House Staff/Residents and GI/Hepatology Fellows – these are physicians who are still in training and work under the supervision of the transplant surgeon and hepatologists; they are an integral part of the team. They are available to care for you on a 24-hour basis while in the hospital.
- Clinical Nurse Specialist/Practitioner – an Advanced Practice nurse who

will assist in your care.

- Transplant Nurse Coordinator – is a nurse who coordinates all elements of your care; he or she will teach you how to take charge of your own care and will help communicate your questions and concerns to the team during the evaluation and post-transplant time.
- Registered Nurses (RNs) – the nursing staff that will be available to assist with your pre- and post-transplant care.
- Physician Assistants – mid-level providers who will assist in your care.
- Social Worker – will meet with you to discuss concerns about financial issues, housing, and also provide emotional support. The social worker will help you organize the non-medical aspects of your care and can help with referrals to community services.
- Dietitian – will work with you to develop a nutritional program to meet your needs both before AND

after transplant in order to maximize your health.

- **Pharmacist** – an integral part of the team who helps in managing dosage, side effects, and interactions of your new medications. The pharmacist will assist you and your nurse in educating you about your medications prior to discharge.
- **Psychiatrist/Psychologist** – these providers can help address any mental health issues that come up in the transplant work-up and can assist you and your caregiver in exploring your feelings about the process and help with stress management. A psychologist or psychiatrist also conducts a pre-transplant psychosocial assessment that is included as part of your application package for liver transplant.
- **Research Coordinators** – these staff members conduct research studies in order to learn new approaches to transplantation. You may be asked to participate in one or more of these studies. Your participation is

completely voluntary; if you decide not to participate, it will not affect the care you receive.

Your Support Person

One of the most important parts of your transplant team is your support person(s). You may have more than one support person. This may be a spouse, parent, close friend, other family member, or some combination of these individuals. This person's job is to help you during the evaluation process and during the critical period of time before and after your surgery when you will be unable to care for yourself.

Who you choose to be your support person is probably the most important decision you will make if you are going to have a liver transplant. They need to be able to provide you with mental and emotional support as well as physical help during the process. This help is crucial for your evaluation, transplantation, and recovery.

Your personal support person will need to be available at all times from the time you are

evaluated until about 2 years post-transplant. These are some of the specific duties your support person will have to agree to:

- Go with you to the pre-transplant evaluation and follow-up appointments (unless other arrangements are made)
- Assist you with transport to the hospital when called in for transplant (unless other arrangements have been made with the pre-transplant coordinator)
- Attend discharge teaching with the transplant coordinator and learn the information in the discharge teaching manual to help you with your self-care after the operation
- **Help you for 24 hours a day for approximately 3 months after your discharge from the hospital after transplant**
- Learn your medications and assume responsibility for monitoring the

correct administration of medications during the early post-discharge period

- Arrange for safe housing for you upon your discharge from the hospital
- Transport you (or arrange for safe transport) to all clinic, lab, or other appointments

As you can see, your support person will play a major role during this process. We cannot stress enough how vital it is to have this personal help. Without a support person, you will not qualify for a transplant.

 **Basics**

*“What is a liver transplant?
When do I need one? How
do people do after one? Who
pays for it?”*

A liver transplant is a medical procedure that may be recommended by your doctor if you have a significant chance of dying from liver disease in the next 1-3 years. We are born with a liver that has many functions needed to maintain our health. Sustained injury, over time, can lead to decreased function and ultimate failure of the liver. There are many causes for this, with hepatitis C and alcohol being the most common. Patients are typically considered for transplant when the liver is working at roughly 10-20 percent of what is considered normal functioning. A few patients each year are referred for liver transplant on an emergency basis for “acute liver failure” – a condition

that causes the liver to suddenly stop working and can lead to death in 1-2 weeks.

As you will read, evaluation for a liver transplant, receiving a liver transplant, and recovering from the procedure takes time, commitment, and is unique to each patient. The key to a successful transplant is the Transplant Team, which consists of you (the recipient), your caregiver/support person, family and friends, and the group of committed health care professionals working with you.

Definitions

A liver transplant replaces a sick (referred to as **cirrhotic**) liver, or a liver with a tumor, 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. Livers for transplant are matched for body size

and blood type.

In rare cases, a living person donates a portion of their liver (called a **living donor**). The VA has not provided living donor liver transplant as of fall of 2008, however, VA policy has changed and living donor transplantation is now being considered on a case by case basis.

Statistics

According to the United Network for Organ Sharing (UNOS), nationwide from 1988-2007:

- About 6,500 liver transplants now occur per year in the US
- Largest age group is 50-64 years old
- Transplant recipients who have hepatitis C have slightly lower rates of survival than the average transplant recipient after 3 years

According to the Organ Procurement and Transplantation Network (OPTN) for transplants performed between 1997 and 2004 in the US:

- Survival rate:

- 1 year after transplant is 87.7%
- 3 years after transplant is 79.9%
- 5 years after transplant is 74.3%
- Because the first liver transplant occurred in 1984, long-term survival rates are not available.
- Currently (August 2008) there are over 16,000 people nationwide waiting for a liver transplant, with 6,493 transplants done in the US in the last year.

Combined, the VA Transplant Centers (Pittsburgh, Nashville, Portland, and Richmond) performed approximately 100 transplants a year in 2006 and 2007. The VA transplant center in Houston started transplanting patients in 2008.

When is a liver transplant considered?

A liver transplant is considered when you might die from liver disease within the next 1-3 years. 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 starts in the liver and is found early enough, a transplant can still be done and offers the best chance at a cure.

Your medical provider may think you need a liver transplant if you have symptoms of severe liver disease, which may include:

- Yellowing of skin or whites of eyes (**jaundice**)
- Fluid in your belly (called **ascites**) or in your legs (called **edema**)
- Vomiting blood or passing blood in your stool from dilated veins (**varices**) in your esophagus or stomach
- Unclear thinking or confusion (called **encephalopathy**) related to the build-up of toxins which affect the brain
- Changes in your liver tests that suggest your liver is working poorly
- Life-threatening bleeding

- Thinning of your muscles, especially in your face, neck, and arms
- Easy bruising or bleeding (due to low platelet count or decrease in “clotting” protein levels)

To treat these symptoms, you may be prescribed a **diuretic** (or “water pill,” which decreases the ascites and edema by increasing urination), **lactulose** (which gives you diarrhea as it helps you get rid of toxins that make you encephalopathic) or a **beta-blocker** (which lowers your heart rate and blood pressure in order to prevent bleeding from varices). Occasionally, an antibiotic is given to prevent infection in the ascitic fluid.

These medications may seem like unusual ways of controlling liver failure, but they are vital and may extend your pre-transplant life. Stopping these medications can lead to a rapid decline in health, hospital admission, or even death.

Cost

The actual liver transplant (surgery) and the seven-day inpatient stay in the

hospital usually costs between \$150,000 and \$250,000. The cost of medications following transplant is about \$12,000 per year (and up to \$20,000 per year if hepatitis B infection is present). The VA covers the cost of evaluation, transplant, and medications for eligible Veterans, as well as travel to and from the transplant center for the Veteran and their support person. Some patients whose income level exceeds a certain threshold may be billed a co-pay for medications and/or services. In certain circumstances, patients receive a transplant outside the VA system and then return to the VA for follow-up care and medications. This service (follow-up appointments/labs and medication costs) is covered by the VA for eligible Veterans.



Evaluation Process

*“What happens after my
doctor tells me that I need a
liver transplant?”*

The following information is based on procedures specific to the VA transplant center in Portland, Oregon. Recovery and follow-up procedures at other transplant centers may be slightly different from those in Portland. The evaluation process is complex and unique to each patient. The process begins at your local VA and will then continue at the transplant center you have been referred to. It is extremely important to not miss any appointments. Failure to show for appointments significantly decreases your chance of being accepted for transplant.

Evaluation: First steps

If you decide to use your VA healthcare benefits, the first step towards a liver

transplant is getting approval for an in-person evaluation at one of the VA transplant centers. There are five VA transplant centers: Houston, Texas, Nashville, Tennessee, Pittsburgh, Pennsylvania, Portland, Oregon, and Richmond, Virginia. 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 is responsible for you and your support person's travel and lodging to the transplant center that you have listed as your preference.

This process begins when your referring provider (usually a hepatologist, although not always) orders tests to evaluate your liver disease. If he or she believes you would benefit from a transplant, they will discuss this possibility with you and your support person. Should you decide that liver transplantation is something you would like to be considered for, you will do further tests and evaluations. This is called the “transplant evaluation” or “work-up.” **This does not mean you are guaranteed to receive a transplant.**

One of the first steps is often evaluation by a psychologist and a social worker trained in evaluating patients for liver transplantation. Once this is completed and they feel you are a reasonable candidate from their standpoint (remember the importance of social support), other medical tests will be ordered to make sure you are healthy enough to go through with the liver transplant operation. These tests include evaluation of your heart and lungs (chest x-ray, echocardiogram, EKG, pulmonary “breathing” tests, cardiac stress test); numerous blood tests and further evaluation of your liver (abdominal CT scan), and a dental evaluation. In some cases, the work-up may reveal a medical or psychosocial problem that would either 1) lead to further testing or evaluation or 2) exclude you as a transplant candidate.

Once the above is completed and you are found to be a reasonable candidate by your primary physician or hepatologist, the test results are assembled and forwarded to the VA National Transplant Program in

Washington D.C. as part of what is called your “**transplant packet.**” A panel of physicians will review your transplant packet. If they decide that your condition warrants going further, they will assign you to a VA transplant center and contact the center about your case. The VA transplant center will then contact your referring medical provider to tell them where and when your “in-person” evaluation will take place. This process takes roughly one to two months from the time your packet is submitted to the Transplant Office in Washington, DC.

In some cases, the panel may decide to defer a decision because they need more information first.

The **in-person evaluation** at the transplant center (the final steps of the “evaluation process”) usually takes approximately one week, although it may take longer. **Recall that your support person(s)/caregiver will need to be with you for this evaluation.** Lodging will be provided for you both. You will meet members

of the transplant team. 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 re-evaluated, and the transplant team will ask you questions about your home/personal life. You will be asked to complete an **advance 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. At the time of your visit to the transplant center, you will also have a surgeon's talk during which the surgeon will go over the procedure, risks, and some of the issues specific to surgery. You and your support person will have plenty of opportunity to ask questions during your stay there.



Listing Process

*“After all these tests and visits
- then what? Will I get listed?
Who makes that decision?”*

Who makes the decision about transplantation?

Once the final evaluation at the transplant center is complete, your case is presented to the Selection Committee (made up of hepatologists, transplant nurse coordinators, transplant surgeons, psychiatrists, psychologists, social workers, dietitians, and chaplains – many of whom you will have met) to determine if you meet the criteria for transplant. They typically will discuss your case the week after you have been there. You and your referring provider will receive a letter in the mail discussing the results of that decision.

Candidacy is determined mostly by the following:

- Presence of advanced liver disease which cannot be cured by other treatments
- At least 6 months abstinence from alcohol and illicit substances. The patient must demonstrate convincing evidence that substance abuse issues have been addressed and can be determined to be of low risk of relapse in the future
- Ceasing any use of any nicotine products
- Stable, clean, and sober support system
- Full understanding of the transplant process
- Ability to demonstrate commitment and compliance to your medical care
- No active infections
- No other medical conditions (heart, lung, or weight issues) that will interfere with the surgery or your recovery or long term health
- No active cancer, with the exception

of some liver cancers

The Selection Committee will then decide and inform you and your referring provider if you are:

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 some medical or psychosocial issues that need to be taken care of (dental work, substance abuse treatment, ceasing nicotine use, improving social support, or further heart testing). Being deferred means that you need to address the concerns brought up during the evaluation before you can be re-considered for acceptance for listing. There is usually a time limit for this to occur. After all concerns are addressed, your referring provider will contact the transplant center to request reconsideration of your case. Your case will be re-discussed at their Selection Committee Conference where members will review how you addressed their concerns and will hopefully recommend

you be approved for listing.

Declined - You may have some medical or psychosocial support issues that disqualify you from being on the waiting list. Sometimes, it is possible that you can be re-referred at a later date if some of their concerns can be addressed or certain medical conditions improve.

The Wait

If you are accepted for transplantation, your name is placed on the waiting list, according to blood type. 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. The US national average waiting time for liver transplantation has increased steadily each year, rising from approximately one month in 1988 to more than a year in 1999. Currently, about half of patients in the United States wait longer than two years for a liver transplant.

During the waiting period, you will follow-up regularly with the provider who referred you to the transplant center. The provider will be responsible for your care, checking your blood

tests, and reporting to the transplant center if your condition changes. It is always a good idea for you to contact the transplant center as well with any concerns or questions that may be better addressed by them. If you wait more than a year, the transplant center will likely bring you in for a clinic visit to touch base with you, answer any questions, and review the status of your overall health.

How do transplant centers decide who gets transplanted first?

In the United States, the federal government is responsible for regulating the listing of patients and the allocation of organs. The method for determining this is complicated. As part of this process, the Organ Procurement and Transplant Network (OPTN), administered by a non-profit organization, the United Network for Organ Sharing (UNOS), has developed a system for determining which patients waiting for liver transplant should have priority. This system, called the **MELD Score** (Model for End Stage Liver

Disease), is based on statistical formulas that predict which individuals are most likely to die over the next 3 months from their liver disease. The number is calculated by a formula using three lab tests (**bilirubin, International Normalized Ratio (INR), and creatinine**) that are routinely checked each time you see your provider for follow-up. These labs tell us how your diseased liver is doing. The MELD usually varies with each lab draw. Lab work needs to be drawn every three months and sometimes more frequently depending upon how sick you are from liver disease. Generally those with the sickest livers (highest MELD scores) will be prioritized. Patients with liver cancers who meet transplant criteria also receive higher priority.

Your Waiting Time

While you wait, continue to take your medications as prescribed. Maximize your health. Follow recommended nutrition, exercise and lose weight if needed. Exercise, walk, and try to keep up some social activities. Keep all doctors' appointments. Make sure

your doctor and the transplant center know of any health changes. Though you may feel too sick to be active, you will have to push yourself to keep active; even short walks will help. It is very important not to lose too much muscle mass since the surgery is more risky if you are malnourished. Set up childcare or guardianship, if needed; make plans for your pets, if needed. If you have concerns about your physical limitations and exercise, discuss it with your medical provider. If you notice a change in your health, you need to let your medical provider and the transplant center know as soon as possible.

Notification

When your name has come to the top of the waiting list, a transplant coordinator will notify you by phone/pager to come to the transplant center. Once you are at or near the top of the list, you may need to reside near the transplant center for up to 2-3 months since you will need to be at the transplant center within 6 hours from the time you are called for transplant. The transplant center will let you know if this is the case.

Notes

Nutrition

Patients with liver disease have to make changes in their diet in order to adjust for decreased liver functioning and to maintain their overall health. Nutrition recommendations are customized for individual patients, both pre- and post-transplant, by the dietitian with the Liver Transplant Team after a thorough evaluation. The following are general recommendations, however, that often apply to transplant and liver disease patients.

Pre-Transplant

Protein Malnutrition – Many patients with end stage liver disease do not eat enough protein. As you prepare for a possible liver transplant, it is very important that you **NOT** restrict the amount of protein you eat. Patients who do not get enough protein start to look thin in the arms and chest and begin to show indentations in their temples.

An unfortunate side-effect of protein consumption is an increase in ammonia in the bloodstream, which can contribute to encephalopathy (confusion and memory difficulties). This makes it even more important for you to take lactulose as prescribed in order to flush the ammonia from your body, while at the same time eating a sufficient amount of protein in your diet. Good sources of protein include poultry, eggs, fish, tofu, and soy protein.

Low Sodium – Symptoms of advanced liver disease include excess fluid and swelling in the belly (ascites) and in the legs (edema). A high level of sodium, or salt, intake increases the amount of water retained in the body, and this can make ascites and edema worse. So it is very important to stick to a low sodium diet, especially when these symptoms start to develop. Even if you are not currently experiencing ascites or edema, you may want to start getting used to a low sodium diet now since you may have to switch to a low sodium diet later. A diet low in sodium has been shown to have other health benefits for many

patients with high blood pressure or hypertension.

Weight Control – If you are overweight, you should work with your providers on a plan to lose weight sensibly and slowly, without causing malnutrition (especially protein malnutrition). Losing excess weight decreases the strain on your liver and other organs, and will make your recovery from surgery easier. You may have had some discouraging experiences in the past trying to lose weight, but shedding even just a few pounds can have significant health benefits.

Blood Sugar Control – Eating smaller meals more frequently helps reduce the risk of low blood sugar. This also helps with weight control.

Exercise – Exercise is a very important strategy to build up your strength prior to surgery. However, your exercise program has to be sensible and should be discussed with your provider. **DO NOT** lift heavy weights since this can strain varices. Walking is likely the most appropriate type of exercise for

you. You may want to see if there are any “mall walking” hours at a location near your home; these are times when the mall is open to the public before most stores open. If you have difficulty walking or have chronic pain that keeps you from walking a significant distance, then some type of aquatic therapy can help with both building strength and controlling chronic pain. There may be an aquatic therapy program available through physical therapy, and you may be able to follow up on the skills you learn at a pool near your home. Arm strengthening exercises are also good to do.

Avoid Herbal Supplements and Vitamins – Some herbal supplements (such as Kava-Kava) can cause liver failure. Since herbal supplements are not regulated by the Food and Drug Administration or any other agency, it may be hard to know the exact dosage of a particular substance you are taking or the contaminants in the product. At this point in your liver disease, it is best for you to take only what is prescribed by your providers to help prevent any

injury to your liver. Remember that even over-the-counter medications can be potentially harmful so check with your doctor before taking these.

Post-Transplant

Immunosuppressive Drugs –

These are the medications taken after transplant to prevent rejection. The side-effects of immunosuppressive medication can be very hard on the body. Unfortunately, the combination of drugs needed to prevent organ rejection can increase the risk of “metabolic syndrome,” which is a collection of health risks that increase your chance of developing heart disease, stroke, and diabetes. Taking these medications can lead to an increase in your blood pressure, cholesterol, blood sugar, and weight gain. Heart disease is the leading cause of death with post-transplant patients after the first three months, so proper nutrition after transplant is very important to control these changes in your body. The transplant pharmacist will work with you and your caregiver to make sure you understand all your medications.

The liver transplant dietitian will conduct an assessment with you after transplant, and you will get a set of nutritional guidelines based on your individual case. Eating a healthy diet now will help ease the transition to your post-transplant diet. A healthy perspective on nutrition is to think of food as medicine, as important as the medications you will take after your transplant. Eat what your body needs, as recommended, without overdosing on any one thing or neglecting any particular food group.

Notes

Surgery

When you arrive at the hospital - Many tests (blood tests, electrocardiogram and chest x-ray) will be done the day of the surgery. A physician will perform a history and physical. Please bring a complete list of all your medications. 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 – This occurs the same day of surgery. It includes consenting to the surgery and intravenous (IV) line placement.

The surgery – Once in the operating room, an anesthesiologist needs to place a number of tubes, lines, and monitors so you can be safely managed for this big operation. The next thing you will remember is waking up in the Intensive

Care Unit. The surgery lasts anywhere from 7 to 12 hours (average). When you have recovered sufficiently, you will be transferred out of intensive care.

The incision for liver transplantation is quite large – it goes across your abdomen and may extend up toward your chest. Once the incision is made, the surgeon will proceed with removing your old liver (leaving behind parts of the major blood vessels and bile ducts to attach to the new liver). While the new liver is being sewn in, you may be placed on **veno-veno bypass** to allow blood to flow *around* the site where the surgeons are working while returning a normal amount of blood back to the heart. During the surgery, you will receive transfusions of blood products and have blood sent for frequent monitoring of clotting factors, blood counts, and body chemistries. The gallbladder is also removed at the time of liver transplant so that it will not cause problems later, since performing another surgery in that location later would be difficult.

At the completion of transplant, you will be taken to the Intensive Care Unit (ICU). You will be kept on a breathing machine (ventilator) for a day or so and will be followed very closely by the staff there. The average length of stay in the ICU is one day, after which you are transferred to the medical floor/transplant unit.

The Hospital Stay and the Clinic Follow-Up

Recovery in the hospital

- Typically, you will be in the hospital 7 to 10 days, but this could be longer and will depend upon your post-operative course.
- Expect some restrictions (walking, food, weight, visitors), but it will be important for you to get out of bed and moving soon after your surgery.
 - You will be able to see visitors as soon as you are on the transplant floor (visitation policies while on the ICU floor vary by facility).
 - Nutrition recommendations will be different for each individual; you will

meet with a dietitian so that you are well informed of the diet that best suits your unique needs.

- Routine tests and labs will be done daily to monitor your progress.
- You will be ready to leave the hospital when you are walking, eating, comfortable with/and understand your medications and aftercare plan, and have your support person(s) able to care for you.

Interim recovery (clinic follow-up while you are residing at VA transplant center lodging)

Once you are out of the hospital, the transplant team will assume all aspects of your medical care. They can be reached 24 hours a day.

- Your medical provider will probably see you once a week, but this can vary as your recovery progresses.
- For the first two to 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 medical 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).

- For patients transplanted for hepatitis C, routine liver biopsies are done at 3, 6, 12 months and then annually post-transplant to evaluate the severity of recurrent hepatitis C.
- 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 that stops the body from rejecting its new liver.
- You will begin physical therapy, which is a major factor in your recovery. Prior to the transplant, your body was extremely sick, emaciated, and out of shape. Physical therapy will assist you in regaining your strength for quicker recovery.

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 referring or primary medical care provider. You and your support person will have a solid understanding of the medications you will need to take. In fact, you may feel like a medication expert **because you will be just as responsible for your health care as your medical providers are.** You are part of your own treatment team! Do not, however, adjust medications without the knowledge of the transplant team.

Notes



Complications/ Medications

Complications

Because several of these possible complications occur more often in the immediate post-transplant period (defined as first 3 months after transplant), transplant centers require you to remain nearby to allow for frequent monitoring by them so they can look for these events and take care of them quickly.

Related to Surgery:

A liver transplant is a complex process that requires hundreds of steps. While there are a number of possible complications, fortunately most are quite rare. One of the reasons you undergo so many tests before the surgery is to decrease the potential risks of heart attack, stroke or death. Despite all these tests, it is important to be aware that these things can happen. Occasionally, the new liver fails to work;

if that happens, the transplant center does everything they can to find a new liver right away. In addition, one of the new **anastamoses** (connections) of the new liver, with blood vessels or other structures in the abdomen, can develop a complication requiring return to the operating room for repair or other procedures to open up the new connections.

Rejection:

Your immune system helps fight infections. It does this by recognizing self (your own cells and proteins) from non-self (those things that are foreign to your body). Anything it sees as non-self is attacked by your immune system and destroyed. Your new liver naturally is recognized as non-self and is attacked by your immune system. This process is called rejection. To control this natural immune response, your providers give you a combination of immunosuppressive medications (prednisone, tacrolimus, azathioprine, mycophenylate mofetil, cyclosporine, and sirolimus). You must take these medications for life. These medications all have side effects

(discussed later) that often lead to the need to take additional medications to control them.

Occasionally, your immune system still rejects the liver, and additional medications may be added. While it is rare to lose your liver to rejection, untreated rejection can lead to permanent liver damage or even death. Rejection is monitored by routine lab work and letting your medical provider know if you are experiencing any symptoms.

Infection:

Because of the immunosuppression needed to prevent rejection, you will be at increased risk for infections. Occasionally, these infections can be fatal. There are things you can do to help prevent infection such as washing hands regularly, **avoiding exposure to possible airborne fungal spores (e.g. avoiding smoking marijuana,** certain occupational exposures), and avoiding contact with sick persons. You do not need to wear masks after you return home.

Since the immune system also plays a role in fighting cancer, you will be at increased risk for developing certain types of cancers such as skin cancer or post-transplant lymphoma (**PTLD**). The lifetime risk for lymphoma is only 1-2%, however, it emphasizes the need for good follow-up.

Related to Immunosuppressive Medications:

These potent drugs have a lot of side effects and potential long-term complications. These side effects will be monitored at your clinic visits, and your providers will make every attempt to control or decrease medication side effects. Most patients, however, will develop one or more complications, which then need to be managed.

Diabetes, kidney problems, high blood pressure, and high cholesterol are some of the more serious side effects. Some of the more annoying side effects include hair loss, insomnia, diarrhea, nausea, headaches, swelling, and neuropathy (nerve symptoms).

Do not take any new medications

without talking with the transplant center or a physician trained in transplant. Many medications can interact with each other and cause elevated levels of immunosuppression, which may lead to serious toxicity. Even antibiotics, herbal remedies, ibuprofen, and grapefruit can do this!

Medications

When you have a transplant, you will need to learn how to plan for your medication needs after transplant. You will be taking medications every day for the rest of your life. You will want to know about them as much as possible – how to take them, how they work, and their side effects.

Your medications are essential to the success of the operation and to your recovery.

Below, you will find a list of the medications you may be taking. There will be about 10-15 medications taken anywhere from once to four times a day. Over time, the number of drugs is tapered off so that usually by one year, you are taking 2-6 medications every day.

- immunosuppressive medications – help prevent rejection of the new liver; first doses are high and then are tapered down; you will take these for life
- antibiotics/antivirals – taken for the first 3-6 months after surgery when the immunosuppression is highest to prevent viral/bacterial infections
- antacids – taken to prevent stomach upset
- antihypertensives – may be prescribed to lower blood pressure
- diuretics (water pills) – may be needed to remove fluid
- multivitamins, calcium, and vitamin D
- insulin – occasionally needed to treat diabetes caused by the prednisone or other immunosuppressive medications
- cholesterol-lowering drugs – may be started later if you develop high cholesterol
- iron – may be prescribed in some

cases if you have low blood counts

- aspirin – may be prescribed if you had narrowing or blood clots in any of the blood vessels supplying the liver

Other Considerations

- You will need to plan travel carefully 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 insect 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 will take to stop your body from rejecting your liver. This means that your body will be less resistant to fighting off other illnesses.
- You will be discouraged from participating in activities that pose a high risk to your health.

- You will need to take medications for the rest of your life 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.
- You will feel better
- Food will taste better – watch your weight!
- Do not drink, smoke, use drugs – this is a lifetime commitment
- *Always keep the transplant center informed of your address and phone number as they follow you for life*



Houston Transplant Center

The information in this section refers to the Houston Transplant Center and is only applicable to you if this is your designated transplant site. Please remember that each transplant facility may handle transplantation differently.

Team Members

Much like at your local facility, your transplant facility will have a team of specialists working with you on your liver transplant. This team includes:

- Transplant Patient and His/Her Support Person (family/friends)
- Transplant Surgeon
- Hepatologist
- Transplant Nurse Coordinator
- Social Worker
- Dietitian
- Pharmacist

- Psychiatrist
- Program Support

Evaluation at Houston

Once you have been approved for evaluation at the Houston Medical Center by the VA National Transplant Program, you will be contacted by the nurse coordinator in Houston to schedule your evaluation. Your evaluation can usually be scheduled within two months. You should plan to stay for approximately one week, although in some cases you may need to stay longer for additional testing.

When your evaluation has been scheduled, you will receive a packet in the mail listing your appointments for the week. It will also include basic information about the program and the lodging unit. You may receive additional materials from other departments at the medical center, but all scheduling will be coordinated through the transplant office. Please call the office or your coordinator if you have any questions regarding the schedule.

Your referring medical center will arrange necessary transportation for you and your support person. Our social worker will call you one to two weeks before your evaluation to give you information about lodging, provide instructions for your first day of appointments in Houston, and answer any questions you may have.

Lodging Information

The Houston VAMC has provided free lodging at the Fisher House for patients and their support person since the first evaluation in 2007. The new Fisher House includes guest suites with private baths, communal kitchen, living and dining rooms, a library, a family room and a manager's office.

Local Information

Houston is located in the Gulf Coast region of Texas, and has a humid, subtropical climate consisting of hot, humid summers and chilly, mild winters. During the summer months, it is not uncommon for the temperature to exceed 90 degrees F. During these months, light, loose fitting clothing is

highly recommended. A bottle of water for hydration is also suggested. Summer in Houston begins around May-June and ends around August-September. During the winter months, you can expect milder temperatures, averaging a high of 63 degrees F and a low of 45 degrees F. Warm, weather-resistant clothing is suggested for winter. Houston also receives a high amount of annual rainfall, so consider packing a water-resistant jacket or umbrella.

The Michael E. DeBakey VA Medical Center has a total of three ATM machines located throughout the 1st floor. There is a two dollar ATM fee for all non-members of the Smart Financial Credit Union. The Credit Union is open Monday-Thursday, 8:30am-4pm and Friday, 8am-3:30pm. Only cash, debit and credit cards are accepted as forms of payment. Checks will not be accepted.

Contact Information



Houston Liver Transplant Team



Michael E. DeBakey VA Medical Center
2002 Holcombe Boulevard
Houston, TX 77030
Phone: 713.791.1414



Nashville Transplant Center

The information in this section refers to the Nashville Transplant Center and is only applicable to you if this is your designated transplant site. Please remember that each transplant facility may handle transplantation differently.

Team Members

Much like at your local facility, your transplant facility will have a team of specialists and support working with you on your liver transplant. This team includes:

- Transplant Patient and His/Her Support Person (family/friends)
- Transplant Surgeon
- Pharmacist
- Hepatologist
- Registered Nurses
- Social Worker

- Dietitian
- Psychologist
- Chaplain
- Clerical Support Staff

You are encouraged to ask questions; the physicians and nurses are good sources of answers to medical questions. The other team members can answer your questions within the area of their expertise. Trust and rapport provide important links between all members of the health care team. We must be able to work together to treat your disease most effectively.

The Facility

The Nashville Transplant Center is part of the Tennessee Valley Healthcare System. The facility is located approximately four miles from downtown Nashville, in an area that is a combination of residential and business and is easily accessible to the Metropolitan Transit Authority.

Making Arrangements

The staff from the Liver Transplant

program will contact you to schedule your appointment in Nashville for your Transplant Evaluation. Plan to stay in Nashville for one week, from Sunday through Friday.

Local Information

Nashville has a varied climate with distinct changes for each season. The winter months can range from 20 to 50 degrees, with a variety of precipitation. The summer months average 70 to 90 degrees and up. Spring and fall are usually very mild with a comfortable climate.

We suggest that you bring casual, comfortable clothing and walking shoes for both patient and support persons. Don't forget to bring a jacket, sweater, or raincoat as the weather can change quickly. Also, it tends to be cool in the hospital waiting areas.

There are several banks in the area, however without an account they are often not willing to cash personal checks. You are encouraged to bring travelers checks or a debit/check card. There are two cash machines within the VA and

several in Vanderbilt.

What to Expect when Listed

We advise that you have either a cell phone or alternate number for us to use to contact you. Make sure that the staff has all of your current contact information. Travel arrangements will be made with your local VA facility for you to fly by Air Ambulance to Nashville for your transplant.

It is very important that we have your correct contact numbers, as the staff will only try to reach you for one hour.

Travelling to Nashville

Normally, patients are seen in Nashville after being listed for transplant every six months to one year. These visits typically last from one to three days.

When you are called for your transplant surgery, it is your responsibility to call for the Air Ambulance. (They will make arrangements for your ground travel once you are in Nashville.)

Arriving at the Vanderbilt Facility

Have your ground transport take you directly to the Emergency Room. You

and your support person will be taken to a room and preparations will begin for surgery. Be prepared, as this process may take several hours.

After the surgery, you will be taken to the Surgical Intensive Care Unit (SICU). After a short stay in SICU, you will eventually be moved to the Guest House Inn.

Lodging Information

While you are in Nashville for your evaluation and transplant (if you are listed), you will be staying at the Guest House Inn.

When you are discharged from the hospital, you return to the Guest House Inn. There your surgeons will follow you for approximately one month. During that time, you will have labs drawn and have a visit with your surgeon.

Sample Schedule (for Evaluation)

On the next page you will find a sample of the schedule you may have while you are in Nashville for the transplant evaluation.

Sample Schedule

	Monday	Tuesday	Wednesday	Thursday	Friday
7 AM					
8 AM	7:30 AM – Report to Transplant Center				7:45 AM – Dietician
9 AM	Labs # 1405113		8:00 AM – Meet with Program Support Assistant 8:45 AM – Meet with Surgeon	9:00 AM – Psychiatry	9:00 AM – Echocardiogram
10 AM	Breakfast from Kitchen to Canteen	9:00 AM – Psychiatry			
11 AM	Chest X-Ray				
NOON	EKG				
1 PM	Meet with Transplant Center Hepatologist	1:00 PM – Social Work Service	1:00 PM – Meet with Liver Transplant Coordinator		
2 PM	2:00 PM – CT Scan			2:00 PM – Receive Feedback from Psychiatry	
3 PM					
4 PM					

Contact Information



Nashville Liver Transplant Team



Tennessee Valley Healthcare System
Nashville Campus
1310 24th Avenue South
Nashville, TN 37212-2637
Phone: 615.327.4751
Toll-Free: 1.800.228.4973
Fax: 615.321.6350

Notes



Pittsburgh Transplant Center

The information in this section refers to the Pittsburgh Transplant Center and is only applicable to you if this is your designated transplant site. Please remember that each transplant facility may handle transplantation differently.

Team Members

Much like at your local facility, your transplant facility will have a team of specialists and support working with you on your liver transplant. Your team will offer a multidisciplinary and comprehensive approach to your care, and will include:

- Transplant Patient and His/Her Support Person (family/friends)
- Transplant Surgeon
- Transplant Coordinator
- Physician Assistant
- Administrative Support Personnel

- Inpatient Nurse
- Pharmacist
- Nutritionist
- Physical Therapist
- Social Workers

The Facility

The liver transplant program at the VA Pittsburgh Healthcare System (VAPHS) has been in existence since its inception in 1989. At the present time more than 475 liver transplants have been performed offering a success rate which meets or exceeds the national average. In January 2004, the VAPHS began the first independent, in-house VA transplant center in the country. This entailed the VAPHS having its own United Network Organ Sharing (UNOS) charter for liver and kidney transplants. The VAPHS independent transplant center's first year proved to be quite successful. Forty liver transplants were successfully performed between January 10 and December 21 of that year.

The goal of the liver transplant program

is to perform approximately 40-50 liver transplants per year. To enhance its innovative, independent, liver transplant program, the VAPHS hired a team of highly experienced and dedicated surgeons.

Evaluation at Pittsburgh

Once you have been approved for evaluation at the VAPHS by the VA National Transplant Program, you will be contacted by the nurse coordinator in Pittsburgh regarding your evaluation. Your evaluation can usually be scheduled within two to three months on an outpatient basis. If you are in more emergent need of evaluation then direct admission to the VAPHS for an expeditious work up may be required. The usual evaluation time frame is approximately one week but may be longer if you require extensive testing. When your evaluation has been scheduled, you will receive a packet in the mail listing your appointments for the week. It will also include basic information about the program and the lodging unit. You may receive additional materials from other departments at

the medical center, but all scheduling will be coordinated through the transplant office. Please call the office or your coordinator if you have any questions regarding the schedule.

Your referring VA medical center will arrange necessary transportation for you and your support person. Payment for the flight(s) are incurred by your primary VA. Payment for transportation via Yellow Cab from the Pittsburgh International Airport to the VAPHS will be incurred by our facility. Our social worker will contact you prior to your evaluation to make your lodging arrangements. The cost of lodging at one of the various local hotels is incurred by the VAPHS. Meals, incidentals and phone calls are the sole responsibility of the Veteran and/or support person. Those Veterans being evaluated without a support person will be lodged in our Hoptel facility located on 6 East within the medical center. Most units have single patient rooms including private baths, phone, bed, TV and desk area. There is also a community kitchen and socializing

area. Meal tickets for breakfast, lunch and dinner are provided. Patients must be able to function independently in order to be lodged in the Hoptel unit. Individuals must be ambulatory and are responsible for bringing and taking their own medications along with being accountable for paying any out of pocket expenses.

Following your transplant evaluation, the transplant team determines if you are an appropriate candidate for liver transplantation. Once listed for transplant, the waiting time is best estimated by your MELD (Model for End Stage Liver Disease) score and your blood type. Wait times and transportation to the VAPHS when a donor becomes available will be explained to you in detail during your transplant evaluation.

The transplant itself may take 6-12 hours. You are usually in the intensive care unit (ICU) for 2-3 days if you do not incur any complications. From the ICU, you are transferred to the 6West liver unit where surgeons and physicians

assistants continue to monitor your progress and make changes regarding your anti-rejection medications. You can anticipate to stay on the 6West unit approximately 10 days to 2 weeks. From the hospital you will be discharged to the local hotel with your support person for a trial of independent living. You will continue to have bloodwork done on an outpatient basis 2 times per week and be seen in the weekly liver clinic on Fridays. Following a total of 30 days from your transplant and again if you are not incurring any complications, you will be able to return home. Your primary VA will be notified of your post transplant recovery period, lab draw frequency and post operative medications. You will need to return to the VAPHS 4 months post transplant for a T Tube removal. Again, if you incur no complications then you will return to the VAPHS on an annual basis. Your transplant coordinator is your primary contact at the VAPHS and will monitor your condition lifelong.

Local Information

Pittsburgh is located in the western region of Pennsylvania, and has a

humid, subtropical climate. The city's climate features abundant precipitation throughout the year and four distinct seasons. Summer temperatures in Pittsburgh can average with highs in the lower 80s and lows in the lower 60s. The warmest months tend to be July through August. Winter temperatures average with highs in the upper 30s and lows in the 20s.

Pittsburgh receives heavy precipitation due to its position near the Allegheny Mountains, and as such the city is subject to many overcast days. May is the rainiest month of the year due to frequent thunderstorms. A durable, weather-resistant coat or umbrella is highly recommended. February is the driest month in Pittsburgh, but snowfalls are not uncommon and cold-weather garments and sturdy, lined shoes are recommended.

All major banks can be found in the general Pittsburgh area. ATMs can be found in the surrounding areas and within the VA hospital. Some ATMs may require a usage fee.

Contact Information

Liver Transplant Division
University Drive C
Phone: 412.688.6155
Fax: 412.688.6942



VA Pittsburgh Healthcare System
University Drive
Pittsburgh, PA 15240
Phone: 1.866.482.7488

Notes



Portland Transplant Center

The information in this section refers to the Portland Transplant Center and is only applicable to you if this is your designated transplant site. Please remember that each transplant facility may handle transplantation differently.

Team Members

Much like at your local facility, your transplant facility will have a team of specialists working with you on your liver transplant. This team includes:

- Transplant Patient and His/Her Support Person (family/friends)
- Surgeon
- Hepatologist
- Clinical Nurse Specialist
- Pre- and Post- Coordinator
- Social Worker
- Psychiatrist

- Pharmacist
- Dietitian
- Chaplain
- Facilitator

Evaluation

Once you have been approved for evaluation at the Portland VA Medical Center by the VA National Transplant Program, you will be contacted by the nurse coordinator in Portland to schedule your evaluation. Your evaluation can usually be scheduled within two months. You should plan your stay for approximately one week, although in some cases you may need to stay longer for additional testing.

When your evaluation has been scheduled, you will receive a packet in the mail listing your appointments for the week. It will also include basic information about the program and the lodging unit. You may receive additional materials from other departments at the medical center, but all scheduling will be coordinated through the transplant office. Please call the office or your

coordinator if you have any questions regarding the schedule.

Your referring medical center will arrange necessary transportation for you and your support person. Our social worker will call you one to two weeks before your evaluation to give you information about lodging, provide instructions for your first day of appointments in Portland, and answer any questions you may have.

Lodging Information

The Portland VA Medical Center has provided free lodging on the Vancouver campus for patients and their support person since the first evaluation in 1988. A brand new facility, Building 18, was opened in February 2006, and includes 30 double occupancy lodging rooms. Each room includes a television, refrigerator, telephone and private bathroom. Three separate communal areas are defined by large kitchens with adjacent living rooms warmed by gas fireplaces, and opening onto outside patios with gas barbecues. Lodgers also have on-site access to three laundry and

computer rooms, as well as a central exercise room.

Local Information

Winter in Portland and the surrounding area typically lasts from November through March and often includes cloudy skies and rain with high temperatures in the 40s and 50s, and low temperatures in the 30s and 40s. Heavier, warmer, and water-resistant clothing is suggested. Summers in the region, June through September, are often sunnier and offer high temperatures in the 70s and 80s and low temperatures in the 50s. Spring and Fall are transitional. A lighter jacket is recommended for some individuals during these transitional seasons.

All major banks are located in the general Portland area. All types of payment are accepted for most transactions in the area. ATM machines are located by the Canteen Service area in the VA facility and payment for any bills received can be completed by check.

Support Groups

Support groups can be a great way for

you to find support outside of your circle of family and friends. Portland offers two different support groups. Please ask your coordinator for information on how to join one, or both, of these support groups.

- The Hepatitis C Support Group for patients and family members meets every 3rd Wednesday from 10:30 am until noon at the hospital.
- A support group for transplant candidates, recipients and family members meets every Wednesday at 7:30 pm in the Transplant Lodging Unit in Vancouver, WA.

Note: These times may be subject to change. Please verify the meeting times with your coordinator.

Sample Schedule

This is a sample of the schedule you may have while you are in Portland.

Sample Schedule

	Monday	Tuesday	Wednesday	Thursday
8 AM	8:00 AM – Meet Transplant Team 8:15 AM – Photo Taken		8:00 AM – Social Work Service	8:00 AM – Psychiatry
9 AM	8:30 AM – Pulmonary Function Test	8:30 AM – Substance Abuse Treatment Program Evaluation	9:00 AM – CT Scan	9:00 AM – Return urine for creatinine clearance
10 AM	9:30 AM – Chaplain Consult	9:30 AM – Nuclear Medicine/ Dobutamine Echo		10:00 AM – Surgical Clinic
11 AM	10:00 AM – EKG Business Office		10:30 AM – Dietician (bring completed questionnaire and support person)	
NOON				12:00 PM – Take dental antibiotic now
1 PM	1:15 PM – Liver Clinic	12:30 PM – Bone Density 1:00 PM – Echocardiogram		1:00 PM – Dental Consult
2 PM		1:30 PM – Pre-Transplant Nurse Coordinator		

Contact Information



Liver Transplant Office (P3-TRANS)
VA Medical Center
3710 SW US Veterans Hospital Road
Portland, OR 97239
Phone: 503.721.7860
FAX: 503.273.5072



Portland VA Medical Center
3710 SW US Veterans Rd
Portland, OR 97239
Phone: 503.220.8262



Transplant Lodging Unit
1601 E Fourth Plain Blvd
Vancouver, WA 98661
Phone: 360.696.4061

Directions

The links provided below can be opened in your web browser. Just type in the addresses below in your browser's address bar to get directions to the Portland VA Medical Center.

<http://www.visn20.med.va.gov/portland/MC/Maps/Portland.asp>

<http://www.mapquest.com/maps/map.adp?zoom=7&address=3710+SW+US+Veterans+Hospital+Rd&city=Portland&state=Or>

Notes



Richmond Transplant Center

The information in this section refers to the Richmond Transplant Center and is only applicable to you if this is your designated transplant site. Please remember that each transplant facility may handle transplantation differently.

Team Members

Much like at your local facility, your transplant facility will have a team of specialists working with you on your liver transplant. This team includes:

- Transplant Patient and His/Her Support Person (family/friends)
- Surgeon
- Hepatologist
- Clinical Nurse Specialist
- Pre- and Post- Coordinator
- Social Worker
- Psychiatrist

- Pharmacist
- Dietitian
- Chaplain
- Facilitator

Evaluation

Once you have been approved for evaluation at the Richmond VA Hospital, you will be contacted by the nurse coordinator in Richmond to schedule your evaluation.

When you are ready for your evaluation, you will arrive at the Richmond airport and take a taxi to the Hospital Hospitality House, a hotel-like facility near Virginia Commonwealth University Hospital, where you will be lodged during your evaluation period.

The day after you arrive, you and your caregiver will go to the Richmond VA Hospital and have blood and urine tests obtained from the lab, and then report to the Gastroenterology Unit (5A-155). The liver transplant nurse practitioner and coordinator will be there to greet you. You will also meet

with a transplant hepatologist, who will take your full history, give you a physical, and will provide more details about the transplant process.

During the rest of the week, you will have additional interviews at the Richmond VA Hospital with a social worker and psychiatrist or psychologist. You will also undergo additional diagnostic testing.

Toward the end of your evaluation process, you will meet with a transplant surgeon at the Virginia Commonwealth University Hospital. After you meet with the surgeon you will be able to return home. The whole process usually takes between 3 and 7 days.

After your visit is completed, the transplant team will meet to discuss your case and make a decision on whether to list you or not. You will be notified of the team's decision by telephone, as well as by a mailed letter.

Local Information

Richmond has a diverse climate with changing and distinct temperatures

in each season. During the winter months, the average high temperature is 48 degrees F and the average low temperature is 29 degrees F. Heavy winter clothing and a coat is highly recommended. Summer months in Richmond average out at a high of 85 degrees F and a low of 65 degrees F, and these months can be very humid. Spring and fall months tend to be balmy with an average high temperature of 67 degrees F and an average low temperature of 44 degrees F. A light jacket may be required for some individuals.

All major banks are located in the general Richmond area. All types of payment are accepted for most transactions in the area. A federal credit union with an ATM is located within the VA facility.

Contact Information

Hunter Holmes McGuire VA Medical Center
1201 Broad Rock Boulevard
Richmond, VA 23249
Phone: 804.675.5000
Toll-Free: 1.800.784.8381
Fax: 804.675.5585

My Local Facility

Though your actual liver transplantation will take place at a Transplant Facility (i.e. Houston, Nashville, Pittsburgh, Portland, or Richmond), a significant portion of your care and monitoring will still take place at your local hospital. Much of your initial work-up and pre-treatment monitoring will take place at your local facility. Your local facility will also take part in the care of your liver long after your liver transplant.

It is important for you to familiarize yourself with your facility and those that are caring for you, from your primary care doctor to your hepatologist and liver transplant coordinator (if he or she is at your facility and not at the transplant facility).

Use the sections below to keep track of this information.

My Local Facility Name:

**My Local Facility Phone
Number:**

**My Gastroenterology
Department Phone Number:**

My Primary Care Provider:

Dr. _____

Ph #: _____

Email: _____

My Hepatologist:

Dr. _____

Ph #: _____

Email: _____

My Transplant Coordinator:

Dr. _____

OR

Nurse _____

Ph #: _____

Email: _____

Your local facility may have a support group set up for patients, who like you, are a part of the transplant process, either planning to have a transplant, or have had one already. These groups are very useful and are there to provide you with an extra layer of support. If your facility has a support group, please write down that information below. A facilitator is the person leading the group, and the coordinator is usually the person who handles the set up and day-to-day operations for your group. It may also be useful for you to jot down the names of few support group members that you can turn to if you have questions or concerns.

My Support Group Facilitator:

Ph #: _____

Email: _____

My Support Group Coordinator:

Ph #: _____

Email: _____

**Name of Support Group
Member (1):**

Ph #: _____

Email: _____

**Name of Support Group
Member (2):**

Ph #: _____

Email: _____

For some patients, hepatitis C is a cause for their need to have a new liver. If this is the case for you, it may be helpful to know who at your facility can help you manage your hepatitis C, or that manages hepatitis C support groups. (Please keep in mind that some facilities may not have a hepatitis C coordinator.)

My Hepatitis C Coordinator:

Ph #: _____

Email: _____

Other Notes:



Patient Testimonials

Patient testimonials may have been shortened to fit into this booklet.

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, 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, Vancouver WA

Donor Mom

Terry's daughter Amy passed away in 2000

I was transplanted in May 2003. With my transplant came a few bumps, which are very uncommon in the transplant world today. Transplants have changed so much since they started that you can be transplanted one year and the next year something has changed for the better, either with the medications or the procedure. Nine months after transplant I went into rejection and developed bad recurrent hepatitis C. My condition was so bad that I was approved for another transplant, but have not yet needed it. After a lot of great doctors and a very positive attitude and some crazy changes and combinations of meds I'm doing GREAT considering. Through everything I've been through since I was diagnosed with hepatitis C in 1995, I kept a very positive attitude and took one day at a time. Never worried about what was going to happen next. I worried about the problem when it happened. Most of all this is out of our

hands and what happens will happen.

Once I was done with all the requirements needed to get on the transplant list I started feeling much better. The stress was not near as bad. No one person goes through this the same. The important things are STAY POSITIVE and do everything possible to stay as healthy as possible, even if you have a bad day. Remember every day is a different day.

With all that has happened with my transplant and knowing how hard it is to receive one plus get through it. I would do it again tomorrow.

*Paul, Veteran
Selah, WA*

When my husband, Wayne, was diagnosed with liver disease, I had no idea of the amazing journey we would travel together to save his life. Even though I had been in the medical field for 30+ years, my knowledge did not prepare me for the unrelenting demands upon my time and emotions. We began the final road in February of 2002. Wayne endured countless tests during the process of being evaluated and then accepted for a new liver. By January 2003, Wayne was critically ill. He had been transported to the Portland VA from the Seattle VA. He was on life support in the Intensive Care Unit. I lived at the "Liver Lodge" in Vancouver, Washington with other family members who were waiting, being evaluated or assisting their loved ones with recovery. These people became my second family and

I will treasure their friendship always. We were so blessed when the call came to us at 11:00PM on January 30, 2003. A liver had been procured and Wayne was scheduled for surgery early January 31, 2003. Thanks to the wonderful giving of the donor family, Wayne was saved. The recovery was long but worth every minute of the struggle. I cannot begin to thank all of the wonderful members of the Portland Liver Team and the ongoing strength of Wayne's Seattle Hepatologist. Being a "caregiver" is the priority for the patient, but without the continued support of our family, friends and the entire medical team, I would have lost faith many times. The process can be frightening and frustrating, but the new life given and to have the person you love still with you makes all the battles fade from significance. Wayne's priorities center around his home and all his beautiful grandchildren, who are so grateful to have him in their lives. We both are avid supporters of the organ donor program and are available to help others who need assistance, questions answered or a strong shoulder to lean on if this journey is one they decide to travel.

*Nada, wife/caregiver for Wayne, Transplant
recipient
Seattle, WA*

It has been almost three years since I had my Liver Transplant at the VA hospital in Portland, Oregon. The most significant thing about a liver transplant, or for that matter any transplant, is it changes your perspective on

life. You tend to have a one day at a time philosophy. The second most profound aspect would be my caregiver “wife” prior to surgery and post operatively -- because of her perseverance and devotion to a headstrong, cranky and usually unreasonably demanding individual! Simply put, I wouldn't be here today had it not been for her. Since my transplant, I attend a Liver Transplant support group for both post-op liver transplants and for individuals contemplating whether or not to start the process of qualifying for a transplant. These group meetings provide these people the opportunity to get important questions answered from people who have already been through the ordeal. For anyone facing the prospect of getting an organ transplant, it cannot be overemphasized that one maintain a positive mindset. The entire process is physically, emotionally and mentally draining and strong support of family and friends is critical for, at the very least a satisfactory recovery. As I mentioned above, I wouldn't be here if not for a very generous family of the Donor, my wife and the will to survive. I'm generally always available to talk with and answer questions for the entire transplant ordeal, and so is my wife for anyone contemplating a transplant.

*Wayne, Liver Transplant recipient 2003, Veteran
Seattle, WA*



Resources

..... **Liver Transplant Contact Numbers and Web Links**

Organization	Phone Number	Web Link
American Liver Foundation	1.800.435.4837	www.liverfoundation.org
The Coalition on Donation	1.800.330.8620	www.shareyourlife.org
National Transplant Assistance Fund	1.800.642.8399	www.transplantfund.org
Organ Procurement and Transplantation Network	1.888.TX-INFO-1	www.optn.org
Transplant Patient Partnering Program	1.800.893.1995	www.tppp.net
Transplant Recipients International Organization (TRIO)	1.800.874.6386	www.trioweb.org
United Network of Organ Sharing (UNOS)	1.888.894.6361	www.unos.org

..... **Hepatitis C and Liver Disease Web Links**

Health Organization	Web Link
Federal Health Organization	
VA National Hepatitis C Program	www.hepatitis.va.gov
Centers for Disease Control Hepatitis Branch	www.cdc.gov/ncidod/disease/hepatitis
Health Finder	www.healthfinder.gov
Food and Drug Administration	www.fda.gov
National Center for Complementary and Alternative Medicine	nccam.nih.gov
National Institute of Diabetes, Digestive & Kidney Diseases	www.niddk.nih.gov
National Institutes of Health	health.nih.gov/result.asp/323

Hepatitis C and Liver Disease Web Links

Health Organization

Web Link

National Library of Medicine	www.nlm.nih.gov
National Institute of Allergy and Infectious Diseases	www.niaid.nih.gov/default.htm

Non-Federal Health Organization

American Association for the Study of Liver Disease	www.aasld.org
American Gastroenterology Association	www.gastro.org
Hepatitis Foundation International	www.hepfi.org
National Foundation for Depressive Illness	www.depression.org
National Network for Immunization Information	www.immunizationinfo.org
World Health Organization	www.who.int/health_topics/hepatitis/en/
Society of Gastroenterology Nurses and Associates	www.sgna.org

Patient Support

Organization

Web Link

Adverse Event Reporting Program	www.fda.gov/medwatch/index.html
Alcoholics Anonymous World Services	www.alcoholics-anonymous.org
HCV Advocate	www.hcvadvocate.org
Hep C Connection	www.hepc-connection.org
Hepatitis Education Project	www.scn.org/health/hepatitis

Clinical Trials

Organization

Web Link

Clinical Trials Registry	www.clinicaltrials.gov
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Travel Information

Organization

Web Link

CDC Healthy Travel Information

www.cdc.gov/travel/index.htm

Mental Health

Organization

Web Link

Center for Mental Health Services

www.mentalhealth.org

Mental Help Net

www.mentalhelp.net

 **Daily Planner**

This attached daily planner can be used to organize your day-to-day activities and/or times to take your liver medication.

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The Transplant Lodging Center in Portland, Oregon

This transplant guide is dedicated to helping veterans

like yourself by providing information regarding the liver

transplantation process.



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