



**Oregon Health & Science University  
Portland Veterans Affairs Medical Center  
Combined Liver Transplant Program**

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**A GUIDE TO  
LIVER  
TRANSPLANTATION**

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# Oregon Health & Science University (OHSU) Portland Veterans Medical Center (PVAMC)

## LIVER TRANSPLANT TEAM

At OHSU/PVAMC we approach your care as a team. The team consists of highly trained professionals all working together towards your well being. The members of the team include doctors, nurses and pharmacists, as well as social workers, dieticians, and pastors. During your evaluation you will have the opportunity to meet many members of the transplant team. Please bring your support person to the evaluation. It is very important for you both to meet the members of the Liver Transplant Team.

### TEAM MEMBERS

#### **Transplant Surgeon**

This is a doctor skilled in transplant surgery. He/She will be the one to actually perform your transplant operation. After the operation the surgeon will care for you on a daily basis. The surgeon will make changes in your treatment and order new tests based on your progress.

#### **Hepatologist**

This doctor is skilled in diagnosing and treating liver disease. The hepatologists work together with the surgeons to

manage your liver disease prior to the surgery. The Hepatologist will also follow your progress after the surgery.

#### **House Staff**

Oregon Health & Sciences University and Portland VA Medical Center are teaching hospitals. This means doctors such as interns, residents and a hepatology fellow are also assigned to your care. They work under the supervision of your transplant physician and hepatologist.

#### **Advanced Practice Nurse**

These nurses function as nurse practitioners and clinical specialists.

#### **Transplant Nurse Coordinator**

The transplant coordinators are registered nurses. They are responsible for coordinating all the elements of your care. The long-term goal of the nurse coordinators is to teach you how to take charge of your own care so you can reestablish a productive lifestyle.

#### **Social Worker**

The transplant social worker will meet with you to discuss housing needs, insurance issues, financial concerns, and disability, and will also provide emotional support and counseling as well as referrals to community agencies.

### **Dietitian**

The dietitian works with you and your physician to develop a nutritional program to meet your special needs before and after transplant and counsel you on the appropriate diet.

### **Pharmacist**

The pharmacist assists the transplant team in managing the dose, side effects, and interactions of your medications. After transplant, prior to discharge the pharmacist will assist the nursing staff in educating you about your medications. You will have the opportunity to practice setting up your medications prior to going home.

### **Psychiatrist**

The transplant psychiatrist can assist you in exploring your feelings, and offer insight into ways to manage your feelings and stress surrounding transplantation.

### **Pastoral Counselor/Chaplin**

Pastoral counselors on the liver transplant team serve as the ethical consultants for the team. They are available for spiritual counseling, and will assist you in setting up relationships with local churches.

### **Research Coordinators**

In order to find new approaches to transplantation, research must be conducted. At any time during your transplant experience you may be approached to participate in a research study. Participation is voluntary.

### **Primary Care Physician (PCP)**

You need to establish a solid relationship with your Primary Care Physician. You need to rely on this doctor for your general medical needs before and after transplant. A referral to the liver transplant program does not mean a transfer of total care. Your primary care doctor will continue to provide your medical care. The liver transplant program will work closely with your primary care doctor to care for you and your liver prior to and after transplant.

### **Others**

There are many other individuals who work with the transplant team. You may interact with any of them during the course of your transplant experience. The goal of the transplant team is to provide a successful transplant experience for you.

### **YOU!**

You are the most important member of the transplant team. The other members of the team will depend on you to participate in your care.

#### ***You are responsible for:***

- 1) Assuming responsibility for making and attending clinic appointments.
- 2) Getting your lab work done and faxed to the Liver Transplant Office.
- 3) Complying with medical treatments.
- 4) Taking care of yourself before and after transplant.

Input from you regarding your physical, emotional and social needs will help shape your treatment program before and after transplant.

## ADVANCE DIRECTIVE

Turn this document in to the Social Worker. The Advanced Directive is your opportunity to identify a health care representative. A health care representative will make health care decisions for you in the event you cannot make them yourself. It is also your opportunity to define the extent of medical intervention that will be administered if your medical condition becomes very serious. You may change your directive at any time. Simply notify the Social Worker and she will ensure the amended document is correctly forwarded.

For the purpose of liver transplantation it is necessary that you complete the following sections of the Advanced Directive.

**Part B-** (The Appointment of a Health Care Representative). For married couples this usually is a spouse. Your representative may be a sibling, parent, adult child or close friend. It is most important that the representative knows your wishes and be able to advocate for you in a difficult situation.

**Part C-** Not necessary to complete, but you may wish to discuss with your family.

**Part D-** (Witnessed Signature)

**Part E-** (Representative Signature)  
This section documents that your representative accepts the responsibility of being your health care representative.



# LIVER TRANSPLANT EVALUATION

Your doctor has referred you to Oregon Health & Science University (OHSU) or Portland VA Medical Center (PVAMC) for liver transplant evaluation. Not everyone with liver disease should or can have a transplant. The evaluation process will help us find out whether liver transplantation is the best option for you.

## THE “WORK-UP”

The evaluation requires a 4 to 5 day stay in Portland, longer if you are a Veteran’s Administration patient. The evaluation is done on an outpatient basis unless you are critically ill and require hospitalization. You will attend a class that will teach you about transplantation and review information from the pre-transplant packet. You will also have the opportunity to ask questions. During the evaluation you will have appointments with many specialists in addition to members of the liver transplant team. You will also have lab work and diagnostic tests performed. The tests vary for each person but in most cases they include the following:

### **Doppler Ultrasound**

This test uses sound waves to create a picture of the liver and other organs. It can also tell us if the large vessels that flow to and from your liver are open.

### **Electrocardiogram (EKG)**

This test tracks the electrical impulses of your heart. It checks the rhythms in your heart, and can help us to determine the overall health of your heart.

### **Echocardiogram**

This test also checks the health of your heart. Similar to the ultrasound, the echocardiogram checks the health of the chambers of your heart, the valves, vessels and blood flow.

### **Chest X-ray**

This is a picture of your heart, lungs, rib cage and surrounding muscle, tissue and lymph nodes. It will help us identify heart disease, lung disease or other problems in your chest.

### **Pulmonary Function Test**

This is a breathing test which measures the capacity of your lungs by having you breathe in and blow out through a special tube. A blood sample may be drawn from an artery in your arm. This will measure your lung’s ability to carry oxygen and remove carbon dioxide from your bloodstream.

### **CT Scan**

This is a computerized image that shows the size and shape of the abdominal organs and the major blood vessels. It will help to identify any tumors or cancer present in your abdomen.

## **MRI**

This is a magnetic image of your abdominal cavity, and may be done in place of or in addition to a CT scan. This will also help identify any tumors or cancer present in your abdomen.

## **Liver Biopsy**

This is a procedure in which a small piece of your liver is taken with a special needle. A liver biopsy can help determine the type of liver disease you have and how much cirrhosis or damage there may be. It also can identify increased iron deposits in your liver.

## **Colonoscopy**

A special tube with a camera is passed through your rectum into your large intestine to check for bowel disease, masses, bleeding, internal hemorrhoids and polyps.

## **Endoscopy/EGD**

This procedure uses a special scope to look into your throat, stomach and small bowel to find out if you have any enlarged blood vessels or ulcers. You will be sedated during this procedure.

## **24 Hour Urine Collection**

Obtain a large plastic jug from your local doctor or lab. This is to collect a sample of urine that includes all urine passed during a 24-hour period. This test will help us check your kidney function. It is important that you collect it correctly. You must bring a copy of the results with you and provide it to the liver transplant coordinator.

## **Blood Work**

The laboratory will draw many tubes of blood on the first day of your evaluation. Some of the tests will help the team understand the status of your liver disease. Other tests check for viral infections, past infection, HIV, tumor and cancer markers, vitamin and mineral levels. Your blood type will be determined at this time.

Depending on your diagnosis, additional studies may be performed. If any of the tests reveal a potential problem, the transplant team may schedule more tests.



# CANDIDACY

After all the tests and consults are completed, your case is presented to the Liver Transplant Selection Conference. This is held once a week. Members of the liver transplant team are present and your case is discussed. There are two decisions to be made at this time.

First, it will be decided if you meet criteria for a liver transplant. Criteria for candidacy includes, but is not limited to:

- The presence of end stage liver disease, which cannot be cured by other medical treatments.
- Negative HIV test.
- At least 6 months abstinence from alcohol and substance abuse.
- Stable support system, such as family or friends.
- Full understanding of the transplant process.
- Ability to understand and demonstrate compliance with the medical care required.
- No active infections.
- No active cancer, with the exception of some liver tumors.
- No other medical conditions that will interfere with your recovery from a transplant (such as heart or lung disease).

Second, the team will decide your candidate category. Categories of candidacy include:

## Accepted

The person meets criteria for transplant. This status continues unless something is discovered in additional work up that is a contraindication for transplant.

## Deferred

The person does not meet criteria for transplant, further testing and or treatment is necessary. Examples: a medical problem that needs specific treatment, counseling for psychiatric diagnosis, or treatment for past alcohol or drug abuse. When the requirements are completed, the case will be represented at Selection Conference.

## Declined

The person does not meet criteria either due to medical or psychosocial reasons. Individuals who make the choice not to follow through with the recommendations from Selection Conference are declined due to poor compliance with the medical care required.

In light of all these guidelines, the selection of a specific patient will be based on the merit of the individual's candidacy. The team will work with patients on an individual basis to establish their candidacy. It is important to remember that the team relies on you to assume responsibility for coming to appointments and completing all of the recommendations from Selection Conference. The coordinators and secretarial staff in the liver transplant office will work with you to schedule appointments for recommended studies and appointments.

# WAITING FOR LIVER TRANSPLANT

We realize that waiting for your transplant is very stressful. People who are waiting on the list are prioritized for medical need, body size, and blood type. Even though the waiting is difficult, there are things to do while you wait.

Maximize your health - follow the recommended nutrition and exercise programs and lose weight if needed. Get on with your life - continue working if possible and stay involved with as many activities as possible. Start or restart hobbies or activities.

Get prepared - pack a hospital bag and make housing arrangements if you do not live in the Portland area.

## THE WAITING LIST

Once all of the recommendations from Selection Conference are completed and you are an acceptable candidate, we will be able to pursue getting insurance authorization for your liver transplant. Your insurance company will need to review your case, confirming that you meet criteria for transplant, and double checking that there are no contraindications for a transplant. When we receive authorization from your insurance company and hospital administration, we can then proceed with placing you on the waiting list.

PVAMC: Once all of the recommendations from Selection Conference are completed we will be able to proceed with placing you on the waiting list

## UNOS

All transplant centers are part of a computerized organ-sharing network that is governed by the United Network for Organ Sharing (UNOS). UNOS is responsible for regulating the listing of patients and the allocation of organs.

All patients are placed on the national waiting list. The patients listed at transplant centers have Local and Regional priority. OHSU/PVAMC patients make up the local group. The regional group includes the addition of the patients at University of Washington in Seattle and the University of Hawaii. Below is a list of the geographic areas that contribute to the local and regional groups.

**National:** Entire USA

**Regional:** Alaska, Washington, Oregon, Montana, Idaho and Hawaii

**Local:** Oregon, Southern Washington and Southwestern Idaho

Livers for transplant must match for body size and blood type. When you are placed on our local list, you will be put into your blood type subgroup: A, B, AB or O. Within that group you will be placed according to the severity of your liver disease.

## MELD/PELD

The MELD is a system of prioritizing patients waiting for liver transplant. It is a statistical formula that determines that the patient with the greatest need will have the highest priority for the next available liver. The MELD (Model for End Stage Liver Disease) is used for adults and the PELD (Pediatric End Stage Liver Disease Model) is used for pediatric patients. The MELD calculates a number between 6 (less ill) and 40 (gravely ill) and is derived from a formula using three lab values: bilirubin, creatinine (kidney function), and the PT or INR (ability to clot blood).

The PELD is used for candidates under the age of 18 and uses the same lab values to determine a number score, as well as other factors specific to growth and development. PELD scores may range higher or lower than MELD scores.

The MELD/PELD will vary with each lab draw. It is mandatory for patients to have lab work done at least every three months to maintain correct placement on the waiting list. Failure to do so will result in your score reverting to your last lowest score until we receive current lab work and can update your MELD/PELD score.

It is important to understand that during your wait for transplant your condition could deteriorate to the point you would no longer survive transplantation, and therefore would no longer be a candidate. The Liver Transplant Team will do everything possible to keep your status active.

## WAITING TIMES

Waiting times depend on your blood type and the number of donors available and are therefore difficult to predict. If you have questions regarding your waiting time once you are listed please talk to the transplant coordinator.

## WHERE TO WAIT

If you do not live in Oregon, it may be necessary for you to come to Portland to wait for your transplant. When you are listed, the transplant team will watch as you move up on the list. When you are likely to be called for transplant you will be notified to come to Portland. You must arrive at the transplant center within 6 hours from the time you are called in for transplant. If you cannot be here within that amount of time, you need to make arrangements to temporarily move to the Portland area.

**OHSU** candidates who do need to stay in Portland while waiting for transplant should plan for housing for approximately 2 or more months prior to liver transplant. Our Social Worker can give you suggestions for low cost housing.

**VETERAN** candidates who do not live in the local Portland area should plan on staying at the VA Housing Unit during the last few months of waiting for transplant. You will receive a call from the VA office notifying you to come out for the rest of your stay.

## GETTING THE CALL FOR TRANSPLANT

While you wait for your transplant, you will carry a beeper or a cell phone. You may purchase or rent one yourself at any time. Be aware that sometimes people call a wrong number causing your pager to beep, (this is a wrong page). If this is a constant problem, contact the company where you received the pager. Whenever the beeper does go off, call the liver transplant program immediately. Keep the following numbers with you at all times:

### **Liver Transplant Office**

503-494-1220

After Hours & Toll Free

1-800-452-1369

When the time comes for you to receive your transplant, the nurse coordinators will first call your home. If we do not reach you, we will use your beeper number. You will experience many feelings of excitement, relief, and/or fear. We recommend you have someone drive you to the hospital. Check in at the Portland VA hospital admitting office (1st floor). You will then go to the Surgical Intensive Care Unit or 9D.

Some important facts to remember are: Do not eat or drink anything once you have received the call to come to the hospital. There is always a chance that the transplant may be canceled if the liver is inadequate.

## ORGAN SELECTION AND MATCHING

The surgeons are particular about what organs they use for transplant. Any time during the day the surgeons may receive a call to notify them of a potential donor. At this time the donor is worked up with several blood studies, diagnostic studies, and an extensive medical and social history. If the donor meets the criteria as a safe candidate for donation, the surgeons procure (remove/retrieve) the organ. This is the operation the surgeons perform to remove the organ from the donor and prepare it for liver transplant. The final decision to use the organ takes place during the procurement when the surgeon has the opportunity to actually see the liver. If at any time during the procurement process the organ appears to be unsuitable, the surgeons will not use it for transplantation.

Matching for liver transplantation is dependent on two factors.

### **1. Blood Type**

Livers are matched to provided identical transplants. In very rare cases compatible un-identical transplants are done to save the life of a critically ill patient. This is a rare exception. The vast majority of transplants are done by matching the donor blood type to the recipient's blood type.

### **2. Body Size**

It is very difficult to put the liver of a very large person into the body of a small person and vice versa. The surgeons will look at the body size of the donor and try to match that closely to the body size of the recipient.

Unlike kidney or bone marrow transplant, liver transplant does not require tissue typing for a successful transplant.

Due to the matching process for liver transplant, the candidate first on the list is not always the one to receive the transplant. Therefore, we do not number the candidates waiting on the list. We can only tell you when you are getting closer to the top, and estimate when your transplant may occur. As discussed previously, expect to wait for some time to receive your transplant.

*Remember: During your wait for transplant your condition could deteriorate to the point you would no longer survive transplant, and therefore would no longer be a candidate.*

All of the members of the transplant team are working hard to get you on the waiting list and transplanted as quickly as possible. Take this time to promote physical and emotional health. If possible, do not turn your back on your favorite hobbies or activities. You may want to consider starting a new hobby or restarting old ones. Walking is an excellent way to promote your physical well being. Talk to your physicians regarding additional information on physical activity and emotional wellness.



# YOUR LIVER TRANSPLANT SURGERY

You have finally been called in for your liver transplant surgery. You are about to begin your journey through liver transplantation. Your emotions may feel like a roller coaster, and everything seems like a blur. It is important for you to have this day planned out ahead of time. How will I get to the hospital? Where do I go? What do I bring? Try and prepare for all of this ahead of time.

When you get the call for your transplant, you need to arrive at the Portland Veterans Hospital admitting office (1st floor). You will then go to Surgical Intensive Care Unit or 9D at the VA Hospital where the nurses and doctors prepare you for the surgery.

The time before the surgery is very busy. A resident or intern will perform a physical examination and take a complete history. Please bring a complete list of all your medications. At this time you will be asked to sign one or more consent forms giving your permission to the surgeons to perform the surgery.

In addition to the physical, you will receive a chest x-ray, EKG, and blood tests. The doctors will also order medications to cleanse your bowels. The nurses will start an intravenous line (IV) for antibiotics to prevent infection. Finally, you will need to scrub with a special antibacterial soap prior to going to the operating room.

## THE OPERATING ROOM

When it is time, the nurses will take you to the operating room on the 3rd floor of the VA Hospital. Once you are placed under anesthesia the transplant team goes to work. Your abdomen will be scrubbed again with a special cleanser, and your body hair will be shaved around the surgical sites. Several different lines and tubes are placed:

## TUBES, CATHETERS AND DRAINS

### Endotracheal Tube (ET tube)

This is a tube placed in the airway (trachea) that is connected to the ventilator. The ventilator breathes for you while you are under the effects of the anesthesia. Your throat may be sore after transplant.

### Central Venous Catheter (CVC)

This is a large IV line that is placed in one of the vessels in your neck. This line is used for giving you medication, fluids and blood products.

### Urinary Catheter

This is a drainage tube that is inserted into your urinary bladder. It drains your urine into a bag. This helps the doctors and nurses evaluate your fluid status, electrolytes, and kidney function.

### **Nasogastric Tube (NG tube)**

This tube is passed through one of your nostrils, down your throat and into your stomach. It is used for keeping air out of your stomach while you are on the ventilator. We also use it to keep the acidity of your stomach balanced. The nurses can also give medications down this tube.

### **Jackson Pratt Drains (JP drains)**

The surgeons place these drains around your surgical site when they have completed the transplant surgery. The drains have attached large clear bulbs, which catch the blood and fluid that is collecting around your surgical site. Draining this fluid helps to prevent swelling and infection.

### **Bile Drainage Tube**

This is used to drain bile from the biliary tree. This drainage tube is connected to a collection container immediately after surgery. Once the drainage slows down and you are stable the tube is capped. This tube stays in for weeks and will be removed during one of your clinic visits.

## **INCISION**

The surgical incision for liver transplant is very large. It goes across your abdomen in a boomerang shape, and may extend up towards your chest. Once the incision is made the surgeon will proceed with removing your old liver, leaving parts of your major blood vessels and bile ducts. The new liver is inserted and attached to the vessels and ducts. During the surgery you will receive transfusions of blood,

platelets, and fresh frozen plasma. You are placed on a monitor that tracks your heart rate, arterial and venous pressure, and respiratory rate. In addition, your blood is sent to the lab frequently to monitor your chemistries, blood counts and clotting factors.

## **LENGTH OF SURGERY**

The average length of time for a liver transplant is 9 hours. This is never the same for each patient, and may vary from less than 6 hours, to greater than 15 hours. The length of time does not predict the success of the surgery. Patients with a past history of abdominal surgery usually take longer during liver transplant because of old scar tissue present in the abdominal cavity. When the surgery is complete, the surgeons close your incision. The incision is closed on the outside with staples. The staples stay in place for approximately three weeks and are removed during one of your clinic visits. After the incision is closed and you are stable you will be taken back to the ICU.

While you are in surgery, your family and friends can wait in the waiting room on the 3rd floor. If the operating room nurses have time they may come out during the surgery to give you a progress report. One identified spokesperson for the family is helpful when communicating to the nursing staff. The spokesperson passes on information to the rest of the family and anyone calling to see how you are doing.

# YOUR POST TRANSPLANT COURSE

## SURGICAL INTENSIVE CARE UNIT (SICU)

You will wake up from the transplant operation in the Surgical Intensive Care Unit at the Portland VAMC (3D). The sights and sounds may seem strange to you. You will wake up with all the tubes, IV lines, and monitors as described in the previous chapter.

The average length of stay in the SICU is 3 days. This will vary depending on how you respond to the surgery, how quickly you recover from the anesthetic, and how sick you were prior to the transplant.

When you wake up you may experience some confusion due to the anesthetic. Nights and days can begin to blend together. It is not uncommon for your sleep pattern to be interrupted.

When you are stable, the doctors will remove some of the monitors and tubes.

### **Endotracheal Tube (ET tube)**

As soon as your body has metabolized the anesthetic, and you are able to breathe on your own the ET tube will be removed, this usually only takes 24-48 hours. It is common to have a sore throat after this tube is taken out.

### **Urine Catheter**

This might be removed in the SICU if the surgeons feel your kidneys are working well.

The nurses will continue to measure your urine until you go home from the hospital.

When you are stable you will be transferred to the Transplant Unit.

## LIVER TRANSPLANT UNIT

The average length of stay on the Transplant Unit is 7-10 days. This makes your total hospitalization stay approximately 14 days. This varies depending on your overall post transplant recovery course.

After your surgery you may feel many different emotions. Many people feel relief that it is over. It is not uncommon to feel depressed or anxious after the surgery. All these emotions are common and most people feel a little of each.

While you are on the Transplant Unit you have some important responsibilities before you can be discharged.

### **Eating**

When you are permitted to eat you will start with clear liquids. If that is tolerated, you will move slowly to solid foods.

### **Daily Activities**

The nurses will expect you to take part in your own care such as brushing your teeth, bathing, combing your hair, shaving, etc. These activities will help make you feel better.

## **Walking**

You will need help at first, but your strength will increase gradually. Walking helps your body get back into shape, and heal faster.

## **Learning**

You will begin learning all about your new liver, how to take care of it, how to prevent infection, your medications, and your clinic and lab schedule. The coordinators, pharmacists and nurses will teach you how to take care of yourself now that you have your new liver. You will receive a Post Transplant Manual. **THIS IS YOUR LIFE LONG GUIDE** . The transplant team expects you to read the manual during your hospital stay. One of the Transplant Coordinators will come to your room to review the content of the manual, answer questions, and review your medications. Prior to your discharge, you will need to complete a worksheet on the information you learned.

## **Coughing and Deep Breathing**

Your nurse will show you how to perform coughing and deep breathing exercises. These exercises aid in preventing pneumonia and will speed your recovery.

## **Tubes and IVs**

As you continue to improve the tubes and IV's will be removed:

- Nasogastric Tube (NG tube)

As soon as your stomach and bowels begin working, and you are able to pass gas, this tube will be removed from your nose.

- Jackson Pratt Drains (JP Drains)

These drainage tubes are removed as the amount of fluid draining into them decreases to a very small amount.

- Central Venous Catheter (CVC)

This is usually the last line to be removed. It may be removed on the day of your discharge.

## **VISITORS**

The liver transplant team encourages visits from your family and friends. Because of the risk of infection, you should caution your friends and family not to visit if they have a cold, flu or some other infectious disease. For the family and friends that cannot visit it is helpful to have a spokesperson for the group. The spokesperson is the one who gets the current updates and passes the information along. This helps keep the nursing staff from having to take time away from your care to answer a number of phone calls.

## **DISCHARGE**

As you can imagine there is a lot to pull together. The Transplant Team will work very hard to get you discharged, but we depend on you to do your part as well. You need to study your manual, practice with your medications, and follow the medical orders from the physician and nurses.

Upon discharge if you do not live in the Portland area you will need to make arrangements to stay. This is because your progress requires close supervision. Even

though you may be stable enough to leave the hospital, you will still need frequent follow up and frequent lab work. It is important for you to be nearby in case of complications after the surgery. The transplant team also wants you to get your lab work done in Portland. This helps the team keep your medication doses stable.

team will continue to monitor your liver function, and medication levels through routine lab work that is sent to us. We will work with your local doctor in managing your care. You may be asked to return to Portland for follow up visits during the first year, for a one year post transplant anniversary visit. Some patients may return yearly thereafter.

**The Transplant Team will discharge you when:**

- ✓ You are physically stable.
- ✓ You know your medications and can set up each dose.
- ✓ You know your clinic and lab schedule.
- ✓ You pass the discharge review worksheet (checked by the coordinators).
- ✓ You have arrangements for a place to stay when leaving the hospital.

**LAB SCHEDULE**

**Lab Schedule Guidelines:**

Post Transplant	Lab Work
1 month	Monday and Thursday
2-6 months	Every Monday
7-12 months	Every other Monday
>12 months	One Monday a month

**OHSU Distant Patients**

The Transplant Team expects you to stay in the Portland area for up to 3 months after your transplant. During that time the physicians will decide when you are stable enough to go home.

**Veterans Administration Distant Patients**

The Transplant Team expects you to stay in the Portland area for up to 3 months after your transplant. You will stay in the Veteran housing unit, or you may rent your own apartment. The social worker will set up your stay at the housing unit while you are in Portland.

At the end of 3 months you will return to your local doctor for care. The transplant

# COMPLICATIONS

Due to the nature of your transplant surgery and the medications you will take after transplant you are at risk for potential complications. Getting your lab work on time and coming to clinic helps us to recognize signs and symptoms of complications early. The sooner we are able to diagnose a complication, the sooner and easier we can treat it. It is important for you to notify the Transplant Coordinators if you are experiencing signs of complications.

## REJECTION

Rejection is the process by which your body recognizes your transplanted liver as being a foreign protein (not part of the original equipment). The body responds with the immune system, its natural defense against foreign proteins. The immune system attacks your transplanted liver. There are medications that can help prevent your body from beginning a rejection episode. These medications are your anti-rejection or immunosuppression drugs. (These are discussed in the next section.)

### Signs and Symptoms of Rejection

You may experience abdominal pain, fever, increasing weakness or fatigue, changes in the color of your stool and urine. However, if you are getting your lab work on time, it is possible you will not be feeling any symptoms. We usually see changes in your liver function tests even before you experience symptoms.

### Treatment for Rejection

We can only diagnose rejection with a liver biopsy. If you do experience rejection we have medications that we use to stop the process, and resolve the rejection. You may need to come to Portland for the biopsy and treatment, depending on how far out from transplant you are.

## INFECTION

The desired effect of the anti-rejection drugs is immunosuppression to prevent organ rejection. Immunosuppression is the weakening of (suppression of) your immune system. However, because your immune system is suppressed you are at greater risk for infection. There are certain things you can do to help prevent infection including washing your hands regularly, no visits from sick family or friends, wearing a mask when in large crowds or around construction sites, and taking your infection-fighting medications. You will be on some of these medications for the first 6 months after transplant.

### Signs and Symptoms of Infection

You may experience a fever ( $\geq 100.5$ ), body chills and/or a productive cough with greenish mucous, fluid retention and/or weight gain. You may have diarrhea or painful urination. Sometimes symptoms of infection can be as vague as simply not feeling well.

## Treatment for Infection

You first need to have your blood, urine and possibly stool cultured to see where the infection might be. If the infection proves sensitive to antibiotics, you will be treated with antibiotics either by mouth or through intravenous infusion. Sometimes the infection is viral and just has to run its course.

## SURGICAL COMPLICATIONS

Surgical complications can be related to leaking at the sites of connection, or narrowing or obstruction at those sites. The sites of connection are at the bile ducts and blood vessels.

### Signs and Symptoms

You may experience abdominal pain, nausea, fever, jaundice and an overall feeling of illness.

### Treatment for Surgical Complications

You would first need to have the suspected site looked at through ultrasound, angiogram or ERCP (a type of endoscopic procedure). Once the problem site is known the doctors may be able to correct it with a simple stent that keeps the connection open. The site may require surgical repair.

## WHEN TO CALL THE NURSE

It is important to remember that if you experience any signs and symptoms of complications you should call your Transplant Coordinator.

### *Appropriate* times to call the on call nurse coordinator:

You should call the on call coordinator if you think you need to see a doctor immediately or need to be hospitalized. Some examples are:

- ✓ Fever of >100.5 degrees F.
- ✓ Severe abdominal pain.
- ✓ Vomiting that prevents you from taking your medications, food, or fluids.
- ✓ Blood in your stools, or vomiting blood.

### Examples of *inappropriate* calls to the on call coordinator:

- ✗ Not being able to sleep.
- ✗ Medication refills. Medications are not refilled after office hours.
- ✗ Lab and study results. The coordinators do not have your chart at home on call.
- ✗ Waiting several days when you are sick, and finally calling after office hours.  
Call as soon as you feel the symptoms.

Please remember that the coordinators are not in the office when they are on call. Call appropriately when you are having a medical emergency. If you have issues that need attention please call during office hours.

# MEDICATIONS

After your transplant, the Transplant Team will place you on several medications. The medications serve many functions, including prevention of rejection and infection, nutritional support, and other medical needs you may have.

## IMMUNOSUPPRESSION MEDICATIONS

In order to prevent rejection the doctors will prescribe medications that you will take every day for the rest of your life. These medications are given to keep you alive. Some anti-rejection medications you may receive are listed below.

### **Prograf (Tacrolimus)**

This medication is used to prevent acute liver rejection and is taken twice a day. The dose may change based on your blood level.

*Side effects* include but are not limited to high blood sugar, tremors, kidney problems, and headache.

### **Prednisone**

This medication is used to prevent and treat acute liver rejection. You will be started on an IV form of prednisone called Solumedrol immediately after transplant. You will change to oral tablets when you tolerate food. You will receive a taper that will tell you how much prednisone to take on a given day. Most patients will stay on 5 mg. per day for life.

*Side effects* include but are not limited to mood swings, trouble sleeping, fluid and sodium retention, high blood sugar, muscle weakness, bone loss, stomach ulcers, impaired wound healing, acne, cataracts, and glaucoma.

### **Mycophenolate Mofetil (MMF or Cellcept)**

It is used to prevent acute rejection. The dose is twice a day.

*Side effects* include but are not limited to diarrhea, vomiting, reduced white blood cells and/or platelets.

## INFECTION-FIGHTERS

The anti-rejection medications suppress your immune system, which weakens the body's ability to fight infection. You will be given medications to help prevent infection for about 6 months.

The following are 3 examples of medications you may be taking after transplant to prevent infection.

### **Trimethoprim/Sulfamethoxazole (TMP/SMX)**

Known as Bactrim, Septra or Cotrim, this is a sulfa type drug used to help prevent bacterial infections such as *Pneumocystis carinii* Pneumonia, PCP for short. You will take TMP/SMX once a day by mouth. If you are allergic to sulfa drugs you will receive Pentamidine once a month instead.

*Side effects* include but are not limited to nausea, vomiting, rash, itching, or loss of appetite.

### **Vanganciclovir (Valcyte)**

This medication is used to prevent viral infections such as CMV, and herpes simplex I & II.

*Side effects* include but are not limited to headache, nausea, decreased white blood cells and platelets.

### **Mycelex Troche or Nystatin Liquid**

This medication is given to prevent fungal infections such as thrush. You will take one of these preparations 4 - 5 times a day after meals and before bedtime. Women may also use vaginal suppositories once a day at bedtime .

*Side effects* include but are not limited to nausea, vomiting, diarrhea, unpleasant mouth sensations.

## **OTHER MEDICATIONS**

You will be on other medications to protect your stomach from acids and ulceration. Some patients need insulin, others may require high blood pressure medication. It is not possible to know ahead of time what your needs will be. You will have your own medication list prepared for you by the pharmacist prior to being discharged from the hospital. You will have time during your hospital stay to learn about your drugs and practice taking them as if you were at home. Your nurse will supervise this.

## **MEDICATION REFILLS**

When your care returns to your primary care physician you will continue to have your immunosuppression medications filled by the transplant team. All other medications should be refilled through your local doctor.

If you are an OHSU patients who needs a medication refill, call your home pharmacy for the refill.

If you need additional refills, have your pharmacist call the Liver Transplant Pharmacy refill number  
(503) 494-4543

Allow at least 2 working days for the refill request to be completed. Remember the coordinators do not refill medications after office hours.

When your Primary Care Physician resumes your care after your transplant, he or she will handle your medication refills.



# IMPORTANT FACTS FOR OHSU PATIENTS

## FINANCIAL INFORMATION

It is important for you to have a full understanding of what your insurance benefits cover and what expenses are your responsibility. Terms and coverage for transplant vary widely among insurance companies. Read your policy and talk to the insurance company benefits office to understand your coverage. Many insurance companies have a co-payment for services or a deductible. Some insurance companies have a lifetime maximum on transplant benefits and caps on medication coverage.

Medications can create a financial strain on the patient after transplant. These medications are required for the rest of your life. It is very important that you understand what kind of medication coverage your insurance benefits supply. Have a clear understanding of what medication costs are your responsibility.

Some insurance packages do not have adequate transplant benefits to cover the cost of the surgery. If this applies to you, you will need to plan to pay for your transplant in other ways. Some options are to arrange a payment system, fund raising, private funds, or by selling some of your assets.

Other costs to consider are food and

lodging for distant patients and their families when here in Portland and transportation to and from the transplant center. Also consider 'lost time' that your employer does not pay for when you are away from work.

The transplant social worker and financial counselors will help you with any questions you have regarding the costs of transplant.

## REFERRALS

Your insurance company may require you to have an identified primary care doctor such as a general medicine or internal medicine physician. Your primary care doctor needs to approve all the visits you make to the Liver Transplant Program. You need to make sure that your primary care doctor has put through the appropriate paperwork to keep your referral to liver transplant updated. If you need to know how many referrals you have left, call your Primary Care Physician.

# THE LIVER AND HOW IT WORKS

The transplant doctors and coordinators will help you understand your specific liver disease during the evaluation process. The American Liver Foundation has information about the various types of liver disease. Their address and phone number is in the back of this booklet.

**Remember:** For general health concerns you should be seen by your local physician. The liver transplant team can assist with liver disease specific problems as described in this chapter.

## HOW IT WORKS

The liver is the largest internal organ in your body. An average adult liver weighs approximately three to four pounds. The liver is located in the right side of the abdomen just beneath the diaphragm and behind the lower ribs. The liver has a right and a left lobe. The main blood vessels of the liver are the hepatic and portal veins, inferior vena cava, and the hepatic artery. Beneath the liver lies the gallbladder, which is the reservoir for bile. The pancreas also lies below the liver and produces enzymes that aid in digestion.

The liver is responsible for many of the body's metabolic and manufacturing functions, including:

1. The metabolism of carbohydrates into glucose (sugar) so your body can use it for energy.
2. Detoxification (cleaning) of harmful substances from the body, this includes alcohol, drugs and other by-products from what you eat and drink.
3. Production of bile, a yellow-green substance that helps your body absorb fats.
4. Metabolism of basic proteins (amino acids) to ensure proper ammonia and levels are maintained.
5. Production of proteins, including proteins that aid in blood clotting.
6. Maintenance of a normal balance of hormones.
7. Filtering blood to remove bacteria and other particles.
8. Storage of minerals and vitamins for your body's use later on.
9. Host defense to assist in fighting infection

## END STAGE LIVER DISEASE

Due to the complex functions of the liver, even the smallest disturbance in any of the functions has a profound effect on the body.

### Disease Symptoms

- Abnormal clearance of bile
- Jaundice (yellow color of skin & eyes)
- Clay colored stool & dark urine
- Pruritus (itching)
- Decreased blood flow through the liver from cirrhosis (liver scarring)
- Varices (enlarged vessels in throat & stomach)
- Hemorrhoids
- Ascites (abdominal fluid build up) & edema
- Accumulation of bile salts
- Inflammation of the liver
- Abdominal pain & fever
- Impaired glucose & glucagon metabolism
- Fatigue and weakness & high blood sugar
- Reduced clotting factor production
- Bleeding, bruising easily
- Impaired protein metabolism
- Encephalopathy (confusion) & insomnia

There are many diseases that can cause liver failure. The following are some of the most common causes of liver failure in adults.

### Viral Hepatitis

prolonged inflammation of the liver due to viral infection. Patients with chronic hepatitis may develop cirrhosis, portal hypertension and/or cancer. Liver failure

may occur within five years. Symptoms of Chronic Viral Hepatitis can be described as flu-like symptoms and may include fever, fatigue, anemia, pruritus (itching), abdominal pain, jaundice, clay colored stools and dark colored urine, anorexia, nausea and vomiting, varices, ascites, bruising, and prolonged bleeding.

### Hepatitis A (HAV)

This disease is transmitted by drinking water or eating food contaminated with fecal matter containing the virus. Shellfish is also frequently a source. Most people recover from the infection within six months and do not require a liver transplant.

### Hepatitis B (HAV)

Transmission is through infected blood and other body fluids such as semen, vagina secretions, breast milk, saliva and open sores. A high-risk history includes blood transfusions or exposures through needle sticks, IV drug use, multiple sex partners, or sexual intercourse with an infected person. Most people fight off the infection themselves; however 5-10% of those infected progress to be a chronic carrier and may eventually develop liver disease and cirrhosis. Liver transplant is a viable option for treating the symptoms of hepatitis B. Those transplanted will receive special treatments before and after a transplant to keep the virus under better control.

## **Hepatitis C (HCV)**

Previously known as non-A, non-B hepatitis, HCV was identified in 1989 and by 1990 the test was available to identify those infected. HCV is transmitted through exposure to blood infected with the virus. A high-risk history includes blood transfusions, IV drug users sharing needles, tattoos, and multiple sexual partners.

Interferon is approved for treatment of HCV, and works for 10-15% of those infected.

## **Alcoholic Cirrhosis**

Damage to the liver cells from alcohol. Scar tissue forms and is permanent. Individuals who develop liver damage from alcohol should stop using alcohol immediately. In many cases the liver function will improve within six months. Continued use of alcohol will result in further cirrhosis, and increasing symptoms of liver disease and failure. Liver damage can develop from alcohol even if a person is not an alcoholic. Women are much more sensitive to alcohol, and suffer the long-term effects of continued drinking sooner than men. Liver transplant is the only option if liver failure develops from alcoholic cirrhosis.

**If you have liver disease and are still drinking, stop!**

Even if you do not have alcoholic cirrhosis, alcohol can increase the effects of your liver disease. For example, if people with hepatitis C drink alcohol, they will advance to end stage liver disease faster than those who do not drink. Persons continuing to drink alcohol are not eligible for transplant.

Symptoms from Alcoholic Cirrhosis may include: jaundice, weight loss, ascites (fluid around the abdomen), enlargement of the spleen, edema (fluid) in the legs, encephalopathy (confusion), GI bleeding.

## **Primary Biliary Cirrhosis (PBC)**

Slow progressive destruction of the bile ducts that interferes with the excretion of bile from the liver. Substances normally excreted in the bile build up in the blood. Inflammation results and eventually will cause scarring and cirrhosis. The initial cause of PBC is unknown. However, disturbances of the immune system and hormones may play a part. Women are affected 10 times more than men. Symptoms include itching, fatigue, jaundice, fluid accumulation and darkening skin.

## **Primary Sclerosing Cholangitis (PSC)**

Bile ducts inside and outside the liver become narrowed due to inflammation and scarring causing bile to build up in the liver. The result is damage of the liver cells. PSC is more common in men than women. 70% of the patients also have inflammatory bowel disease. Symptoms include fatigue, itching, jaundice, and fever and chills from infection in the bile ducts.

## **Autoimmune Hepatitis**

Progressive inflammation of the liver associated with an abnormality of the immune system. 70% of the patients with autoimmune hepatitis are women. Treatment with Prednisone and Imuran has been shown to decrease symptoms. Symptoms include fatigue, abdominal discomfort, jaundice, aching joints, itching,

spider angiomas on the skin, ascites, and encephalopathy.

### **Alpha-1 Antitrypsin Deficiency**

Alpha-1 antitrypsin is a protein made by the liver important in preventing the breakdown of enzymes in various organs of the body. Adults with this deficiency may also suffer from emphysema. Symptoms from alpha-1 antitrypsin include fatigue, poor appetite, ascites and edema, jaundice, itching, nosebleeds, bruising and varices.

### **Wilson's Disease**

The liver fails to rid the body of copper resulting in excessive amounts of copper in the liver, brain and other organs. Wilson's disease is an inherited disorder. Wilson's disease is a chronic progressive state. However, it can cause acute fulminate hepatitis in which the liver failure progresses rapidly. Other symptoms of Wilson's disease include mental difficulties, unsteady walk, kidney damage and copper in the eyes known as Kayser-Fleischer rings.

### **Hemochromatosis**

An inherited metabolic error in which the body absorbs more iron than the body needs. The iron is stored in the liver, and cirrhosis can develop. Individuals with hemochromatosis usually have bronze to slate gray appearing skin. This condition can affect the heart in the form of abnormal rhythms, or congestive failure. A liver biopsy sent for iron quantity levels helps to diagnose hemochromatosis.

### **Hepatoma**

A malignant tumor in the liver. Sometimes it is possible to surgically remove the tumor. The tumor must be relatively small for transplant to be a successful option. Special treatment to prevent further growth is necessary prior to liver transplant.

## **WHEN TO SEEK MEDICAL ATTENTION**

You should seek immediate medical attention if you experience any of the following liver failure symptoms:

- Vomiting blood or coffee ground-like material
- Blood in your stools or black tar-like stools
- Weight gain of more than 4 pounds in a week
- Shortness of breath
- Confused thinking
- Fever over 100 degrees F

# LIVER FAILURE MEDICATIONS

Your doctors try to minimize your symptoms of liver failure by prescribing medications that control specific side effects. The more commonly prescribed medications are outlined below. If you have any questions regarding these medications, please talk to your physician or nurse.

## **Lactulose**

This is a laxative used to prevent and treat encephalopathy. It decreases the pH in the colon making it difficult for the intestine to absorb ammonia. This decreases the ammonia circulating in your blood and improves mental function.

The dose of Lactulose varies by patient, but is designed to produce 3 to 4 soft stools a day.

## **Neomycin**

This is an antibiotic, which destroys bacteria and reduces toxins in the intestine. It is used to help treat encephalopathy.

## **Furosemide (Lasix)**

This is used to decrease the build up of extra fluid in the feet, ankles, legs and abdomen. Lasix can deplete potassium from the blood stream. Your potassium level is monitored when you are on Lasix and you may require a potassium supplement.

## **Spironolactone (Aldactone)**

This is also used to decrease the build up of extra fluid, without depleting the potassium from the blood. Aldactone can cause

gynecomastia (breast swelling) and tenderness. It may also result in high blood potassium levels.

## **Propranolol (Inderal)**

This medication decreases the pressure in the blood vessels and thus prevent esophageal varices and gastric varices (enlarged blood vessels of the esophagus and stomach). This helps to prevent hemorrhage of these vessels.

## **Zinc Sulfate**

This is a nutritional supplement that replaces zinc in your body. Zinc promotes healing and protects against infection. Liver disease can cause zinc deficiency.

## **Multivitamin**

A nutritional supplement to replace important vitamins and minerals in your body. A prenatal vitamin is commonly prescribed due to the extra minerals it contains.

## **Pain Medication**

Individuals with liver disease may have medication prescribed for pain. Pain medications are closely supervised. We require that you receive your pain medications from one source, either your local physician or the liver transplant program. There are several types of pain medications used. For any questions you have been regarding your medication please talk to the physician prescribing the medication.

*Note:* The transplant coordinators and physician reserve the right to question anyone with suspected problems with pain medications. Abusive behavior will be cause

for investigation by the team, and could potentially inactivate your status as a transplant candidate.

### **Herbal Medications**

Do not take herbal medications. These include but are not limited to capsaicin (cayenne or red pepper), echinacea purpurea, garlic, ginger, ginkgo biloba, ginseng, milk thistle, saw palmetto, St John's Wort, valerian. Other herbal medication that may not be safe at any dose include arnica, belladonna, bryony, calamus, chaparral, coltsfoot, comfrey, European mistletoe, false hellebore, foxglove, germander, henbane, Indian snakeroot, kava kava, licorice (candy is o.k.), life root, lily of the valley, lobelia, ma-huang (Ephedra), male fern, mandrake, oil of worm wood, pasque flower, pennyroyal, periwinkle, pheasant's eye, squill, thorn apple, yellow jasmine, yew, yohimbe. Transplant patients should never take medications or herbs intended to "boost" their immune system.

## **OTHER RESOURCES**

These organizations/web sites can provide you with additional information about liver disease and transplant.

### **American Liver Foundation**

1425 Pompton Avenue

Cedar Grove, NJ 07009

(800) 223-0179

<http://www.liverfoundation.org>

### **American Organ Transplant Association**

(AOTA)

P. O. Box 441766

Houston, Texas 77244

(281) 493-2047

<http://www.a-o-t-a.org>

### **National Foundation for Transplants**

(formerly Organ Transplant Fund)

1102 Brookfield, Suite 200

Memphis, TN 38119

(800) 489-3863

[www.transplants.org](http://www.transplants.org)

### **Transplant Recipients International Organization**

The Northern Brewery

1327 Jones Drive, Suite 105

Ann Arbor, Michigan 48105

(734) 998-7314

<http://www.transweb.org>

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

700 North 4th St.

P.O. Box 2484

Richmond, VA 23218

1-888-TXINFO1

[www.unos.org](http://www.unos.org)