



# The UCSF Liver Transplant Program

*An Introduction for Patients and Their Families*

## Table of Contents

---

1. Introduction
2. What to Expect in the Pre-Transplant Evaluation
3. While You Wait
4. Alternative Options
5. Common Complications of End Stage Liver Disease
6. Medications
7. Dental Work
8. Resources

## 1. Introduction

---

Welcome to the Liver Transplant Program at UCSF. As an introduction to our program, we would like to provide you with a brief overview of the liver transplant process. This will hopefully answer some questions you may have. In this booklet, we include information about the transplant process at UCSF as well as information about treatment options and the waiting list for transplant. We also discuss some common complications of liver disease and recommendations for pain medication.

We are committed to providing you with quality care and information. If you have any further questions, please use the resources located at the back of this booklet.

## 2. What to Expect in the Pre-Transplant Evaluation

---

### *Referrals*

Transplant candidates must be referred to the program by their community physician. Community physicians can make this referral by calling (415) 353-1888. Once a referral is made, the pre transplant scheduler will call to schedule the patient for a Phase I liver transplant evaluation.

### *Phase I Evaluation*

At UCSF, the liver transplant evaluation is done in two phases. Phase I is the first step in helping the Liver Transplant Team determine if transplantation is an appropriate treatment option. This Phase I evaluation is done at the UCSF Transplant Clinic. The evaluation starts at 7:00 am and ends somewhere between 2:00 and 4:00 pm. You must have a support person accompany you to this evaluation.

### **On the day of your evaluation you:**

- must have a support person accompany you to your appointment
- should bring a snack to eat after the ultrasound is done
- should bring a list of your medications (including doses)
- any medical records that you may have

### **On the day of your evaluation you will consult with a:**

- transplant coordinator
- hepatologist (liver specialist)
- transplant surgeon
- transplant social worker
- financial counselor
- liver transplant support group

## *Herbal Medications*

Many patients like to use herbal medications along with their prescribed medications. Milk Thistle is a popular herbal medication taken by many patients with liver disease. Milk Thistle is one of the herbal medications that liver patients may safely take. However, there are many other herbal medications which are harmful to the liver. Don't take other herbal medications without first discussing this with your transplant physician.

## **7. Dental Work**

---

It is important that you have your teeth in good repair prior to transplant in order to prevent post-transplant infections. If you need dental work, you may receive Novocain as a local anesthetic. If your platelet count is low and/or you have a prolonged bleeding time due to your liver disease, you may need to receive an infusion of platelets or fresh frozen plasma prior to a tooth extraction. Your dentist will need to check your blood work before extracting any of your teeth.

## **8. Resources**

---

### *Contact Information for Transplant Team*

Mailing Address: 350 Parnassus Ave, Suite 805, San Francisco, California 94117

Message line: 1-800-548-3789

Appointment scheduling line: (415) 353-2318

24 hour emergency contact line: (415) 353-1888

### *Fax lines:*

Pre-transplant patients: (415) 353-2558

Post-transplant patients: (415) 353-8917

### *Web Sites*

- <http://www.ucsfhealth.org/livertransplant> (UCSF site)
- <http://www.unos.org> (UNOS site)
- [www.transplantliving.org](http://www.transplantliving.org) (UNOS website for patients)
- [www.ustransplant.org](http://www.ustransplant.org) (Scientific Registry of Transplant Recipients)
- [www.liverfoundation.org](http://www.liverfoundation.org) (The American Liver Foundation)

### *Hepatic Encephalopathy*

Encephalopathy is a change in level of consciousness, thinking, and behavior. Encephalopathy is caused by a sick liver's inability to clear ammonia from the bloodstream. Some patients with encephalopathy may suffer from day-night sleep pattern reversal, develop shakiness or become comatose. Encephalopathy can be treated by the use of medications. It is very important that caregivers keep a close eye on the patient and notify the patient's physician if the patient's confusion gets worse. Patients with encephalopathy should never drive.

### *Variceal Bleeding*

Patients with end stage liver disease have scarred (cirrhotic) livers that cause high pressure in the liver vessels. This high pressure causes vessels found in the stomach, esophagus, and intestines to become swollen. These swollen vessels are called varices. Varices can burst and cause internal bleeding. When this occurs, patients may vomit blood or pass blood in their stool. This is a medical emergency. If this occurs, you must be evaluated in your local emergency room immediately.

### *Liver Cancer*

Patients with cirrhosis (scarring of the liver) are at higher risk of developing primary liver cancers. This is especially true if you have cirrhosis caused by Hepatitis B, Hepatitis C, alcohol, or fatty liver disease. Patients with these diseases should have an imaging study of their liver (ultrasound, CT or MRI) done every six months to screen for liver cancers. These patients should also have a blood test called an Alpha-fetoprotein (AFP) done every six months. We are able to successfully transplant patients with small liver cancers. While you wait for transplant, you may have procedures done (chemoembolization, radiofrequency ablation or hepatic resection) to prevent the cancer from growing while you wait for a liver to become available. UNOS provides cancer patients with additional MELD points.

## **6. Medications**

---

### *Pain Medication*

There are many pain medications that patients with end stage liver disease should avoid.

- Aspirin-can cause bleeding
- Ibuprofen, Motrin, Advil, and other non steroidal anti inflammatory drugs-can cause kidney failure
- Narcotics (Vicodin, Codeine, Darvon, Darvocet, etc.)-can cause confusion

Do not use these medications unless your transplant hepatologist says that you may do so. Tylenol is the best pain medication for patients with end stage liver disease to take. Patients with liver disease can take Tylenol as long as they take no more than two grams or 2000 mg per day (no more than 4 extra-strength pills per day).

### *Sleeping Pills*

Many prescribed sleeping pills cause confusion in patients with end stage liver disease and are often addicting. If you are having difficulty sleeping, your transplant hepatologist may recommend other medications such as Benadryl, trazadone or melatonin.

## 4. Alternative Options

---

### *Living Donor Transplant*

Usually, livers for transplantation are obtained from people who have died and whose families have given permission for their organs to be donated. However, there are not enough of these donors available. Due to the organ shortage, many patients waiting for liver transplant die on the list or become too sick to undergo transplant.

In light of the organ shortage, living donor liver transplantation may be an important alternative for some transplant candidates. In living donor liver transplantation, a piece of liver is surgically removed from a live donor and transplanted into a recipient after the recipient's diseased liver has been removed. Living donor liver transplantation is possible because a healthy liver has the ability to regenerate. A donor can be a family member or close friend of the recipient. A donor must be between 18 and 55 years old, in good general health, and have a compatible blood type. Please notify our Living Donor Nurse Coordinator at 1-800-548-3789 if you have additional questions about live donation.

### *High Risk Donors*

A "high risk" donor liver poses a higher risk for not functioning well or of transmitting disease to the recipient. However, it is an appropriate option for a patient who is very symptomatic with complications of liver disease, but whose MELD score is still too low to receive a transplant. The Transplant Team will provide you with more information on this option and help you decide if it is right for you.

### *Disease Transmission in Donated Organs*

All organs are carefully tested and screened prior to transplant for viruses, infections, cancers, etc. Despite this screening, in very rare circumstances, undetected viruses, infections or cancers can be transmitted to recipients.

## 5. Common Complications of End Stage Liver Disease

---

### *Ascites/Edema*

Patients with liver disease often accumulate fluid in their legs/feet (edema) and within their abdominal cavities (ascites). Patients with ascites/edema must adhere to a low sodium (table salt) diet-no more than 2 grams of sodium per day. It is also important to avoid white salt substitutes which are high in potassium. Water pills (also called diuretics) are often given to patients with ascites/edema. These medications may alter your electrolyte levels and may affect your kidney function. Your local doctors will monitor your kidney function/electrolytes levels via blood tests while you are on these water pills. If your ascites/edema cannot be managed with sodium restriction and water pills you may need to have the fluid drained. For some patients, a TIPS procedure may be considered. A TIPS procedure involves placing a small tube in the vessels of the liver to decrease fluid pressure.

### *Spontaneous Bacterial Peritonitis (SBP)*

Patients with ascites may develop an infection in their abdomen. This is called spontaneous bacterial peritonitis (SBP). Symptoms of SBP include abdominal pain, fever, chills and feeling ill. It is important that you report these symptoms immediately to your local physician. SBP is treated with a course of antibiotics and may require hospitalization.

**You will also undergo some preliminary tests including:**

- blood/urine tests
- abdominal ultrasound with Doppler-this exam is done to image your liver and view the blood vessels of the liver

*Team Conference*

After your Phase I evaluation is complete, your case will be presented at a weekly transplant conference. Its purpose is to determine the severity of your liver disease and to make preliminary recommendations regarding your future care and possible transplant candidacy.

*Phase II Evaluation*

If listed, the Phase II of the evaluation is generally done with your local physician. We will send a letter to you and your local physician outlining the Phase II tests that need to be completed.

*Activation*

Once all of your test results are completed, received, and reviewed by the transplant team your case will be reviewed again by your hepatologist. We will send a packet to your insurance company to seek authorization for your transplant. You will need to get a pager/beeper or cell phone so that we can reach you once an organ becomes available. We will also ask you and your support person(s) to come to a patient education class. The patient education class will give you more information about the transplant surgery, the transplant hospitalization and common post transplant complications, medications and care.

**3. While You Wait**

---

*MELD Scores*

Patients are listed on the deceased donor transplant waiting list by their blood type and MELD score. The Model for End Stage Liver Disease (MELD) is a numerical scale ranging from 6 (less ill) to 40 (gravely ill). UNOS uses MELD scores to prioritize patients on the waiting list. If a patient is listed, more information on MELD scores will be provided.

*Waiting on the List*

While you are waiting on the liver transplant list, it is important for you to notify us if your phone number, address, or insurance changes and if you are admitted to your local hospital. Your insurance company may mandate that you get authorizations for follow up appointments with UCSF. If you are unsure if your insurance company requires authorizations for these follow up appointments, please contact your insurance case manager or our UCSF financial counselor at (415) 353-8776. While you wait on the list, you need to continue to get care from your primary care physician and your local gastroenterologist.

