

Living with Your New Liver

Patient Information About Hospitalization and Preparing to Care for Yourself at Home

California Pacific Medical Center's Liver Disease Management & Transplant Program has developed this manual as a learning tool to assist you during your liver transplant hospitalization and return home. This information is designed to help you reach your optimal level of health. We encourage your questions, suggestions and concerns and have provided "notes" sections throughout the manual for your convenience.

Your *participation* and *compliance* is necessary for a successful transplant outcome. The Liver Transplant Program functions as a team of which you, the patient, are the most important member.

**24-hour transplant service phone number:
415-600-1000**

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Emergency Information

If you become very ill following your discharge from California Pacific Medical Center, you should consider the illness as potentially serious and seek medical help immediately. **Call 911 in emergency situations and have an ambulance take you to the nearest hospital if you experience any of the following:**



- **Chest pain**
- **Difficulty breathing**
- **Unconsciousness**
- **Significant bleeding (or vomiting blood, bloody stools)**

The Liver Transplant Service’s 24-hour emergency line is 415-600-1000. This number enables you to reach the transplant doctor “on call” for patient emergencies. When you call the Liver Transplant Service’s emergency line, provide the following information:

- Patient’s full name
- Date of birth
- Area code and phone number where you can be reached
- Specific reason for call
- Name of hospital to which patient is being taken

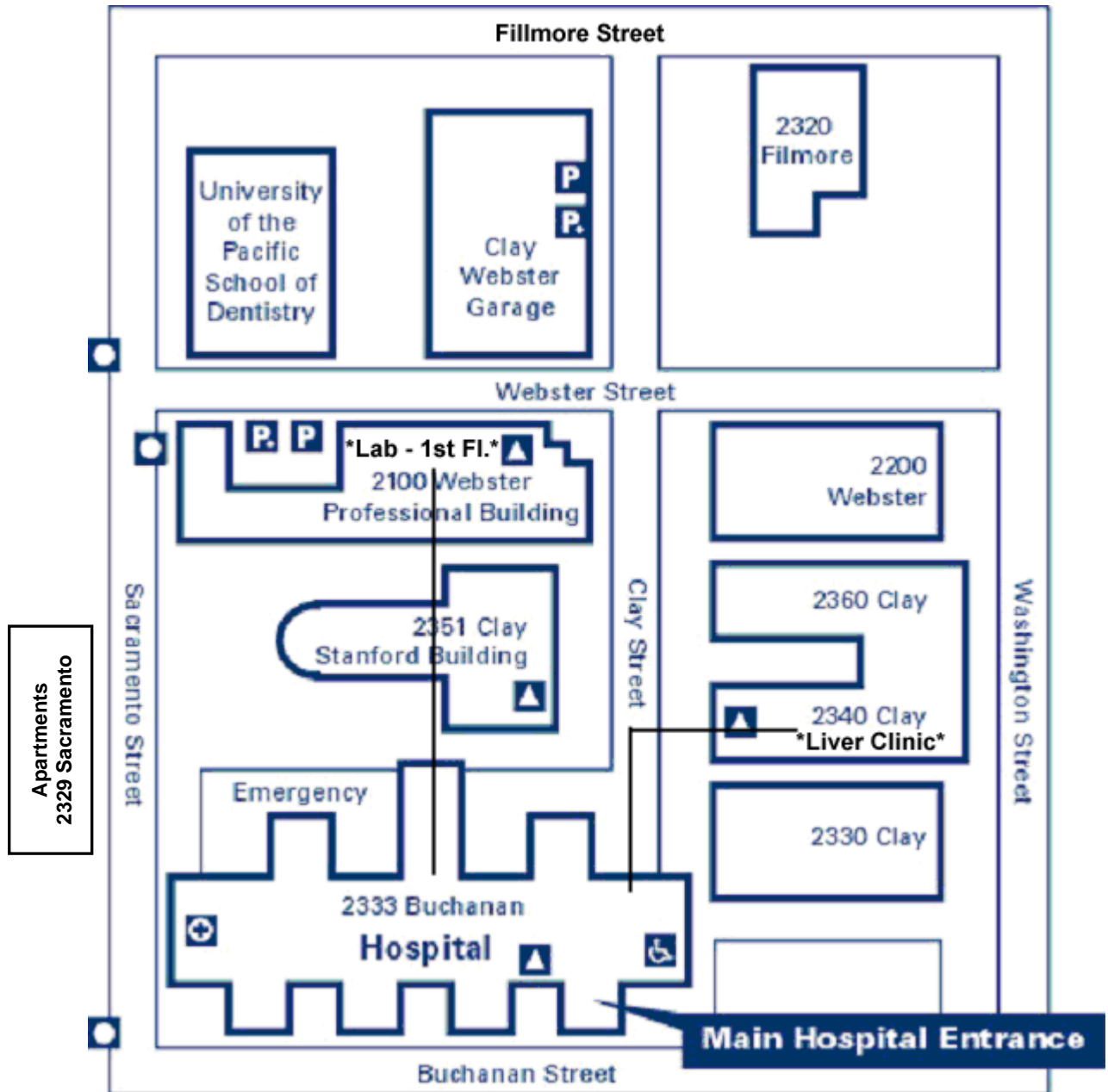
Non-Emergency Situations

The Liver Transplant Coordinators can be reached at 415-600-1000 during business hours (Monday through Friday from 8:30 am to 5:00 pm). Non-emergency calls that should be directed to your liver transplant coordinator include:

- Change of address/phone number notification
- Reporting or obtaining labs and biopsy reports
- Making clinic appointments
- Medication refills

The liver transplant service also accepts emergency calls 24 hours a day at 415-600-1000. When you call this number, be sure to give the information mentioned above. It is important that you don't try to self-diagnose symptoms that may be related to rejection or infection; instead contact your transplant coordinator with concerns.

Pacific Campus Map



From Apartment to Liver Clinic: Enter the hospital through the Emergency Room entrance off Sacramento Street (where ambulances enter). You will be on Level A. Turn left past elevators and continue to the loading dock. Walk across the driveway area to 2340 Clay Street. The clinic is on the 4th floor.

From Apartment to Lab: Enter the hospital through the Emergency Room entrance off Sacramento Street (where ambulances enter). You will be on Level A. Take the elevator to the 1st floor. Follow the “Main Route” signs from the 1st floor through the Stanford Building to the Professional Building. Once in the Professional Building, take the elevator to the lab on the 1st floor.

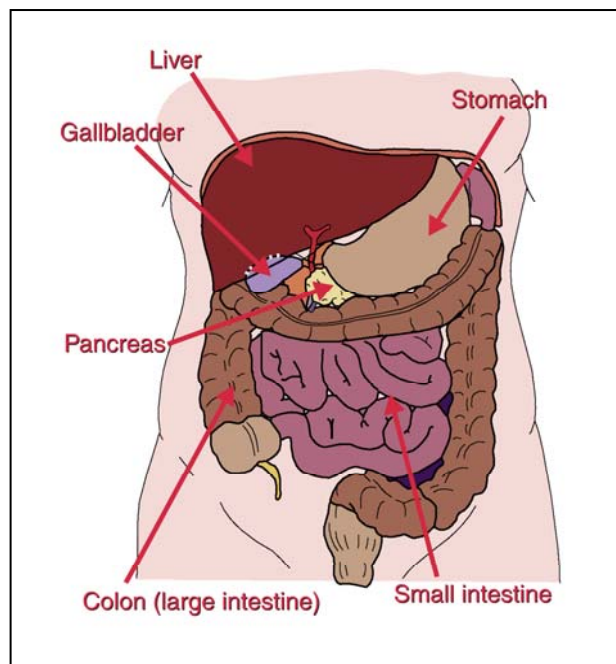
Transplant Surgery

Now that you have your new liver, you may be curious as to what happened during surgery and the reasons for your incisions and drainage tubes. The following is a description:

In the Operating Room

Following the administration of anesthesia, you were taken to the operating room where a team of about 10 physicians, nurses, physician assistants and technicians helped perform your liver transplant. After inspecting your donor liver and marking important structures to be connected during surgery, the liver transplant surgeon made a Y-shaped incision in your abdomen to open your abdominal cavity. Because your liver lies in part behind your rib cage, special retractors are used to help hold open your abdominal cavity so the surgeons can more easily maneuver. Next, the surgeon uses clamps to block blood flow from the major veins and arteries supplying your liver. Your diseased liver is detached from the arteries and veins, and removed from your body.

The new liver, which has been on ice awaiting transplant, is placed in the same position as your diseased liver. The veins are first connected with sutures, followed by the hepatic artery and bile duct. After it is successfully sutured, blood flow to your liver is resumed while the surgeons observe to ensure the new organ is working properly. After ensuring that the new liver is functioning well,



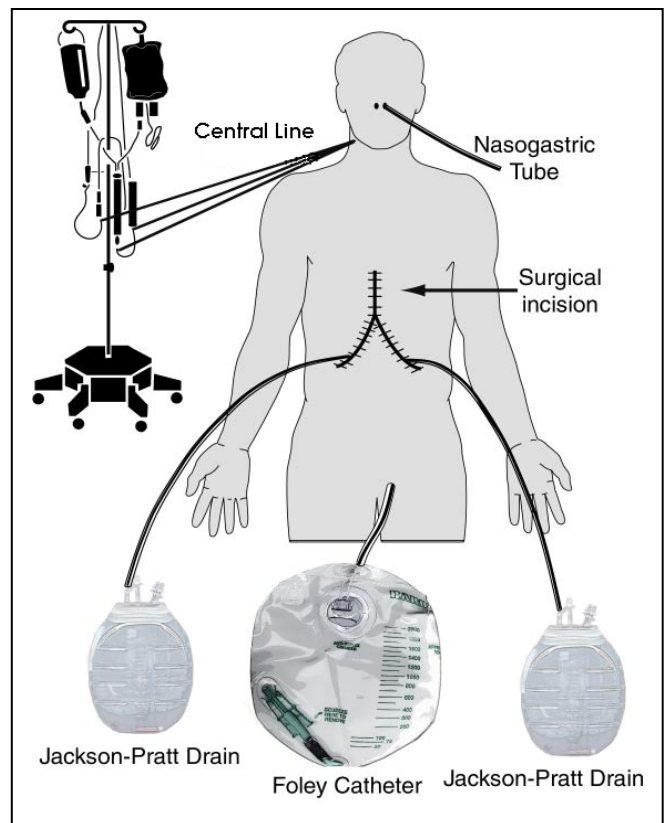
the clamps expanding your chest cavity are removed and the surgeon uses surgical staples to help the incision heal.

While each transplant is different, typically patients spend about 8 hours in the operating room. The surgery itself lasts 5-6 hours. Following surgery the ICU nurse will wake you to prepare you for coming off the ventilator. Your breathing tube will also be removed in about 6-12 hours.

Following Surgery: Wounds and Tubes

When you awake following surgery, you will find that you have surgical incisions and drainage tubes. The location of, reasons for and care of these wounds and tubes is described below.

Surgical Incision: You have a large incision shaped like an upside down Y on your abdomen. This incision is closed by surgical staples and, for the first few days after surgery, covered by a dressing. The nurses will cleanse this incision and examine it for signs of infection (redness, swelling or drainage) on a regular basis. The staples will stay in place 2-3 weeks. At your clinic visit following surgery, the transplant coordinator or physician assistant will remove your staples and apply steri-strips over the incision area.



Jackson-Pratt Drain (JP): A tube

known as a Jackson-Pratt drain is inserted during transplantation to drain fluid from the surgical site. This tube exits through your abdomen via a small incision. It is normal for tissue that has been manipulated during surgery to produce fluid. The fluid must be drained to prevent swelling of the abdomen and possible infection. The JP drain is usually removed on the second or third day after your transplant, but may be left in longer.

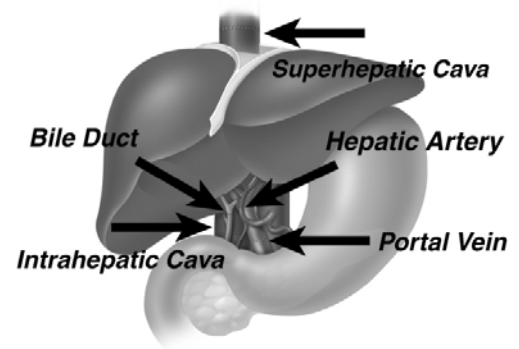
Foley Catheter: A urinary drainage tube (Foley catheter) is inserted into your bladder during surgery to accurately measure your urine output. This catheter will remain in place for a few days after surgery. The nurses will clean the site where the catheter

enters your body on a daily basis and measure the amount of urine output every shift.

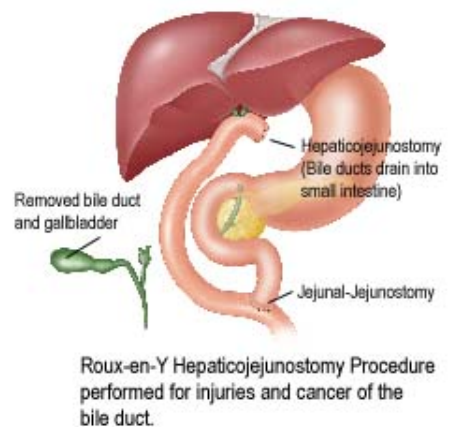
Nasogastric Tube: Until your stomach and intestines begin to function normally, you will need to have a nasogastric (NG) tube to drain the fluids your stomach and intestines are unable to digest. This tube is passed through your nose into your stomach at the time of your transplant surgery and typically remains in place 2-5 days after the operation. Once you are passing gas and have had a bowel movement, the NG tube can be removed and you may start drinking liquids.

Central Line: The central line helps your doctor and nurse determine your volume status so they can accurately regulate intravenous (IV) fluid or give diuretics as needed. This line is also used for blood draws and administering IV medications.

Connections: Surgeons make a total of five connections when attaching the new liver in your abdomen. The first three connections are the superhepatic cava, intrahepatic cava and portal vein. Once these connections are made, blood starts flowing to the liver. Next, the hepatic artery and bile duct are connected.



Duct-to-Duct or Roux-en-Y Method: During surgery, your bile duct may have been reconstructed using one of these methods. The duct-to-duct method involves attaching the bile duct from the donor liver directly to the end of your bile duct. The Roux-en-Y method—used when the donor bile duct and your bile duct do not match in size or if you have a diseased bile duct—involves attaching a the new bile duct to a portion of your intestine, which is re-routed to swing up near your new liver.



Daily Hospital Routines

Intensive Care

After your transplant operation, you will stay in the medical-surgical intensive care unit (MSICU) for one to two days. The MSICU is a specialized nursing unit in which you are closely monitored. The visiting hours may be limited in the MSICU, so your visitors will need to check with the nurses before coming to the hospital.

Once your vital signs are stable and you no longer need a ventilator (usually 1-2 days following your surgery), you will be transferred to the Transplant Unit on the 6th floor.

Nursing Shifts

There are three nursing shifts in a 24-hour period. The shifts are:

Day:	7:00 am to 3:30 pm
Evening:	3:00 pm to 11:30 pm
Night:	11:00 pm to 7:30 am

During the half-hour overlap between each shift, the nurses are in a conference called change-of-shift report. The nurses going off duty share information about what occurred on their shift and what the oncoming nurses can expect. There is always someone available in urgent situations; however, the nursing staff would appreciate it if you saved your less critical calls for those times other than change-of-shift report (7 – 7:30 am, 3 – 3:30 pm, 11 – 11:30 pm).

Rounds

Your attending physicians will visit you daily following your transplant. At this time, the transplant team will see you at your bedside to check on your progress, discuss your care, order new treatments, tests or medications and examine you. This is the best time to ask your doctors questions and report any changes in your condition. If you have questions for your doctors, it is a good idea to write them down so you have a reminder of your concerns when they are at your bedside.

Rounds are also a time for your attending physician to discuss specific issues with the house staff. This is an educational opportunity for the interns and other staff members.

Some of their conversation may be confusing to you because of the technical language; therefore, if you have any concerns during this discussion, please notify the team.

Meals

The Food & Nutrition Department delivers your meals at approximately 8:30 am, 12:15 pm and 5:15 pm. Depending on your diet modification, snacks may also be provided at specified times. A menu for the following day will come on your breakfast tray. Please complete your menu selections by midmorning and leave it on your side table for the volunteer to pick up.

Family members are allowed to bring special foods from home for you. Since you may be on a modified diet, please check with the nurse first. There is a small refrigerator and freezer on the transplant units where foods from home may be stored. Make sure all foods from home are labeled with your name, room number and refrigeration date. A microwave is also available if food needs reheating. Please check with the nurse about safety precautions before using the microwave.

Vital Signs

The nurses will take your vital signs (blood pressure, pulse, temperature, respiratory rate) when they begin their shift, enabling them to assess your condition early in their shift. Your vital signs may be checked again depending on how stable they have been, whether or not you are receiving blood products, what medicines you are taking, etc.

Intake and Output

Measurement of the amount of liquid you drink and get intravenously (intake) is compared to the amount you urinate and drain through your various tubes (output). The terms “intake” and “output” are frequently abbreviated as I & O.

The nursing staff will teach you how to measure and record your own I & O. Your intake and output is recorded for each 8-hour nursing shift and compiled every 24 hours by the evening shift. These totals, along with your weight, give the team valuable information about your fluid balance and how well your kidneys and liver are functioning.

Weight

Your daily weight is used to assess your body's fluid balance. It is important for you to be weighed every morning before breakfast, wearing the same amount of clothing. The nursing assistant will bring the scale to your bedside between 7:30 - 8:00 am to assist you.

Bathing/Showers

After the last JP drain has been removed (usually 2-3 days after surgery), you can take a shower. If you have a central line (CVP), however, check with your nurses prior to showering so they can help you remove or dress it before bathing.

When you are showering, remember the following:

- Shower once a day to keep your incision clean and for good hygiene;
- *Lightly* soap the incisional areas and carefully rinse;
- Gently pat your incision dry after finishing in the shower. Towel drying by rubbing can cause accidental removal of the staple(s) from the incision;
- Bubble baths, saunas, jacuzzis and swimming pools are not recommended until your wounds are completely healed;
- Do not use any powders, lotions or oils on your incision until it heals completely.

Action Steps

- Write down any questions for your doctors and ask them during rounds.
- Learn how to measure and record your intake and output (I & O).
- Have your weight checked every morning with the nursing assistants' assistance.

Notes and Questions to Ask

Transplant Team Members

During your hospital stay, the following team members will contribute to your care:

Surgeon

The transplant surgeon performs your liver transplant and helps guide you through recovery. Following your surgery, you will wake up in the medical-surgical intensive care unit (MSICU), a specialized area of the hospital where close monitoring is in effect for 24 hours. The surgeon, along with your hepatologist and ICU team, monitors your vital signs and the function of your transplanted liver to ensure it is working properly. Additionally, they decide what medications you'll take and observe your wound to see that it is healing as necessary.

Hepatologist

Just as before your surgery, the hepatologist continues managing your medical care following transplantation. The hepatologist and surgeon guide the transplant team through your recovery and monitor any possible rejection or infection of your new liver. To help prevent rejection, the hepatologist and surgeon will determine what immunosuppressive medications you need. Your hepatologist and surgeon will also oversee your post-transplant follow-up care and examine you at clinic appointments once you are discharged from the hospital.

Anesthesiologist

The anesthesiologist administers a general anesthetic prior to your liver transplant surgery and monitors your heart and lung function throughout the operation. In addition to the anesthetic, a central line is placed into one of your large veins at the time of surgery. The catheter is used for administering medications, monitoring pressures and retrieving blood for laboratory tests directly from your circulatory system.

Hospitalist

The hospitalist provides day-to-day management of patients in the hospital, both before and after liver transplantation and works closely with the transplant surgeon and hepatologist to deliver care.

Physician Assistant

The physician assistant is a healthcare professional who assists the physician with patient care. His or her primary role is to assist with the liver transplant operation and post-operative care of transplant patients.

Transplant Nurse Coordinators

The transplant nurse coordinators are in charge of coordinating all aspects of the transplant process, including your pre-transplant evaluation, transplant hospitalization and post-transplant follow-up. Their many responsibilities include patient and family education throughout the entire transplant process and ongoing communication. The transplant coordinators are also involved in the organ procurement and retrieval process, as well as community and professional education. They are an integral part of the transplant team and work very closely with *all* of your physicians including your referring doctor, the transplant surgeons and your hepatologists.

In addition to the transplant nurse coordinator, an *inpatient* transplant nurse coordinator will teach you about your immunosuppressive medication and post-transplant care prior to your discharge from the hospital. You will also review this discharge guide with your inpatient coordinator, who will help ensure you understand how to care for your new liver.

Staff Nurse

The hospital's staff nurses are responsible for coordinating the efforts of all your caregivers. Since nurses spend the greatest amount of time with you during your stay, they are in the unique position to evaluate your well-being, meet your immediate needs and act as a link among the various team members. They are available to provide a range of services, interventions and expertise, and to represent your best interest.

The nursing staff is committed to keeping you well-informed about every aspect of your health care needs and emphasizes patient education. They offer instruction and information both formally and informally, and try to include your family or caregiver(s) in the learning process.

House Staff

California Pacific Medical Center is a teaching hospital. This means that interns, residents and fellows will follow your care along with your attending physician. Your intern, a physician in the first year of training after medical school, is responsible for the current and ongoing knowledge of your condition. The intern will examine you daily and present a summary of your status to your attending physician daily during rounds. He or she is also available to you and your nurses to discuss your daily care and progress. There is always an intern and resident available during the night. Even if the night doctor is not your regular intern, this physician has been fully informed of your case prior to taking “call” and is prepared to deal with any emergency situations during off-hours. Your attending physician or an associate is also available in emergencies.

Social Worker

The liver transplant social worker is part of the Liver Transplant Team and involved with you from the time of your initial evaluation. The social worker provides the team with a psychosocial assessment that includes a social history and assessment of the patient’s and family’s coping abilities, motivation, compliance and support system. Practical issues such as who will stay with you after discharge from the hospital and the availability of funds for living expenses while in San Francisco are assessed. When necessary, the social worker can offer suggestions about how to initiate fundraising.

The social worker provides counseling and emotional support to both you and your family, from the time of evaluation through post-discharge. Additionally, a Liver Transplant Support Group, facilitated by the social worker, provides both inpatients and outpatients with a comfortable place to share questions, concerns and experiences. The support group is not a classroom situation, but rather an opportunity to share feelings and emotional experiences with others who have gone through a similar crisis.

Throughout the transplant process, the social worker advises about practical problems such as local lodging, transportation, insurance, financial concerns and referrals to Medi-Cal and State Disability.

Clinical Dietitian

A registered clinical dietitian evaluates your nutritional status and helps with any related problems. If your appetite is poor, the dietitian will provide you with nutritional supplements to increase your caloric intake. Prior to discharge, the dietitian is available for nutrition information and counseling. If you are on a special diet, written information will be provided to assist you in the transition from hospital to home.

Psychiatrist

It is not uncommon for patients with liver disease facing a transplant or those who have already undergone transplantation (or their families) to have difficulty dealing with their hospitalization and/or illness. When this occurs, a consultation with the psychiatrist may be requested by the patient or transplant team member. These consultations not only assist the patient and family in dealing with their feelings, but also help the hospital staff to better understand what the patient is experiencing.

Physical Therapist

An exercise program, varied according to each individual's condition and needs, is an essential component of your recovery. The program is one of steadily increasing activity in preparation for discharge. Progressive exercise programs are supervised by a registered physical therapist. If necessary, a physical therapy program may be continued in the outpatient setting. This will be arranged prior to your discharge.

Chaplain

The chaplain provides direct pastoral care for patients' and families' spiritual needs. This may be done by incorporating prayer, scripture and sacraments while respecting your religious traditions.

Financial Counselor

The financial counselor is available to assist you with questions concerning your medical insurance coverage and to offer financial guidance for your hospital stay.

Laboratory Work

While you are in the hospital recovering from your transplant operation, you will have daily blood tests, usually around 5:00 am. The various tests performed are often called “lab tests.” They include a complete blood count (CBC), FK506 (Prograf) level, liver function tests (LFTs) and a comprehensive panel to monitor electrolytes and kidney function.

Patients often express concern about the amount of blood required for lab tests. Be assured that we make every effort to consolidate tests; however, additional blood work is sometimes needed at other times during the day. Your glucose, potassium and blood count levels may also need to be checked more than once a day.

Following is a description of lab tests and values commonly monitored during your hospitalization. These values are recorded daily on your transplant flow sheet. You should become familiar with these tests and what they mean. After you leave the hospital, you will need to continue getting lab tests at certain intervals and should keep track of your labs on the chart provided in this handbook. If you have any questions about your lab tests, please discuss them with your coordinator or physician.

Liver Function Tests

Test	Normal Range	Indication
* Protime (PT)	PT: 11.5 – 14 seconds PTT: 23 – 35 seconds	Measures the liver’s ability to make clotting factors
* Bilirubin	Total: 0.3 – 1.0 mg/dL Direct: 0.0 – 0.3 mg/dL	Evaluates the liver’s ability to clear bilirubin from blood and excrete it in bile
ALB (albumin)	3.5 – 4.8 g/L	Indicates the liver’s ability to make this protein
Cholesterol	150 – 240 mg/dL	Indicates the liver’s ability to make and excrete this fat
Ammonia	3 – 37 µm/L	Indicates the liver’s ability to clear this toxin.

* Indicates one of the five main tests used to monitor your liver function.

Liver Enzyme Tests

	Test	Normal Range	Indication
*	AST (aspartate aminotransferase); also SGOT	12 – 45 U/L	Liver enzyme that measures damage to liver cells
*	ALT (alanine aminotransferase); also SGPT	7 – 40 U/L	Liver enzyme that measures damage to liver cells; slightly more sensitive test than AST
	AP (alkaline phosphatase); also called AKP or ALK PHOS	37 – 107 U/L	Liver enzyme that measures blockage of flow to the bile
	GGT (gamma glutamyl transpeptidase)	8 – 69 U/L	Liver enzyme that measures both damage to liver cells and blockage of flow to the bile

Electrolytes, Kidney Function and Pancreas Function Tests

Test	Normal Range	Indication
Na (sodium)	136 – 145 mEq/L	Measures electrolytes (minerals) in blood
K (potassium)	3.5 – 5.3 mEq/L	Measures electrolytes (minerals) in blood
Cl (chloride)	98 – 106 mEq/L	Measures electrolytes (minerals) in blood
Ca (calcium)	8.7 – 10.7 mg/dL	Measures electrolytes (minerals) in blood
P (phosphorus)	2.6 – 4.9 mg/dL	Measures electrolytes (minerals) in blood
Mg (magnesium)	1.6 – 2.4 mg/dL	Measures electrolytes (minerals) in blood
Amy (amylase)	34 – 122 U/L	Measures pancreatic inflammation
BUN (blood urea nitrogen)	7.0 – 22 mg/dL	Indicates kidney function
Cr (creatinine)	0.5 – 1.2 mg/dL	Indicates kidney function

Complete Blood Count (CBC) Tests

Test	Normal Range	Indication
* WBC (white blood cells)	3,500 – 11,000	Measures your body’s ability to fight infection
* HCT (hematocrit)	35 – 47%	Measures red cells while carrying oxygen
* Plt (platelets)	140,000 – 450,000	Measures blood clotting component

Testing of Immunosuppressive Medication Efficacy

Test	Normal Range	Indication
* FK506 (Prograf)	5 – 12 ng/mL	Shows level of immunosuppression; helps physicians know whether higher or lower doses are necessary to prevent infection.
Cyclosporine	75 – 350 ng/mL	Measures safety, toxicity and efficacy
Rapamycin	3 – 18 ng/mL	Measures safety, toxicity and efficacy

* Indicates one of the five main tests used to monitor your liver function.

Action Steps
<ul style="list-style-type: none"> ○ Become familiar with your lab tests and learn what they mean. ○ Continue your lab tests as advised following discharge from the hospital.

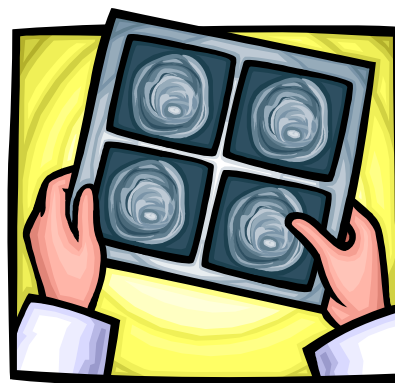
Notes and Questions to Ask

Tests and Procedures

During your hospitalization, diagnostic procedures are used to determine the status of your liver transplant and general physical condition. Some of the tests you may need to have performed during your post-operative period include:

Chest X-Ray

A chest x-ray is obtained prior to surgery to determine a baseline picture of your lung status. X-rays may also be ordered post-operatively at your physician's discretion to check any change in your pulmonary status. Chest x-rays are quick and painless, and require no preparation except the removal of all jewelry on your chest. They are performed in the Radiology Department but may also be done at the bedside if necessary.



Liver Biopsy

A liver biopsy is performed to determine what is occurring in your liver and can help make a precise diagnosis of rejection in a transplanted liver. This procedure is usually performed in your room using local anesthesia. It takes about 20 minutes. During the procedure, a specially designed needle is inserted through the abdomen to obtain a small sample of liver tissue. Once the needle is removed, firm pressure is applied to stop any bleeding that may occur. This procedure does not require hospital admission; only an observation period. Following the procedure, your vital signs and the puncture site are checked regularly.

Percutaneous Transhepatic Cholangiogram (PTHC)

A PTHC is an x-ray study used to rule out problems such as a bile leak or bile duct obstruction following transplant. For this procedure you will first receive local anesthesia and intravenous sedation, after which a fine needle is placed in your right side and guided into your bile duct. The radiologist checks the needle's location

frequently and takes x-ray pictures at various intervals. Once the needle is in the correct area, a small amount of dye is injected to obtain a clear picture of your bile ducts.

You will need to have intravenous antibiotics *prior* to your PTHC and will need to remain very still during the procedure. If you are an outpatient, you may be admitted to the hospital's Same Day Care Unit on the day of your PTHC. You will be able to go home following completion of the test. The PTHC takes approximately one hour.

Endoscopic Retrograde Cholangiopancreatography (ERCP)

ERCP is procedure in which a fiber-optic tube is sequentially placed in the throat, esophagus, stomach and duodenum to evaluate the pancreas, main bile duct and bile ducts in the liver. Intravenous sedation is administered prior to ERCP and during the procedure, pictures are taken using an x-ray machine. Monitoring devices for oxygen, pulse and blood pressure are in place during the procedure. Although there is a tube in the throat and esophagus, it is very easy to breathe during an ERCP. In all, the procedure takes about one to two hours.

Liver Scan (HIDA scan)

A liver scan assesses the bile flow from your transplanted liver using a dye injected directly into your vein. The scan, which is performed in the Nuclear Medicine Department, requires no preparation on your part. You will simply be asked to lie on a stretcher while a machine projects images onto a screen and records the results. There is no pain and the test takes approximately one hour.

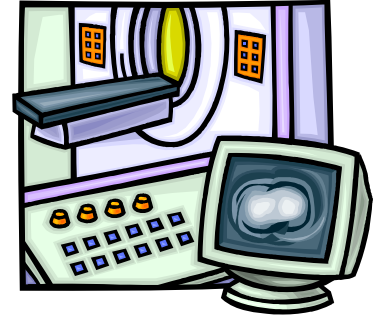
Liver Transplant Ultrasound (US)

An ultrasound uses sound waves to locate and outline internal organs and note any abnormalities. If you develop unexplained abdominal pain, a sudden rise in your liver enzyme tests or a fever, an ultrasound may be necessary. This procedure is performed in the Radiology Department and first involves an ultrasound technician applying a light coating of special sound wave-conducting jelly over your abdomen to allow the ultrasound probe to move easily on your skin. During the procedure, the technician can visualize your liver and its blood vessels, noting any abnormalities. An ultrasound

usually requires no preparation on the patient's part and the procedure takes about a half an hour.

Computed Tomography (CT) Scan/Magnetic Resonance Imaging (MRI)

CT scans and MRIs are special x-ray techniques that enable visualization of a specific tissue layer. With these tests, it is possible to view organs and surrounding areas, layer by layer, allowing a more precise picture of abnormalities should they exist. You may be requested to drink a liquid dye prior to a CT exam. An MRI exam requires no advance preparation. Both procedures take approximately 20 minutes.



Liver Angiogram

A liver angiogram is used to evaluate the hepatic artery and abdominal blood vessels. During the procedure, a plastic tube is inserted into an artery in your groin and threaded up the artery to the area being evaluated. The procedure takes approximately one hour and is performed in the radiology department.

Swan-Ganz

A swan-ganz helps evaluate blood flow and pressures in your heart. It is performed by inserting a tube on the right side of your neck to measure heart pressure. The procedure takes approximately 30 minutes and is performed in the ICU.

Medications

After surgery, you will need to take several types of medications to prevent infection and rejection of your new liver. While you are in the hospital, the nurses and members of the transplant team will assist you in learning about these medications. We expect you to learn the names of your medicines, their purpose, dosage and possible side effects.

On days when you have your labs drawn, *do not* take your medications that morning. After your labs are drawn, you can resume your usual medication schedule.

Immunosuppressive Medications

Your immune system rejects anything foreign in your body, including transplanted organs and infectious agents. To prevent rejection of your new liver, this system is suppressed, or slowed down, with powerful drugs called immunosuppressives. After your transplant operation, you must take these drugs *exactly* at your prescribed dosages for the *rest of your life*. If you



take too little medication, your immune system will destroy your new liver. If you take too much, your body will be less able to fight off infection and you will be more likely to develop side effects.

Even with the proper dosages of your medications, however, you may experience some side effects. This is normal. Altering your medications independent of the physician's prescribed dosage can have *serious* consequences. Never change your dose or stop taking your medicine without a doctor's order. You should also not drink any grapefruit juice while taking immunosuppressive medication because it can interact with their efficacy.

Generally, medications have two brand names:

- 1) Generic (or chemical) name
- 2) Brand (or product) name

Both names refer to the same drug (e.g., prednisone and Deltasone, azathioprine and Imuran). Based on habit, nurses and doctors often call some drugs by their generic name and others by their brand names.

All medications that you are required to take after surgery will be ordered and set up for you in a medication cassette by the inpatient coordinator at the time of discharge from the hospital. Most medications you were taking before your transplant will be discontinued.



Do not take ANY medications (including over-the-counter medicine such as Nyquil or ibuprofen) other than what has been prescribed by your transplant team without first discussing it with them first. Report *any* side effects from your transplant medications to your nurse coordinator.

Following is a list of immunosuppressive medications and information about their purpose and dose. The drugs are listed by their generic name, with the brand name in parentheses. **It is very important that you report *any* drug-related side effects you experience to your nurse coordinator, even if that side effect is listed below.**

Immunosuppressive Drugs (Anti-rejection Medications)

FK506 Tacrolimus (Prograf™)

Purpose: This immunosuppressive medication is given with steroids to help prevent rejection of your liver.

How Supplied: Prograf is available in .5 mg, 1 mg and 5 mg capsules

Dose: Your Prograf dose is adjusted according to your weight, kidney function, liver tests and Prograf blood levels. It is taken twice a day on an empty stomach. Swallow the pill whole.

Side Effects: Patients taking Prograf may experience the following side effects that may go away during treatment. If they continue or are bothersome, check with your doctor.

- nausea
- headache
- constipation
- tremor
- difficulty sleeping
- decreased appetite

If you have any of the following side effects, *check with your doctor as soon as possible:*

- constant hunger and thirst
- frequent or dark urination
- diarrhea
- vomiting
- unusual bleeding or bruising
- rash
- tingling or numbness in hands/feet
- itching
- fever or chills
- swelling in feet or legs

Mycophenolate Mofetil (CellCept™)

Purpose: This immunosuppressive medication is given to help prevent rejection of your liver.

How Supplied: Mycophenolate is available in 250 mg and 500 mg capsules. This drug is *always* taken with Prilosec.

Dose: The dose of Mycophenolate is initially 1,500 mg twice a day. It is taken at breakfast and dinner. Swallow the pill whole.

Side Effects: Patients taking Mycophenolate may experience the following:

- increased sensitivity to sun
- decreased WBC and platelets
- intestinal ulcers
- loss of appetite
- stomach pain
- nausea and vomiting
- diarrhea
- weakness
- shakiness
- muscle pain

If you have any of the following side effects, *check with your doctor as soon as possible:*

- bloody or black stool
- itching
- frequent urination
- diarrhea
- sore throat
- fever or chills
- unusual bleeding or bruising
- swelling in hands, ankles or feet
- skin rash
- vomiting blood or material that looks like coffee grounds

Prednisone (Deltasone™)

Purpose: Prednisone is both an anti-inflammatory steroid and immunosuppressive drug. It is taken in small doses for routine immunosuppression and in large doses to treat rejection episodes.

How Supplied: Prednisone is available in 1, 5, 10 and 20 mg tablets. The pills are divided in the center, making it easy to break a pill in half if necessary. At discharge you will receive a supply of 5 mg tablets.

Dose: Your Prednisone dose is determined by your body weight and liver function. This medication should be taken with meals or antacids to decrease stomach irritation. Prednisone is dosed as a “taper” meaning you will begin with a high dose, decrease to smaller doses and eventually discontinue the medication.

Side Effects: Patients taking Prednisone may experience the following side effects:

- increased susceptibility to infection
- night sweats
- salt and water retention
- mood swings and/or insomnia
- skin changes (bruising, sun sensitivity)
- increased appetite (may result in weight gain)
- increased fat deposits on face, neck, shoulders and abdomen (will diminish as dose is lowered)
- acne may develop on the face, neck and back (will diminish as dose is lowered)
- cataracts and glaucoma develop in some patients on steroids; eye examinations should be performed at least once or twice a year
- increased blood sugar may develop; this may be a short-term problem or develop into diabetes. Patients who are already diabetic may have to increase their insulin dose in response to higher blood sugars.
- joint pains in hips and/or knees (notify us if this occurs)

Sirolimus (Rapamune®)

Purpose: This immunosuppressive medication is given to help prevent rejection of your liver.

How Supplied: Liquid form (in bottle or packets). Pill form will be available in the future.

Dose: Rapamune is available in packets of 1 mg, 3 mg or 5 mg. You will take one dose a day, at the same time every day.

Side Effects: Patients taking Rapamune may experience the following side effects:

- nausea, vomiting, diarrhea
- delayed wound healing
- hypertension
- numbness/tingling in joints (hypokalemia)
- acne
- elevated cholesterol/triglyceride levels
- increased creatinine that may affect kidney function (your team will monitor this through lab work)
- stomach upset
- rash
- anemia
- low potassium
- lower WBC

Cyclosporine (Sandimmune®, Neoral®)

Purpose: Cyclosporine is an immunosuppressive that works to prevent your body from rejecting your liver.

How Supplied: Gelcap capsules (25 mg and 100 mg) or liquid form.

Dose: Cyclosporine doses are adjusted by your transplant physician according to your weight, liver function and blood levels. If taking liquid cyclosporine, do not use styrofoam cups. Additionally, do not take Neoral and Sandimmune together. *They are not interchangeable.*

Side Effects: Patients taking Cyclosporine may experience the following side effects:

- diarrhea, nausea or vomiting
- numbness/tingling in joints
- increased facial hair
- elevated blood pressure
- creatinine increase
- gum swelling/tenderness

Action Steps

- Learn what your immunosuppressive medications look like, their purpose, dose and side effects.
- Never change your dose or stop taking your medicine without a doctor's order.
- Call your transplant team at (415) 600-1000 if you are concerned about side effects.

Notes and Questions to Ask

Antifungal Medications

Fungal or yeast infections take many forms. Typically, these infections develop in moist environments such as on the webs of fingers and toes, nails, genitals and skin folds. Fungal infections may also develop in the mouth and will appear as white patches that may come off when you eat or brush your teeth. Common symptoms of fungal infections include white, creamy places in the mouth or vaginal areas, trouble swallowing and diarrhea. To treat these symptoms, one of the following antifungal medications may be prescribed:

Nystatin® (Mycostatin) Oral Suspension

Purpose: Prevention and treatment of oral yeast infections

How Supplied: Liquid form

Dose: Nystatin is given in liquid form for you to swish around your mouth and swallow. Retain the dose in your mouth as long as possible before swallowing. You should take 4 doses a day, after each meal and at bedtime.

Side Effects: Rarely, patients taking Nystatin may experience the following side effects:

- nausea
- vomiting
- anorexia
- upset stomach

Fluconazole®

Purpose: Prevention and treatment of oral yeast infections

How Supplied: In 100 or 200 mg capsules

Dose: Typically, patients take one 200 mg capsule once a week

Side Effects: If Fluconazole is prescribed for daily dosing, your Tacrolimus dose will need to be reduced.

Antiviral Medications

While taking immunosuppressive drugs, you will be more susceptible to other types of infections including viral and fungal illnesses. It is necessary for you to take certain medications to prevent these infections from occurring. A description of antiviral medications follows.

Acyclovir (Zovirax®)/Valcyte/Ganciclovir (Cytovene®)

Purpose: Prevention of certain viral infections, particularly cytomegalovirus (CMV), herpes, shingles and chicken pox.

How Supplied: Acyclovir is available in 200 mg capsules
Valcyte is available in 450 mg capsules
Ganciclovir is available in 500 mg capsules

Dose: Typically, 2 doses of Acyclovir are required daily. In some cases, you may be prescribed 4 – 5 doses daily. Acyclovir is typically used for 2– 3 months or as needed.

Side Effects: Patients taking antiviral medications may experience the following side effects:

- nausea
- vomiting
- headaches
- diarrhea
- changes in mental status

Pneumonia Medications

Patients who are taking immunosuppressant medications are more prone to developing pneumonia caused by an unusual organism called *Pneumocystis carinii*. You will need to take medicine to prevent this lung infection for the rest of your life. There are two types of treatments:

Trimethoprim and Sulfamethoxazole (Septra™, Bactrim™ or Dapsone™)

Purpose: Prevention of pneumocystis carinii pneumonia (PCP) and rocardia

How Supplied: Tablet form

Dose: One tablet on Monday and one on Thursday for five years

Side Effects: You should *not* take Trimethoprim or Sulfamethoxazole if you are allergic to sulfa or have G-6 P-D deficiency. Patients taking these medications may experience the following side effects:

- nausea/vomiting
- decrease in white blood count
- changes in liver and kidney tests

Peptic Ulcer Medications

Because of the side effects of steroid use, many patients may need to take anti-ulcer medications to prevent peptic ulcers. The peptic ulcer medications most commonly prescribed are:

- *Protonix®*, *Prevacid®* or *Aciphex®*

Purpose: Prevention of stomach or intestinal ulcers; required while taking CellCept.

How Supplied: Capsule

Dose: Typically, one tablet once or twice a day

Side Effects: Patients taking anti-ulcer medications may experience the following side effects:

- nausea/vomiting
- diarrhea
- changes in taste
- headache

Diuretics

A diuretic (water pill) may be necessary following surgery to help you excrete excess fluids via the kidney. Typically, only a small dosage is necessary and diuretics are only required for about one month post-transplant. Commonly used diuretics include:

- *Furosemide (Lasix®)*

Purpose: Increase the excretion of fluids that may contribute to ascites and leg edema

How Supplied: Pill

Dose: Your diuretic dose is adjusted according to your weight and kidney function

Side Effects: Patients taking diuretics may experience the following side effects:

- electrolyte imbalances
- muscle cramps
- weakness and fatigue
- hearing disturbances (ringing in ears)
- dehydration
- low blood pressure

Anticoagulant Medications

You may need to take anticoagulant medication following transplant surgery to prevent the formation of blood clots. This medication, which helps with blood flow, is needed when the blood vessels of the new liver are small. Your physician will determine if an anticoagulant drug is necessary. If so, the following will be prescribed:

Aspirin

Purpose: Prevents clot formation in small blood vessels of the new liver

How Supplied: Tablet form

Dose: Your weight will determine the dose of aspirin and whether you will need it once a day or every other day. Generally, the dose is either one 81 mg tablet or one 325 mg tablet.

Side Effects: Patients taking anticoagulants may experience the following side effects:

- increased bleeding
- nausea/vomiting
- gastrointestinal bleeding
- drowsiness

Antihypertensive (High Blood Pressure) Medications

Because some of your immunosuppressives may cause high blood pressure, it is frequently necessary to take one or more antihypertensive following your transplant operation. Following is a list of the most commonly used antihypertensives and their side effects.

- *Clonidine (Catapres®)*
- *Diltiazem (Cardizem®)*
- *Labetalol (Normodyne®; Trandate®)*
- *Metoprolol (Lopressor®)*
- *Nifedipine (Procardia®, Procardia X-L®)*
- (see "Diuretics" page)

Purpose: Lower blood pressure and prevent possible strokes

How Supplied: Capsule or tablet form

Dose: The dosage of your antihypertensive medication is adjusted to your blood pressure control and any side effects that occur.

Side Effects: Patients taking antihypertensives may experience the following side effects:

- low blood pressure
- weakness/fatigue
- headaches
- dizziness
- nausea/vomiting
- changes in some lab tests

Special Note: Diltiazem is a mild antihypertensive that also helps increase cyclosporine absorption. Some patients may need to use Diltiazem for blood pressure control *and* to increase low cyclosporine levels.

Rejection

Although rejection is a frightening word, it is a normal and expected occurrence following transplantation. Your body's immune system views your new liver as a foreign invader and attempts to fight it off. Most patients experience some rejection in the first 7 to 900 days following surgery, although it can occur at any time after transplantation.

It is important to learn about the physical signs and symptoms of rejection so you can promptly notify the transplant office and/or your local doctor.

Rejection Indicators

The following symptoms may indicate rejection, but do not always appear before a rejection episode. Therefore, it is critical that you get your lab work drawn as ordered and attend your routine check-ups. If you experience any of the symptoms listed below, please immediately call the transplant office at 415-600-1000 for advice and/or possible treatment.

- **Fever:** If you have a fever of 99° - 100°F (37.8°C) for *more than 24 hours*, or if you develop a sudden fever of 101°F or greater, you must notify your local physician and/or the transplant office at 415-600-1000. Before calling the transplant service, however, always take your temperature.
- **Flu-like symptoms:** These may be associated with fever, chills, joint and muscle aches or a general feeling of “not feeling well.” If these symptoms occur (even if everyone in your household has the flu), notify your transplant coordinator.
- **Abdominal pain or tenderness around your liver**
- **Fatigue, malaise or lethargy**
- **Sudden increase in abdominal size/ascites**
- **Lack of appetite**
- **Dark-colored urine**

- **Light-colored stool**
- **Jaundice (yellow skin and/or eyes)**
- **Elevated liver function tests**

Treating Rejection

The diagnosis of rejection is difficult and may involve “ruling out” other problems to prevent unnecessary treatment. Therefore, for your safety, daily lab work and other diagnostic studies, including a liver biopsy, may be obtained before starting treatment.

Rejection may be acute (one-time, severe episode) or chronic (prolonged) and varies in each patient. In most cases, liver rejection is reversible with *prompt* intervention. However, when acute rejection cannot be controlled, there can be a rapid and progressive deterioration of liver function and re-transplantation may be necessary.

Please ask your physician or transplant coordinator if you have specific questions regarding your drug therapy. There are many drugs used alone or in combination to prevent and treat rejection. They include:

- Intravenous steroids (also known as pulse steroids)
- Increase in oral prednisone dose then tapering the dose until discontinued
- Cyclosporine/FK506 dose adjustment
- Initiation of Imuran or an additional immunosuppressive drug

Action Steps

- Learn about the signs and symptoms of rejection.
- Get your lab work drawn as ordered and attend routine check-ups to monitor possible rejection episodes.
- Call your transplant team at 415-600-1000 if you have signs of rejection.

Notes and Questions to Ask

Infection

Infections are another possible transplant complication. Because the immunosuppressive medications you are taking make you more susceptible to infection, you need to know the signs and symptoms of infection and alert the Transplant Service at 415-600-1000 should they occur.

Following transplantation, you should avoid close contact with people who have contagious diseases. *Measles*, *mumps* and *chicken pox* are especially dangerous to immunosuppressed patients. If you are exposed to any of these illnesses, you *must* notify the Transplant Service immediately as you will need to be immunized within 48 hours of exposure.

In general, good hand washing is one of the best ways to prevent the transmission and spread of disease. Symptoms of infection include the following:

- **Fever:** A fever is a signal that your body is trying to fight “something.” If you experience a prolonged low-grade temperature of 99° - 100°F (37.8°C) for more than 24 hours or a sudden, high temperature of 101°F (38.5°C) or greater, you may be fighting an infection and must notify your transplant nurse coordinator at 415-600-1000 and/or your local physician.
- **Cough:** A cough may be an indication of an infection in your lungs. Notify your transplant nurse coordinator and/or your local physician if you have a cough that persists for more than 24 hours.
- **Wound infections:** Drainage from a cut or wound—as well as redness, swelling and tenderness—can be an indication of infection. If you experience these signs, notify your transplant nurse coordinator and/or a local doctor.
- **Viral Infections:** You should avoid direct contact with people who have viral infections such as a cold, the flu, cold sores (herpes simplex I), genital herpes (herpes



simplex II), shingles (herpes zoster) and chicken pox (varicella zoster). For example, do not kiss someone who has a cold sore or have sexual intercourse with someone who has active genital herpes. Delay a visit with someone who has a case of the flu or an active cold. If you get herpetic lesions (characterized by painful, red, fluid-filled blisters) it is important to notify your transplant coordinator for treatment. These precautions are especially important the first month post-transplant when your immunosuppressive drug doses are high.

As previously discussed, if you are exposed to infection and experience a prolonged low-grade temperature of 99° - 100°F (37.8°C) for more than 24 hours or a sudden, high temperature of 101°F (38.5°C) or greater, you may be fighting an infection. If this occurs, notify the transplant nurse coordinator at 415-600-1000 and/or your local physician.

Other Common Infections

In addition to viral infections, you are more susceptible to other infections while taking immunosuppressive medication. The following are some additional infections you may experience. *All of these infections must be treated*; an overview of medications is found on page 29.

- Oral: Yeast infections (candida) in the mouth are characterized by white patches on the tongue that cannot be brushed away and may be painful.
- Urinary tract: Symptoms of a urinary tract infection include pain, burning, difficulty in starting your urine stream and feelings of urgency or frequent urination.
- Vaginal: Yeast infections in the vaginal area are characterized by discharge, odor, itching and pain.

- **Gastrointestinal:** Signs of a possible gastrointestinal infection include nausea, vomiting, diarrhea and abdominal pain. If these signs persist for more than 24 hours, you must contact the transplant coordinator so you can receive your immunosuppressive medications by another route and try to identify the cause of gastrointestinal symptoms.

Action Steps

- **Avoid direct contact with people who have viral infections.**
- **Wash your hands well to prevent disease transmission.**
- **Alert the Transplant Team at 415-600-1000 if you experience infection symptoms.**

Notes and Questions to Ask

Discharge Checklist

Once you are eating well, able to walk without assistance, have stopped all intravenous medications and your liver tests and cyclosporine/FK506 levels have stabilized, you are ready to be discharged from the hospital.

If you and your support person are unprepared and do not know your medications, daily post-transplant routine and how to take your blood pressure, it *can* and *will* delay your discharge from the hospital. Your support person is expected to be available at the hospital daily.

The following is a checklist of things that are *essential* you complete *prior* to discharge. This checklist will be completed with the help of the inpatient transplant coordinator so that everything is in place at the time of your discharge. Keep in mind that sometimes discharge plans change to ensure that you are fully ready for release from the hospital. We appreciate you and your family's flexibility in these cases.

- Read this entire manual so you will know about your medications, precautions and necessary lab work
- Know the signs of rejection
- Know the signs of infection
- Know all of your medications including their 1) name, 2) dosage, 3) frequency, 4) actions of the drug and 5) side effects
- Know how to take your blood pressure and your blood pressure parameters
- Identify the person who will stay with you when you are discharged

- Identify where you will stay. If you plan to stay in the hospital apartments, make sure your name is placed on the waiting list. This can be done through your social worker or the hospital cashier
- Obtain a standing lab order slip from your discharge nurse
- Know that during the first month after transplant, you will have blood work drawn Monday and Thursday at California Pacific's Lab between 7-8 am, *before* taking your morning medications.
- Obtain a clinic appointment
- Know how you will obtain your medications prior to discharge and how to obtain refills following discharge. Your transplant coordinator will assist you with obtaining your discharge medications.

Things to Remember

When to Call the Transplant Coordinator

The Liver Transplant Nurse Coordinators are available Monday through Friday from 9:00 am to 5:00 pm to answer questions, review laboratory results and discuss other medical/non-medical concerns. **It is important that you don't try to self-diagnose symptoms that may be related to rejection or infection; instead contact your transplant coordinator if you have concerns.**

After 5:00 pm and on weekends, there is a transplant physician "on call" for patient emergencies only (i.e., fever). Please do not phone the physician on call for matters that can be managed during office hours (i.e., prescription refills). **The 24-hour Transplant Service number is 415-600-1000.**

New Medications

Do not take any medications unless they have been prescribed for you by a physician. This includes over-the-counter medications such as:

- Ibuprofen (i.e., Advil, Motrin): this may harm your kidneys
- Aspirin or aspirin products (i.e., Alka Seltzer, Bufferin) *unless ordered by your doctor*: these may increase stomach irritation
- Cold medications or cough syrups containing alcohol (i.e., Nyquil).

If your physician starts you on a new medication, always check with the Transplant Service first. Many medications interfere with the immunosuppressive medications, especially with cyclosporine/FK506.

Nausea, Vomiting and Diarrhea

If you are nauseated or have been vomiting and cannot take your medications, please call the Transplant Service immediately so that we can arrange to admit you to a hospital to receive them intravenously, if appropriate.

If you have diarrhea that persists longer than 24 hours, please notify the transplant coordinator. Additionally, if you are troubled with persistent constipation, contact your transplant coordinator. *Do not* give yourself an enema as there is a great risk of developing an infection in your intestinal tract.

Medic-Alert Tags

Be certain to order a Medic-Alert bracelet/necklace and wear it at all times. It should include:

- An alert that you are a liver transplant patient
- Transplant center name and phone number:
California Pacific Medical Center 415-600-1000
- List of other underlying health conditions (diabetes, hypertension, etc.)
- Any allergies



Your transplant coordinator will give you a Medic-Alert order form and wallet card at time of discharge.

Prescription Refills

You should always maintain a *minimum* of one week's supply of medications. When your supply is down, it is your responsibility to notify your local pharmacy to get refills.

If a new prescription refill is needed, the appropriate time to obtain this from the Transplant Service is during your clinic appointment or regular office hours, *not during non-office hours or weekends*.

Donor Families

Due to privacy and confidentiality laws, transplant patients are only given information about the age and sex of their donor. We will provide you with a brochure from California Transplant Donor Network (CTDN) on how to write to donor families. We strongly encourage you to send a note of thanks to the donor family. You can either

send letters directly to CTDN at the following address or give the letter to your social worker to mail. If you mail directly to CTDN, enclose your card or letter (placed in unsealed envelope) in an envelope addressed to CTDN. Include a separate piece of paper on which you have written your full name, telephone number and the date of your transplant. Mail to:

California Transplant Donor Network
1000 Broadway, Suite 600
Oakland, CA 94607
Phone: 510-444-8500
Toll-free: 888-570-9400
Fax: 510-444-8501

Support Group

The Liver Transplant Support Group meets Monday and Thursday from 10:00 – 11:30 am in the California Pacific Cafeteria, Dining Room 1. The support group provides inpatients and outpatients, family members and friends a place to share questions, concerns and experiences. For further details, contact Marjorie Davis, LCSW, or Yader Rodriguez, MSW, liver transplant social workers at (415) 600-1035 or 600-1036, respectively.

Travel

When leaving home for any substantial length of time—such as vacation—let us know and we will help you arrange your blood tests appropriately. The Liver Transplant Service can give you the name of the nearest transplant center so that if you require help while away, you will know who to contact.

You should note that the Transplant Service *cannot* call prescriptions across state lines, so please remember to take plenty of medications with you and carry them *on yourself* (not in baggage) when traveling.

Action Steps

- Do not try to self-diagnose; contact your transplant coordinator with concerns.
- Do not take *any* medications that have not been prescribed by a physician.
- Order a Medic-Alert bracelet.
- Always maintain *at least* a one week's supply of medications.

Notes and Questions to Ask

Daily Monitoring: Blood Pressure, Temperature and Weight

Upon discharge from the hospital, you will need to take your blood pressure twice a day. Many of your medications can cause hypertension (high blood pressure) and lead to strokes, so it is essential that you take your antihypertensive medication if required and monitor your blood pressure carefully.

Blood pressure (BP) is the measurement of the force exerted by the heart as it pumps blood from the heart through the body. The maximum pressure exerted against the arteries when the heart contracts is the *systolic pressure* (top number). The minimal pressure exerted against the arteries when the heart is at rest is the *diastolic pressure* (bottom number). These numbers are recorded as 120(s)/80(d).



You will be given a digital blood pressure cuff in the hospital and instructions on its use. You should use this blood pressure cuff twice a day in the hospital to learn your blood pressure trends and to check the cuff's accuracy. You will also need to check your temperature twice a day after your leave the hospital. If you do not have a thermometer, we will provide you with one.

We will monitor your weight twice a week during clinic visits to help determine your body fluid status.

Action Steps	Notes and Questions to Ask
<p>Take your blood pressure and temperature twice a day after leaving the hospital.</p> <p>A thermometer will be provided if you don't already have one.</p>	<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

Temperature and Blood Pressure Monitoring

Month _____

Date:	Morning Blood Pressure	Morning Temperature	Evening Blood Pressure	Evening Temperature
1				
2				
3				
4				
5				
6				
7				
8				
9				
10				
11				
12				
13				
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31				

Normal Blood Pressure is 120/80

- Report blood pressure greater than 160 (top #)
- Report blood pressure less than 90 (top #)

Normal Temperature is 98.6°

- Report low-grade temperature of 99° – 100° for more than 24 hours
- Report temperature of 101° or greater

Call (415) 600-1000 and speak with primary coordinator during business hours or on-call physician after business hours.

Blood Sugar Monitoring & Insulin Coverage

(to be used by diabetic patients or those who develop Prednisone-induced diabetes)

Month _____

Date	Breakfast Blood sugar	Insulin Given	Lunch Blood Sugar	Insulin Given	Dinner Blood Sugar	Insulin Given	Bedtime Blood Sugar	Insulin Given
1								
2								
3								
4								
5								
6								
7								
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***Report blood sugars greater than 400 or less than 80**

Call 415-600-1000 to speak with primary coordinator during business hours or on-call physician outside of business hours.

Clinic Instructions

Before you are discharged, your coordinator will have scheduled your first Liver Transplant Clinic. The Clinic is held on Monday and Thursday at 2340 Clay Street, 4th Floor. When you come to your clinic appointments, always bring this discharge booklet and your insurance card(s). Upon arrival, check in with the receptionist for your appointment. After your initial visit, you will be responsible for scheduling all clinic appointments. You should do this at the end of each visit.

The day of your clinic appointment, it is mandatory that you have your blood drawn (Monday and Thursday between 7:00 – 8:00 am) before taking any medications. You may do this in one of two ways:

California Pacific Medical Center Outpatient Lab

Location: 2100 Webster Street, 1st Floor (lobby level)

Hours: Monday – Friday, 7:00 am – 6:00 pm

Remember to bring your lab slip to have your blood drawn. Keep in mind that the Outpatient Lab is closed on Saturdays and Sundays, so if you have a weekend emergency, you must go to the Hospital Laboratory located on the second floor of the hospital (at 2333 Buchanan Street). Saturday and Sunday are the only days with this exception.

Local Lab

To have blood drawn at a local lab near your home, follow these steps:

- 1) Ask your transplant nurse coordinator for a standing lab order that you will need to bring with you to the lab
- 2) At your Liver Transplant Clinic visit, bring the name and phone number of your local lab.

The morning you have your blood drawn, *do not eat breakfast* and *hold* your cyclosporine/FK506 until **after** your blood work is done. You may hold your other morning medicines until you eat if you wish.

Action Steps

Have your blood drawn the day of your clinic visit.

The morning of your lab work, do not eat breakfast or take your cyclosporine/FK506 until finished.

Bring necessary items to your clinic visit, including this discharge manual.

Notes and Questions to Ask

Nutrition

Good nutrition is important following your surgery. To help your wound heal, you need to eat well and get adequate calories and protein. You should eat frequently—3 meals and 2-3 snacks a day—and try to include high-protein foods in each feeding. As your recovery progresses and your wounds heal, you will need to follow a low-cholesterol, low-saturated fat and low-sodium diet. You will also need to make sure you get an adequate amount of calcium in your diet through foods or calcium supplements.

The following are some general nutritional guidelines. After your transplant, your physician will order an appropriate diet based on your nutritional needs and liver function level. If you are placed on a modified diet, the dietitian can help you make appropriate food selections.

You should be advised that if complications develop post-transplant, you may need to be fed via intravenous tube feedings and/or total parenteral nutrition (TPN). Tube feedings and/or TPN will supply you with all the proteins, fats, vitamins and minerals necessary for wound healing and will provide your new liver with fuel to work. Once you are able to take food by mouth, this intravenous nutritional support will be discontinued.

Protein Heals Wounds

Protein helps heal wounds. During your transplant recovery, you should include one source of high-protein food in each meal and snack. Sources of protein include: dairy (milk, yogurt, cheese, cottage cheese), eggs, meat, poultry, fish, peanut butter and tofu. A dietitian will meet with you prior to discharge to discuss the best sources of protein for your condition.

Watch your sodium, fat and cholesterol intake

After your wounds are healed (usually about two months following your transplant), you will need to follow a low-cholesterol, low-saturated fat and a 3,000 – 4,000 mg sodium diet. You will need to follow this diet because of your medical history and/or the side effects of the medications you are taking for your new liver. You will be

instructed to use the salt shaker sparingly in cooking or on the table and to avoid foods high in sodium (cured meats/vegetables, convenience foods and seasonings containing salts. Additionally, you should select lean meats, reduced-fat dairy products and eat less of/avoid high-fat food.

Calcium Keeps Bones Healthy

Keeping your bones healthy is important. Some immunosuppressive medications can affect your bones and it is essential that you have between 1,000 to 1,500 mg of calcium daily. The dietitian will review the sources of calcium in your diet. You may need a calcium supplement if you do not get enough in your diet.

Eat a well-balanced diet

Eating just one food will not supply all the nutrients your body needs. Selecting a variety of foods provides you with a balanced diet. The food groups you need to select from each day are:

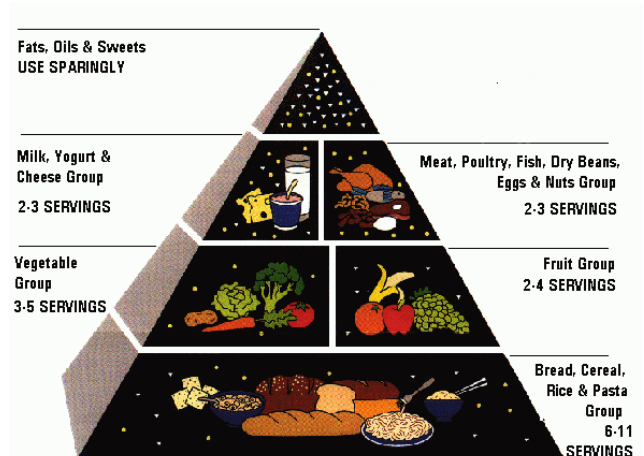
- Meats, poultry, fish, eggs, tofu and legumes (dry peas and beans)
- Dairy products (milk, cheese, yogurt)
- Whole grain and enriched breads, cereals and grain products
- Fruits and vegetables
- Water

Meats, poultry, fish, eggs and legumes

These foods are needed to build muscle and repair tissue as well as provide vitamin B, iron and other minerals. Foods include: poultry, fish, shellfish, peanut butter, dry beans and nuts.

Dairy products

Dairy products are excellent sources of protein, calcium and vitamin D, and are needed for healthy bones and teeth. Milk, cheese, cottage cheese, yogurt and custards are examples of dairy products.



Source: U.S. Department of Agriculture

Bread, cereal, rice and pasta

This group provides vitamin B, fiber, minerals and calories.

Fruits and vegetables

Fruits and vegetables are good sources of ascorbic acid and vitamin A as well as minerals and fiber. Foods include: citrus fruits and juices, melons, berries and apples. Also included are dark green and deep orange vegetables, such as spinach, broccoli, carrots and sweet potatoes.

High calorie foods (including nutritional supplements)

High calorie foods and nutritional supplements provide calories needed for energy. Some of these foods can also supply extra vitamins and minerals to supplement your diet. Foods include: butter, margarine, cream cheese, cookies, sugar, jam, candy, sherbet and jello. Nutritional supplements can also supply needed calories, proteins and vitamins in a concentrated form. Ask the dietitian to assist you in selecting a nutritional supplement if it becomes difficult for you to consume enough calories.

Water

Liquids maintain the body's water balance and provide a moist environment for normal body functions to occur. Liquids include water, coffee, tea, juice, soups, popsicles and ice. Try to drink at least 6-8 cups (2 quarts) of water daily. Avoid drinking grapefruit juice and eating grapefruit because it may reduce cyclosporine absorption, an immunosuppressive medication.

Low Cholesterol, Low Saturated Fat and Sodium Restricted Diet

Food Groups	Emphasize the Use/ Suggested Foods	Moderate Use/ Use Less Often	Beware of These/ Avoid
Soups Made from suggested foods (1 sv. Canned soup – ½ tsp. Salt	Clear, salt-free broths; homemade soups from suggested foods; skim fat from top		Instant soups (ex. Cup of Soup), bouillon, regular canned soups, cream soups made with cream, whole milk butter, animal fat
Vegetables Contain no cholesterol unless added	All vegetables when prepared with suggested ingredients and fat allowance	Fresh olives and avocado (both high in fat)	Pork & beans, fried, creamed, animal fat added (ex. refried beans), pickles, sauerkraut, canned olives and tomato products
Fruits & Juices Contain no cholesterol unless added	All fruits and juices, salt-free tomato juice	Coconut	Fruit desserts and juices prepared with eggs or butterfat; V-8 and tomato juice
Grains & Cereals Contain no cholesterol unless added	All grains/cereals prepared with suggested ingredients	Commercially prepared pancakes, waffles and muffins	Butter rolls, commercial biscuits, muffins, donuts, sweet rolls, commercial mixes containing eggs, etc.
Potatoes & Starch Contain no cholesterol unless added	All potatoes, rice, pasta when prepared with suggested ingredients	Commercially prepared pasta – read labels	Potato au gratin, egg pasta, fried potatoes, chips, made with cream, cheese, butter and/or bacon fat
Seafood 3 oz – 50 mg cholesterol	All white fish, salmon, halibut, tuna, sole, clams, oysters, scallops, crab	Shrimp, lobster, abalone, whole sardines	Calamari (squid) – 3 oz – 240 mg cholesterol
Poultry 3 oz – 80 mg cholesterol	All chicken, turkey, capon without skin and extra fat	Lean duck, goose without skin or fat	Fatty poultry such as goose and fatty chicken, and fatty duck
Red meat, beef, veal, lamb, pork (usually high in fat) 3 oz – 90 mg/chol (3 oz ham – ½ t. salt)	Lean 2-3 x week, baby beef, very lean cuts, chuck, flank, skirt, top round, bottom round, tenderloin, pork tenderloin, lean veal chops, roast, lean lamb – remove fat. Read labels and buy 85% - 90% lean	Restaurant prepared ground beef, hamburger, roast, steaks, porterhouse, t-bone, roast, rib, chuck, rump, pork chops, leg, roast, veal cutlet, ground, cubed, veal unbreaded	Organ meats (ex. brains – 3 oz – 2,000 mg/chol), liver (3 oz – 300 mg/chol), mutton, spareribs, sausage, luncheon meats, bacon, salt pork, prime rib, corn beef, ground lamb, frankfurters, frozen pkg. Dinners, smoked meats and fish, anchovies and caviar
Dairy products 1 c. whole milk – 35 mg 1 c. 2% fat milk – 22 mg 1 c. non-fat milk – 5 mg	Non-fat milk, buttermilk and yogurt, all non-fat dairy products are acceptable. Read labels	Low-fat milk, buttermilk, chocolate milk, yogurt, USE ALL low-fat products in moderation	Whole, buttermilk, chocolate milk, dairy cream, ½ & 1/2, sour cream, (IMMO), non-dairy creamer from coconut & palm oil/saturated fats
Cheese 1 oz. reg cheese – 35 mg 2 oz. cheese – ½ t. salt ¼ c. low-fat cottage cheese = 22 mg/chol	Cheese made from skim, non- fat milk, (ex. Farmers mozzarella, Borden's Lite Line, Laughing Cow, reduced fat/calorie cheese, Lifeline, fat-free cheese)	Cheese made from low-fat milk	Cheese, regular made from whole milk or cream, (ex. cheddar, jack, swiss, brie, cream cheese, cheese spreads)
Eggs 1 yolk – 215 mg/chol 1 egg white – 0 mg/chol	Egg whites, egg substitute made from egg whites (ex. Egg Beaters, Second Nature, Scramblers)		Egg yolks, products and sauces prepared with egg, egg yolk or whole eggs

Beverages	Coffee, tea, decaffeinated coffee, carbonated drinks, fruit juices		Milkshakes made from cream, ice cream and whole milk
Desserts Limit if calories are a concern – only prepare from suggested foods. Use fat allowance only.	Angel food cake, jello or gelatin desserts (made without cream, butter, etc.), Popsicles, sherbet, water ice, non-fat desserts (ex. Fudgesicle, Weight Watchers desserts, sorbet, non-fat frozen yogurt, cake, cookies made with suggested foods.	Ice milk, frozen low-fat Mocha Mix desserts	Cakes, cookies, pies, puddings made with butter, cream, coconut milk, whole milk, eggs, coconut oil, palm oil or hydrogenated fats. Commercial cakes, cookies, mixes, frozen desserts, baked products made from the above listed ingredients.
Concentrated Sweets	Sugar, honey, jam, jelly, syrup, pure, sugar candy, marshmallows		Chocolate candy, candy made from cream, butter, eggs, whole milk or coconut milk
Fats & oils Vegetable oil – 0 chol 1 t. oil – 45 cal 1 t margarine – 45 cal 6 small nuts – 45 cal 1 t butter – 45 cal 1 t butter – 15 mg/chol	Restrict intake – use only the amount indicated on your diet (3-6 t. daily). Allowed fats are mono-unsaturated fats (ex. olive oil, canola oil), polyunsaturated oils and fats (ex. safflower, corn, soybean, sesame, cottonseed, sunflower, olive), old-fashioned peanut butter without added fat, select margarine with first ingredient as liquid oil (one of those listed above). Fat-free Mocha Mix.	Sautéed foods at restaurants, nuts, avocado, hydrogenated peanut butter, Mocha Mix, as a non-dairy creamer	Butter, bacon, meat drippings, lard, vegetable shortenings, coconut or palm oil, or products using these oils. Margarine with first ingredient as partially hydrogenated oil. Non-dairy creamers made with saturated fat; commercially prepared gravy & sauces. Coconut milk.
Condiments/Spices 4 T catsup or mustard – ½ t salt; 1 T soy sauce – ½ t salt	All herbs and spices as tolerated; vinegar, lemon	Catsup, mustard	Gravies, cream sauce, made from drippings, and animal fats (ex. cheese sauce, butter sauce), salt, seasoning salt (ex. garlic and/or onion salt)

Action Steps

Eat protein to help your wound heal.

Limit cholesterol, saturated fat & salt.

Have 1,000 -1,500 mg of calcium Daily.

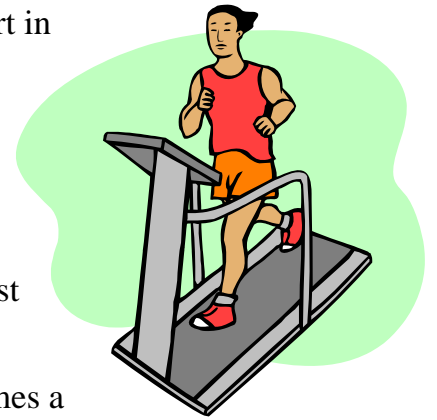
Eat a well-balanced diet.

Drink plenty of fluids.

Notes and Questions to Ask

Activity and Exercise

After your operation, physical activity plays an important part in your recovery. Walking, for example, has many benefits to the entire body such as expanding the lungs, reducing general muscle aches, stimulating gastrointestinal tract activity and increasing muscle strength. While you are in the hospital, you will see a physical therapist daily who will assist you in an individualized exercise program. In addition to the exercise program, you are expected to take a walk several times a day to increase your stamina in preparation for your discharge.



Exercise

When you return home and resume many of your household duties, you may feel very tired and have less energy than in the hospital. Your energy level will slowly increase. Continue the exercises you learned in the hospital and get outside daily for a walk. Gradually increase the distance you walk each day. Exercise is necessary for a healthy lifestyle and minimizes the adverse effect of Prednisone on your muscles and bones.

Driving

It is recommended that you *do not drive for several weeks* after your surgery and then, only if it *does not* cause you excessive incisional pain. If you are experiencing blurry vision as a result of your medications, *do not drive*. Typically, patients can begin driving about 6-8 weeks after their staples are removed.

Lifting

Avoid lifting more than 15 pounds for three months after your surgery. This allows time for your wound to heal. To avoid excessive physical strain, avoid pushing or pulling large objects such as furniture for at least 3 months.

Returning to Work

Most patients can return to work 2-3 months following surgery. However, this depends on the type of work you do. If you are unable to return to your former occupation, the

social worker can assist you in finding a vocational rehabilitation center for possible job retraining.

Sex and Birth Control

Sexual activity may be resumed as soon as you are feeling up to it. After transplantation, women should continue to have a yearly pap smear and gynecological exam. Anal intercourse is not recommended for transplant patients because Prednisone causes the rectal tissues to become easily irritated or torn. Female patients may experience some degree of vaginal discomfort, irritation or dryness also caused by Prednisone. A lubricant such as K-Y jelly may be used to relieve such problems (Vaseline® is not recommended).

Women usually begin menstruating a few months after liver transplantation. In some women, Prednisone can prevent menstrual bleeding even though ovulation does occur. Therefore, a pregnancy can occur even if a monthly period does not. There are several acceptable methods of birth control available to transplant patients. These include spermicidal foams, condoms and diaphragms. These methods are safe and effective birth control measures when used *correctly*. Birth control pills *should not* be used unless it has been discussed and cleared with your transplant physicians. The IUD (intrauterine device) is also not advised due to the risk of infection.

Female transplant patients who wish to have children should thoroughly discuss the matter with their transplant physicians. Pregnancy can create difficulties and should not be considered for at least one year following surgery. All anti-rejection medicines must be taken throughout pregnancy to prevent rejection. At this time, little is known about the effects of cyclosporine or FK506 on a developing fetus. While there are no known birth defects attributed to cyclosporine or FK506, there is a chance these medications could cause an increase in spontaneous abortion.

Action Steps

Exercise and take a walk daily after returning home.

Avoid heavy lifting or pushing/pulling heavy objects for at least 3 months.

Practice safe sex and use condoms for sexual activities.

Notes and Questions to Ask

Other Precautions

Alcohol

Following your liver transplant, you should not drink *any* alcoholic beverages, foods or medication *containing or prepared with* alcohol (i.e., desserts or medications such as Nyquil or mouthwash). Alcohol is processed by the liver and may produce changes in the organ. These changes can be confused with signs of rejection or liver infection.

Alcohol consumption will be detected through laboratory blood and urine tests. Random testing of alcohol levels in your blood and urine may be performed routinely as part of your follow-up care.

Sun

Prednisone may increase your sensitivity to the sun, making you more prone to sunburn and sun poisoning. To guard against overexposure—even if you were never prone to sunburn previously—you should *always* use a sunscreen with a sun protection factor (SPF) of at least 15. As a general guideline, the higher the SPF number, the greater the protection offered by the cream or lotion.

Vaccinations

Following transplant surgery, patients have a high risk of infection because of a weakened immune system. The anti-rejection medications taken to prevent rejection of a new organ weaken the body's ability to make antibodies and may cause a decreased response to vaccines. Therefore, transplant patients may need larger or additional doses of some vaccines to ensure their efficacy. A health care provider or transplant physician can assess the response to a vaccine and adjust the dosage accordingly.

Influenza (flu) vaccines are recommended for transplant patients, but not mandatory. The flu vaccine is given annually before the flu season (September through November). Other vaccinations, such as those required for travel abroad, should be cleared through the transplant office *prior* to receiving them. In addition to influenza vaccination, tetanus shots are acceptable and the pneumonia (pneumococcal pneumonia) vaccine is advocated. You should get revaccinated for pneumonia every five or six years.

Transplant patients should avoid “live virus” vaccines such as those for polio and measles, mumps and rubella (MMR) because the live virus may in fact cause these illnesses in immunosuppressed patients.

Pets

Patients should not get any new pets for three months following their transplant surgery and not change cat and/or bird litter during this timeframe as well. If you already have pets, be sure to keep them clean and healthy so your immune system will not be affected.

Action Steps

Do not consume alcoholic beverages or medications/ foods containing alcohol.

Wear SPF 15 or higher.

Other than the flu and tetanus vaccines, check with your transplant coordinator first.

Notes and Questions to Ask

Glossary

Albumin	A circulatory protein that prevents swelling.
Abscess	Localized infection.
Angiogram	A radiologic exam used to determine if there is any blockage in the veins or arteries to or from an organ.
Antibody	Part of the immune system that helps the body fight infection and foreign substances.
Antigen	The “marker” that stimulates antibody production.
Ascites	Fluid accumulation in the abdominal cavity, often as a result of severe liver disease.
Bile	A yellow or greenish fluid secreted by the liver that aids in digestion and absorption of fats.
Biliary artesia	Congenital malformation in which part of the biliary tract is missing.
Bilirubin	A chemical that is excreted by the liver in the bile. It may accumulate in the blood of patients with severe liver disease.
CAT/CT Scan	A 3-dimensional x-ray of the internal organs used to detect a mass, abscess, tissue damage or bleeding in the body.
Cholangiogram	Injection of dye into the bile ducts directly or through a T-tube to see if bile is flowing into the intestine.

Cirrhosis	Progressive scarring disease of the liver.
Coagulopathy	Abnormal blood clotting.
Creatinine	A product of muscle metabolism, creatinine level is a number that is watched closely and serves as a very good indicator of kidney function.
Crossmatching	A test of compatibility between the potential donor's and prospective recipient's blood that can also evaluate the closeness of tissue match between organ donor and recipient (done before transplant).
Cyclosporine	A potent immunosuppressive drug that acts specifically to helper T cells.
Diaphragm	The large muscle that separates the chest and lungs from the abdominal organs; it is the main muscle used for breathing
Diastolic	The bottom of two blood pressure numbers, which measures the force of the heart muscle at rest, when it expands and fills with blood.
Echocardiogram	The use of sound waves to determine how effectively the heart is pumping.
Electrocardiogram (EKG or ECG)	The heart beating pattern traced on paper by the use of electrodes placed on the chest; used to determine the type of heart rhythm and any injury to the heart tissue (EKG or ECG).
Encephalopathy	Change in consciousness, thinking abilities and behavior that occurs with advanced liver disease and is caused by the accumulation of waste from protein breakdown.

Endoscope	A small telescope-like instrument that can be inserted into the esophagus to examine the esophageal lining, stomach and part of the small intestine.
Endotracheal tube	An airway tube inserted through the mouth leading to your windpipe to help you breathe during surgery.
Foley catheter	A tube inserted into the bladder to drain urine.
Gallbladder	The pear-shaped organ that lies behind and slightly below the liver on the right side of the abdomen. It is a reservoir for bile.
Gastroenterologist/ Hepatologist	A doctor who is specially trained in the diagnosis and treatment of diseases of the digestive system, including the liver.
GFR (glomerular filtration rate)	A nuclear medicine exam that assesses kidney function.
Glucose	A type of sugar found in the blood.
Graft	Your new liver.
Helper T cell	The “commander in chief” of the immune system. This is the specialized white blood cell that gives battle orders to other members of the immune platoon in combating infection or foreign invaders.
Hepatitis	Inflammation of the liver, usually caused by a viral infection.
HIDA scan	Measures liver’s ability to function by removing a radioactive dye from the blood stream and passing it into the intestine.

Hypertension	This term does not mean you are very tense or nervous. It is another word for high blood pressure.
Immunosuppressive medication	A drug that is taken every day following transplantation. It helps prevent the recipient's immune system from attacking and rejecting the new liver.
Imuran (azathioprine)	An immunosuppressant drug sometimes used to help prevent your body from rejecting your new liver.
Intravenous (IV)	Refers to fluids and medications that are injected into a vein through a needle or catheter.
Jaundice	A yellowish discoloration of the skin and eyes resulting from high levels of bilirubin in the blood.
Liver biopsy	A procedure in which a small sample of liver tissue is removed for microscopic examination to detect diseases or conditions such as rejection.
Liver enzymes	Refers to the enzymes AST, ALT, alkaline phosphates and GGT that are released by the liver cells and other parts of the body.
Noncompliance	Failure to take medicine as prescribed, or making daily decisions that may shorten the lifetime of the transplant.
Petechiae	Small spots of blood leakage in the skin or membranes frequently seen with poor blood clotting.

Portal hypertension	Elevated blood pressure in the portal vein. It is a common complication of cirrhosis of the liver and is the cause of varices.
Portal vein	Vein that carries blood and nutrients to the liver.
Prednisone	A steroid hormone taken by most transplant recipients to help prevent rejection.
Pruritis	Itching that can be caused by high bilirubin levels.
Sclerotherapy	Treatment of varices by the injection of chemicals that cause clotting of the veins. This is often used to prevent or stop bleeding from swollen esophageal or stomach veins.
Sepsis	Severe infection
Spider angioma	Small red dilation of small vessels near the skin that look like a spider's web.
Systolic	The top blood pressure number that measures the force of contraction of the heart muscle as blood is pumped out of the heart chambers.
Thrombosis	The formation or presence of a blood clot.
TPS/TIPS	An x-ray procedure performed to decrease portal hypertension. The acronym stands for Transjugular Intrahepatic Portacaval shunt.
T-tube	A small rubber tube that is temporarily inserted into the bile duct connection to allow healing after surgery without scarring or blockage.

Ultrasound

The use of sound waves from an instrument on the skin to produce a picture of the internal organs; often used to detect masses; abscesses, bile duct size or to determine the blood flow in the liver veins.

Varices

Swollen blood vessels often found in the stomach, esophagus and intestines when there is high pressure in the liver veins and can cause gastrointestinal bleeding.

Vena cava

The largest vein in the body, the vena cava returns blood to the heart.

You

The most important member of the Transplant Team. You are the lucky person who will be enjoying life again, starting off with good, healthy habits.