

**LIVER TRANSPLANT
DISCHARGE MANUAL-PATIENT
INFORMATION AND INSTRUCTIONS**

FORWARD

The Liver Transplant Program of Stanford Hospital & Clinics has developed this discharge manual as a learning tool to assist with your recovery from liver transplant. We hope that the information provided will enable you to reach your optimal level of health. We encourage your questions, suggestions, and concerns. Your participation and compliance is necessary to ensure the success of your transplant. As the lifetime caretaker of your new liver, you will need to:

- Learn your medications and adhere to your medication schedule.
- Follow your schedule for laboratory tests and transplant clinic visits.
- Actively participate in self-care activities such as monitoring your weight, blood pressure, and temperature.
- Maintain good communication with your transplant team and other health care providers.
- Adopt healthy lifestyle habits that will enable you to achieve your optimal level of wellness.

The Liver Transplant Program functions as a team of which you, the patient, are the most important member.

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TRANSPLANT TEAM MEMBERS

Listed below are the team members who contribute to your care:

1. Staff Nurse

The staff nurses in the hospital are responsible for your direct patient care during your hospitalization. Since nurses are the individuals who 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 to the various team members. They are available to provide a range of services, interventions and expertise, and to represent your best interests.

2. House Staff

Stanford Hospital & Clinics is a teaching hospital. This means that interns, residents and fellows will be following you 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 will present a summary of your status to your attending physician every day during rounds. Interns are 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.

3. Transplant Coordinators

The transplant coordinators are in charge of coordinating all of the different aspects involved in the entire transplant process. This includes pre-transplant evaluation, hospitalization for your transplant operation and the post-transplant follow-up. Their many responsibilities include patient and family education throughout the entire transplant process and ongoing communication between all members of the transplant team. This assures a smooth transition from the transplant phase to the post-transplant period. The transplant coordinators are also involved in the organ donation 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 Stanford Hepatologists.

4. Social Services

The liver transplant social worker is a part of the Liver Transplant Program. This team member is involved with you from the time of your initial evaluation. The social worker provides the team with a psychosocial assessment which includes a social history and assessment of the patient 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 Palo Alto are assessed. When necessary, the social worker can offer suggestions about how to initiate fund raising.

The social worker provides counseling and emotional support for both you and your family, beginning in the evaluation period and continuing into the post-discharge phase. The social worker facilitates a weekly Liver Support Group which is offered to pre- and post-transplant patients and families, both inpatient and outpatient. This support group provides a comfortable place for participants to share questions, concerns and experiences which they have in common. 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, and transportation.

5. Physician Assistant

The physician assistant is a health care professional who assists the physician with the care of patients. The physician assistant's primary role in the Liver Transplant Program involves the retrieval of donor organs, assistance with the liver transplant operation, and post-operative care of transplant patients.

6. Clinical Dietician

The registered clinical dietician will evaluate your current nutritional status and help you with any nutritional problems. If your appetite is poor, the dietician will offer and provide you with nutritional supplements to increase your calorie intake.

Prior to discharge, the clinical dietician will be 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.

7. Psychiatry

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

8. Physical Therapy

An exercise program, varied according to each individual's condition and needs, is an essential component of 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.

9. Chaplain

The chaplain provides direct pastoral care service for the spiritual needs of patients and families. This may be done by incorporating the resources of prayer, scripture and sacraments while respecting the religious tradition of the patient.

10. Financial Counselor

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

THE LIVER TRANSPLANT OPERATION

An incision in the shape of an upside down T is made over your abdomen and your lower right ribs are moved upward to see the liver.

Your old liver is removed.

Your new liver is then placed in the abdomen and the anastomoses or surgical connections are made in the following order:

1. Hepatic Vein or Inferior Vena Cava Anastomosis—to allow blood to leave the liver and return to the heart.
2. Portal Vein Anastomosis—between your portal vein and the portal vein of the donor. The portal vein provides 80% of the blood supply to the liver.
3. Hepatic Artery Anastomosis—between your hepatic artery and the hepatic artery of the donor. The hepatic artery provides 20% of the blood supply to the liver.
4. The Biliary Anastomosis—performed by either the bile duct-to-bile duct method (Choledochocholedochostomy), or the bile duct to intestine method (Choledochojejunostomy). This allows for bile to drain out of the liver into the intestine.

After your liver transplant surgery you may not be able to eat or drink for a period of about 3 to 7 days until your stomach and intestines return to normal function.

WOUNDS AND TUBES

When you awake after surgery, you will find that you have surgical incisions and drainage tubes. The following describes the location of, reasons for, and care of these wounds and tubes:

1. You have a large incision shaped like an upside down T on your abdomen. This incision is closed by surgical staples and, for the first few days after surgery, is 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 14-21 days. When they are removed, Steri-strips will be applied over the incision area. In some instances, your abdominal wound will be left open to prevent or treat infection and facilitate healing. Your abdominal wound will be cleansed and the dressing changed 2 to 3 times daily.
2. In rare instances, you may require venous to venous bypass during your transplant. Because of this, you may also have two smaller incisions, one under your left arm and one in your left groin area. These incisions are from tubes used during bypass to take the blood away from the surgical area during your operation. The tubes are removed and the wounds are closed at the end of the operation. The nurses will observe these areas for signs of infection routinely.
3. Three tubes, known as Jackson-Pratt drains (JPs), are inserted during the operation so that fluid is easily drained from the surgical site. These tubes will exit through your abdomen via small incisions. It is normal for tissue that has been manipulated during surgery to produce fluid. This must be drained to prevent swelling of the abdomen and possible infection. These tubes are labeled as "A", "B" and "C". These drains will be removed prior to discharge.
4. 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 the first 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.
5. Until your stomach and intestines begin to function normally, you will need to have a nasogastric (NG) tube. This tube is passed through your nose into your stomach at the time of your transplant surgery. It will drain the fluids your stomach and intestines are unable to digest. The NG tube may remain in place for 2-5 days after surgery. Once you are passing gas and have had one bowel movement, the NG tube can be removed and you may start drinking liquids.

6. If, during your transplant operation, you were able to have your bile duct attached by the duct-to-duct method, you will not have a tube coming through your abdominal wall. In the duct-to-duct method, the bile duct from the donor liver is attached directly to the end of your bile duct.
7. If you do have a bile tube, then your bile duct was attached by the "Roux-en-Y" method. This method is used when the donor bile duct and your bile duct do not match in size, or if you have a diseased bile duct. In the Roux-en-Y method a portion of your intestine will be re-routed to swing up near your new liver so that the new bile duct can be connected to this portion of the intestine. A small thin plastic tube (stent) is placed inside the area where the intestine and the bile duct are sewn together. The stent serves as a bridge for bile to flow through while the tissue surrounding your new bile drainage area heals. The stent may be connected to a bag to allow the bile to drain out for a period of 7 days after the transplant.
8. Approximately one week after transplantation, the drainage bag will be removed and the biliary stent will be closed off. The bile will then flow through the bile duct and into the intestine. The biliary stent may remain in place for 4-6 weeks at which time it is removed in the transplant clinic by the transplant surgeon.

DAILY HOSPITAL ROUTINES

Intensive Care (E2)

After your transplant operation, you will be staying in the ICU for several days. The ICU is a specialized nursing unit where you can be more closely monitored than is possible on the regular hospital unit. The visiting hours may be limited in the ICU, so your visitors will need to check with the nurses before coming to visit.

Once your vital signs are stable and you no longer need a ventilator, you will be transferred to the Transplant Unit on the third floor.

Transplant Unit (E3)

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. The nursing staff would appreciate if you saved your less critical calls for those times other than change-of-shift report.

Rounds

Attending physicians will make visits twice a day to the transplant patients. At that 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 questions of your doctors and report any changes in your condition. If you have questions for your doctors, it is a good idea to write them down so that 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 conversations may be bewildering to you; therefore, if you have any concerns during this discussion, please let the team know.

Meals

The Dietary Department delivers your meals at approximately 7:30 AM, 11:30 AM and 5:00 PM. Depending upon 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 so the menu will be available 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 where perishable foods from home may be stored on the transplant unit. Make sure all foods from home are labeled with your name and room number. A microwave is also available if food needs to be heated. 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 shifts. This will enable them to make an assessment of your condition early in the shift. Your vital signs may be checked again depending upon 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 instruct you on 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.

Daily 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 and wearing the same amount of clothing. The nursing assistant will bring the scale to your bedside between 7:30 AM and 8:00 AM and assist you.

LABORATORY WORK

Blood tests will be drawn on a daily basis while you are in the hospital recovering from your transplant operation. The various laboratory tests that are performed are often called "lab tests." These tests include a complete blood count (CBC), cyclosporine or Prograf level, and liver function tests (LFTs). Daily blood work is drawn at 5:00 AM.

Patients often express concern over the amounts of blood required for these tests. Be assured, we make every effort to consolidate the lab tests. However, periodically, additional blood work will need to be done at other times during the day. Such levels as your glucose, potassium or blood count may need to be checked more than once each day.

The following lab tests and values are those we commonly monitor throughout your hospitalization (they will be recorded daily on your transplant flow sheet). We will continue to follow these tests at intervals after your discharge from the hospital. It is a good idea for all liver transplant patients to be familiar with these tests and what they mean.

<u>Liver Function:</u>		
<u>Test</u>	<u>Normal Range</u>	<u>Indication</u>
Protime (PT) and Partial thromboplastin time (PTT)	PT: 11.5-14 seconds PTT: 23-35 seconds	Measures liver's ability to make clotting factors
Bilirubin	Total: 0.3-1.0 mg/dl Direct: 0.0-0.3 mg/dL	Evaluates liver's ability to clear bilirubin from blood and excrete it in the bile
ALB (albumin)	3.5-4.8 g/L	Indicates liver's ability to make this protein
Cholesterol	150-240 mg/dL	Indicates liver's ability to make and excrete this fat
<u>Liver Enzymes:</u>		
<u>Test</u>	<u>Normal Range</u>	<u>Indication</u>
AST (aspartate amino-transferase); also SGOT	12-45U/L	Liver enzyme which measures damage to liver cells
AL T (alanine amino-transferase); also SGPT	7-40 U/L	Liver enzyme which measures damage to liver cells; slightly more sensitive than AST
AP (alkaline phosphatase)	37-107U/L	Liver enzyme which measures blockage of bile flow
GGT (gamma glutamyl transpeptidase)	8-69 U/L	Liver enzyme which measures both damage to liver cells and blockage of the flow of bile

<u>Chemistry Panel:</u>		
<u>Test</u>	<u>Normal Range</u>	<u>Indication</u>
Na (sodium)	136-145 mEq/L	Measure electrolytes (minerals) in blood
K (potassium) Cl (chloride) Ca (calcium) P(phosphorus) Mg (magnesium).	3.5-5.3 mEq/L 98-106 mEq/L 8.7-10.7 mg/dL 2.6-4.9 mg/dL 1.6-2.4 mg/dL	
Amy (amylase)	34-122 U/l	Measures pancreatic function
BUN (blood urea nitrogen) Cr (creatinine)	7.0-22 mg/dL 0.5-1.2 mg/dL	Indicates kidney function
<u>Complete blood count (CBC):</u>		
<u>Test</u>	<u>Normal Range</u>	<u>Indication</u>
WBC (white blood cells)	3,500-11,000	Measures body's ability to fight infection
HCT (hematocrit)	35-47%	Measures red cells while carrying oxygen
Pl T (platelets)	40,000-450,000	Measures blood clotting component
<u>Immunosuppressive medication drug levels:</u>		
<u>Test</u>	<u>Normal Range</u>	<u>Indication</u>
Cyclosporine (Neoral) Tacrolimus (Prograf)	300-500 ng/mL 5-20 ng/mL	Measures level of immunosuppression medication in blood

TESTS AND PROCEDURES

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

1. Chest X-ray
2. Liver biopsy
3. T -tube cholangiogram/PTHC
4. Liver scan/HIDA scan
5. Ultrasound (US), CT scan and MRI

Chest X-ray

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

Liver biopsy

A percutaneous needle liver biopsy is a safe method of obtaining liver tissue for microscopic examination. It is useful in the diagnosis of liver disorders and helpful in making a precise diagnosis of rejection of the transplanted liver. This procedure is usually done in your room using local anesthesia and intravenous sedation. A specially designed needle is inserted through the abdomen and a small sample of liver tissue is obtained. The needle is then removed and firm pressure is applied to the site to stop any bleeding which may occur. Following the procedure, you will be instructed to lie on your right side for approximately two hours. Vital signs and the puncture site will be checked regularly. A bedside chest X-ray may be obtained after the procedure is completed.

T -tube cholangiogram

A T-tube is placed during surgery to maintain patency of the bile duct and prevent spillage of bile into the abdominal cavity. AT-tube cholangiogram is an X-ray procedure in which dye is injected directly into the biliary system via your T -tube. This test is used to determine if any obstruction or leak is present.

It may be necessary to do a T -tube cholangiogram test even after your discharge. It is very important that you are given an **INTRAVENOUS ANTIBIOTIC PRIOR TO THE EXAMINATION TO PREVENT INFECTION**. Your local physician should prescribe a broad-spectrum cephalosporin or another appropriate antibiotic. Call the transplant coordinator if you have additional questions.

Percutaneous transhepatic cholangiogram (PTHC)

If you do not have a T -tube but need to have a cholangiogram done to rule out problems such as a bile leak or bile duct obstruction, the alternate method is to do a PTHC.

This is an X-ray study done in the Radiology Department. After you have been given local anesthesia and some intravenous sedation, a fine thin needle is placed in your right side and guided into your bile duct system. The radiologist will need to check the needle's location frequently so you will have X-ray pictures taken at intervals. Once the needle is in the correct area a small amount of dye will be injected to get a clear picture of your bile ducts. It is important to remain very still during this procedure. Small children and infants who require this procedure may need to have general anesthesia. You will need to have intravenous antibiotics prior to the test. If you are an outpatient you may be required to be admitted to the hospital's Same Day Care Unit (ATU) on the day of the test. However, you will be able to go home after the test has been completed.

Liver scan - HIDA scan

A liver scan is performed in the Nuclear Medicine Department. This test is relatively simple and requires no preparation on your part. The purpose of the scan is to assess the blood flow to your transplanted liver using dye which is injected directly into your vein. During the procedure, you will be asked to lie on a stretcher while a machine projects images on a screen and records the results. There is no pain and the test lasts approximately one hour.

Liver transplant ultrasound (US)

Ultrasound is a procedure usually done in the Radiology Department. This test utilizes sound waves to locate and outline internal organs and note any abnormalities.

If you should develop unexplained abdominal pain, a sudden rise in your liver enzyme tests or a fever, it may be necessary to do an ultrasound. At that time, the US technician will apply a light coating of special sound wave conducting jelly over your abdomen to allow the US probe to move easily on your skin. By doing this, the technician will be able to visualize the liver and its blood vessels. The ultrasound usually requires no preparation on the part of the patient and the whole procedure takes about one half hour.

CT scan-MRI

CT scans and MRIs are special X-ray techniques that allows for visualization of a specific layer of tissue. With these tests, it is possible to view organs and the 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 the CT exam. An MRI exam requires no prior preparation.

MEDICATIONS

After surgery you will need to take several types of medications to prevent your body from rejecting your new liver and to prevent certain kinds of infections. You may also need a diuretic or an antihypertensive. These medications will be started immediately after your transplant operation. You will be expected, while you are in the hospital, to learn about your medicines. This will include learning the names of your medicines, what they are for, what each dose is, and the possible side effects.

The nurses and members of the transplant team will assist you in learning about your medications.

IMMUNOSUPPRESSIVE MEDICATIONS

Your immune system rejects anything foreign in your body, such as infectious agents or transplanted organs. This system must be slowed down or suppressed to prevent the body from rejecting your new liver. To achieve this, you must take powerful drugs called immunosuppressants. 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, your immune system will reject, and ultimately 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. However, even at your proper dosage, you may experience some side effects. This is normal. Altering your medications independent of the physician's prescribed dosage can have serious consequences.

Medications often have two names; the generic (or chemical) name and the brand (or product) name. Both refer to the same drug. E.g. Prednisone or Deltasone, Azathioprine or Imuran, etc. Based on habit, nurses and doctors often call some drugs by their generic name (e.g., Prednisone, Cyclosporine) and other drugs by their brand name (e.g., Imuran). The drugs listed below are listed by their generic name, and the brand name is in parentheses.

Prednisone (*Deltasone*)

Action: Prednisone is an anti-inflammatory steroid, which also is an immunosuppressive drug. It is taken in small doses for routine immunosuppression and in larger doses to treat episodes of rejection.

How supplied: Prednisone is available in 1,5,10 and 20 mg tablets. There is also a liquid form for pediatric patients. The pills are divided in the center, making it very easy to break a pill in half if necessary. At discharge you will receive the 5mg tablets.

Dose: Your dose is determined by your body weight and your liver function. Changes in your dose should be made only by the Liver Transplant Team.

Side Effects:

- Increased susceptibility to infection
- Salt and water retention
- Increased appetite, which may lead to weight gain.
- Acne may develop on the face, neck and back. This acne will diminish as your drug dose is lowered.
- Increased fat deposits may be seen on your face, neck, shoulders and abdomen and will diminish as your dose is lowered.

- Cataracts and glaucoma develop in some patients on steroids. Eye examinations should be performed at least once or twice a year
- Joint pain may occur in hips and/or knees. Notify the Liver Transplant Program if this occurs.
- Increased blood sugar may develop. This may be a short-term problem or become diabetes. Patients who are already diabetic may have to increase their insulin dose in response to higher blood sugars.
- An increased risk of stomach ulcers is a side effect of steroids. Take your Prednisone with meals to help decrease any irritation of the stomach lining that may occur.
- Mood swings and insomnia is usually experienced when taking high doses of prednisone.
- Skin changes may occur. You may experience thinning of the outer layer of the skin with increased bruising, sensitivity to the sun, and slower healing.
- Night sweats often occur.

Tacrolimus (*Prograf, formerly called FK506*)

Action: Prograf is an immunosuppressive drug that is given initially with steroids to help prevent rejection of the new liver. After the initial transplant period, Prograf can also often be used as the only immunosuppressive drug.

How supplied: Prograf is available in 0.5 mg, 1 mg, and 5 mg capsules.

Dose: The Prograf dose is adjusted according to weight, kidney function, liver tests, and Prograf blood levels. It is taken two times a day; usually the best times are two hours after breakfast and two hours after dinner.
Prograf can be taken with liquids such as water, tea or clear juices. Do not eat solid food or dairy products 2 hours before taking your Prograf dose or 1 hour after taking the dose. Remember: never change your dose or stop taking your medicine without a doctor's order.

Side effects:

- Agitation
- Headache
- Decreased appetite
- Insomnia
- Flushing
- Tingling of the palms of the hands and/or soles of the feet

- Altered kidney function usually first noted on lab tests
- Increased blood sugar (diabetes)
- Stomach upset/diarrhea

Sirolimus (Rapamune)

Action: Sirolimus is an immunosuppressive drug that may be given with Prograf to help prevent rejection.

How supplied: Available in 1 mg capsules.

Dose: The Sirolimus dose is adjusted according to the liver tests and according to Sirolimus blood levels that are monitored with standing labs. Sirolimus is taken once a day, approximately 4 hours after the morning Prograf dose. The most common administration time for Sirolimus is at 2 PM. Sirolimus should be taken consistently either with or without food.

Side Effects:

- Increased cholesterol and lipids
- Increased blood pressure
- Lowered blood level of Potassium
- Diarrhea, nausea
- Decreased blood counts
- Increased susceptibility to infection or tumors, as with all anti-rejection or immunosuppressive medications

Cyclosporine (Neoral)

Action: Neoral is an immunosuppressive drug, which prevents your body from rejecting your transplanted liver. Neoral can be used as the primary immunosuppressive drug instead of Prograf in patients that are unable to tolerate Prograf.

How supplied: Liquid Neoral is available in 50cc bottles at a concentration of 100 mg/cc. It is also available in capsules in 100 mg and 25 mg sizes.

Dose: Neoral doses are adjusted by your physician according to your weight, kidney function, liver tests, and cyclosporine blood levels. The liquid Neoral is mixed in either fruit juice or chocolate milk. You will be taught how to measure your dose before you are discharged.

Side effects:

- Diarrhea, nausea, or vomiting may occur at first.
- Elevation in blood pressure may occur.

- Increases in liver function tests or kidney function tests may develop. If these do go up, it may be necessary to decrease the dosage.
- Increased hair growth, usually on the face, arms and legs, may occur.
- Mild shaking of the hands or tingling in hands and/or feet may occur.
- Fibrous tissue may develop in the breasts.
- Gum swelling and/or tenderness may develop.
- An increased susceptibility to infection will occur.
- An increased susceptibility to tumor-like growths of the internal organs.
- Hot flashes or sweating may occur.

Mycophenolate Mofetil (*CellCept*)

Action: CellCept is an immunosuppressive drug that can be given together with your Prograf/Neoral and Prednisone if required to prevent rejection.

How supplied: CellCept is available in 250mg and 500 mg capsules.

Dose: The dose of CellCept is usually 1 to 1.5 grams twice a day. The best times to take the medication are 1 hour before or 2 hours after eating a meal. CellCept can be taken with liquids such as water, tea or juice but should not be taken with solid foods or dairy products.

Side effects:

- Diarrhea
- Nausea, vomiting
- Decreased white blood cell count Increased susceptibility to infection

Azathioprine (*Imuran*)

Action: Imuran is an immunosuppressive drug that is only rarely used to prevent rejection.

How supplied: Imuran is available in 50 mg tablets that are scored and may be evenly divided.

Dose: The dose of Imuran is adjusted according to your white blood count (WBC). If you are taking Imuran, you must take it every day unless advised otherwise by the Liver Transplant Program.

Side effects:

- Increased susceptibility to infection.
- Nightmares sometimes occur when taking Imuran.
- Decreased white blood cell counts can result from Imuran.

ANTIVIRAL DRUGS

Because you are taking immunosuppressive drugs, you will be more susceptible to other types of infections including viral and fungal illnesses. It will be necessary for you to take certain medications to prevent these illnesses from occurring.

Acyclovir (*Zovirax*)

Action: Prevention of certain viral infections, particularly cytomegalovirus (CMV) and herpes.

How supplied: 200 mg capsules.

Dose: Usually given twice a day, but may be required 4- 5 times daily.

Side effects:

- Headaches
- Nausea, vomiting and diarrhea
- Changes in mental status

Ganciclovir (*Cytovene*)

Action: Prevention and treatment of CMV or EBV infections.

Dose: Given intravenously once or twice a day. Also available in 250 mg capsules.

Side effects:

- Nausea, vomiting
- Decrease in blood cell count
- Headaches
- Altered kidney function

Valgancyclovir (*Valcyte*)

Action: Prevention of cytomegalovirus (CMV) infection.

Dose: Available in 450 mg capsules. Usual dose is either 450 mg or 900 mg daily.

Side effects:

- Nausea, vomiting, or diarrhea
- Decreased white blood cell count
- Altered kidney function

Hepatitis B Immune Globulin (*HBIG*)

Action: Prevention of the Hepatitis B virus from re-infecting the new liver after transplant.

Dose: Given intravenously daily for seven days after the liver transplant, then once a month for an indefinite period.

Side effects:

- Chills
- Back pain
- Rash
- Flushing

ANTIFUNGAL DRUGS

Nystatin (*Mycostatin*) Oral Suspension

- Action: Prevention and treatment of oral yeast infections.
- Dose: Given in liquid form to swish in mouth and swallow 4 times per day, after each meal and at bedtime. Do not eat or drink anything for 20 minutes after taking Nystatin.
- Side effects:
- Nausea, vomiting
 - Anorexia

Nystatin (*Mycostatin*) Vaginal suppository

- Action: Prevention of fungal vaginitis.
- Dose: One suppository each night.
- Side effects:
- Stinging or burning.

Fluconazole (*Diflucan*)

- Action: Treatment of fungal infections.
- Dose: Usually given intravenously, but also available in tablets. Not often used after hospitalization since can increase Prograf blood levels and requires frequent lab monitoring.
- Side effects:
- Nausea, vomiting
 - Diarrhea
 - Increases absorption of Prograf
 - Altered liver and kidney function
 - Decreased blood counts

DRUGS TO PREVENT PNEUMONIA

Patients who are taking immunosuppressive 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 at least the first year after transplant. There are two types of preventative treatments.

Trimethoprim and sulfamethoxazole (*Septra or Bactrim*)

Note: Do not take if you have an allergy to SULFA DRUGS.

Action: Prevention of *Pneumocystis carinii* pneumonia (PCP).

Dose: One tablet (single strength, abbreviated SS) once daily on Mondays, Wednesdays, and Fridays.

Side effects:

- Nausea, vomiting
- May decrease white blood count.
- Altered kidney and liver tests.

Pentamidine (*NebuPent*) - Inhalation

Action: Prevention of *Pneumocystis carinii* pneumonia. Used in patients unable to take Septra due to allergy or side effects.

Dose: Inhalation treatment once a month.

Inhalation side effects:

- Shortness of breath
- Tightness in chest
- Burning of eyes and mucous membranes

ANTIHYPERTENSIVE DRUGS

Your immunosuppressive medications can cause high blood pressure. It may be necessary to take one or more antihypertensive medications for several months or longer after your transplant operation. The most commonly used antihypertensives include:

Nifedipine (*Procardia*; *Procardia XL*)

Atenolol (*Tenormin*)

Metoprolol (*Toprol XL*)

Action: Lower blood pressure and prevent possible strokes.

Dose: Adjusted to blood pressure control and side effects.

Side effects:

- Low blood pressure
- Dizziness
- Weakness/fatigue
- Nausea and vomiting
- Headaches
- Changes in some laboratory tests

DRUGS TO PREVENT OR TREAT PEPTIC ULCERS

Because it is necessary for patients to take steroids initially after transplant, anti-ulcer medications also need to be taken. Some of these medications are:

Ranitidine (*Zantac*)

Famotidine (*Pepcid*)

Omeprazole (*Prilosec*)

Lansoprazole (*Prevacid*)

Nizatidine (*Axid*)

Action: Prevention or treatment of stomach or intestinal ulcers.

Dose: Usually one tablet once or twice daily.

Side effects:

- Nausea, vomiting, diarrhea
- Anorexia
- Changes in taste

DIURETICS

A diuretic ("water pill") may be necessary after surgery to help you eliminate excessive fluids through the kidneys. Commonly used diuretics include:

Furosemide (*Lasix*)

Spiroinolactone (*Aldactone*)

Hydrochlorothiazine (*HydroDIURIL*)

Action: Increases the excretion of fluids and helps decrease swelling around the abdomen and in the legs/feet.

Dose: Your diuretic dose will be adjusted according to your weight and kidney function. Diuretics are often no longer needed within one month of your transplant.

Side effects:

- Electrolyte imbalances
- Dehydration
- Muscle cramps
- Low blood pressure
- Hearing disturbances - ringing in the ears
- Weakness and fatigue

BILE THINNER

A medication to thin your bile may be required to help bile drain through narrowed bile channels in the transplanted liver. This medication makes the bile more water soluble and helps decrease bile congestion in the liver, thereby helping to normalize your liver function labs. You may have also been on this type of medication prior to your transplant. These medications include:

Ursodiol (*Actigall*)

Ursodiol (*Urso 250*)

Dose: Actigall comes in 300 mg capsules and Urso 250 comes in 250 mg tablets. Both are usually ordered for three to four times daily.

Side effects:

- Nausea, vomiting, diarrhea
- Abdominal discomfort
- Headache

REJECTION

Although rejection is a frightening word, it is a normal and expected occurrence following transplantation. The body's immune system attempts to "fight off" and destroy your new liver, which is viewed as a foreign invader. Most patients experience some rejection in the first one to ninety days following surgery, although rejection can occur at any time after transplantation. It is important to learn about the many physical changes you may experience if there is a disturbance in your liver function so you can promptly notify the transplant office and/or your local doctor.

Signs and symptoms of rejection:

1. Fever. If you have a fever of 37.8' C/1 00°F or higher 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 (650) 498-7878.
2. Abdominal pain/tenderness over your liver.
3. Fatigue, malaise, lethargy.
4. Sudden increase in abdominal size/ascites.
5. Lack of appetite.
6. Dark colored urine.
7. Light colored stools.
8. Jaundice (yellow skin and eyes).
9. Elevated liver function tests.
10. Flu-like symptoms. These may be associated with fever, chills, joint and muscle aches or a generalized feeling of "not feeling well". Notify the transplant coordinator if these symptoms occur even if everyone in your household has the flu.

Unfortunately, these symptoms 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 checkups.

If you develop any of these signs and symptoms, please call the transplant office at 650-498-7878 immediately for advice and/or possible treatment.

Treatment of Rejection:

The diagnosis of rejection is difficult and may involve first 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 your treatment. Rejection may be acute or chronic and varies in each individual patient. Please ask your physician or transplant coordinator if you have specific questions regarding your rejection drug therapy.

INFECTION

Infections are another possible complication of transplantation. You are most susceptible to infection because of the medications that you are taking to prevent rejection. It is important for you to know the signs and symptoms of infection and to alert the Liver Transplant Program if they should 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 do have an exposure to any of these illnesses, you **MUST** notify the Liver Transplant Program immediately as it may be necessary for you to be immunized within 48 hours of the exposure.

Good hand washing is one of the best ways to prevent the transmission and spread of disease.

Fever

As mentioned above, a fever is a signal that your body is trying to fight "something". If you experience a low-grade temperature (100°F/37.8°C) for more than 24 hours or a sudden high temperature (101°F/38.3°C or greater), you may be fighting an infection and must notify your transplant coordinator and/or your local physician.

Cough

This could be an indication of an infection in your lungs. Notify the transplant coordinator/local doctor if this persists for more than 24 hours.

Wound Infections

Drainage can be an indication of an infection in a cut or wound. Notify the transplant coordinator or local doctor if this occurs. Redness, swelling and tenderness are also signs that a wound might be infected.

Viral Infections

The common cold, the flu, cold sores (herpes simplex I), genital herpes (herpes simplex II), shingles (herpes zoster), and chicken pox (varicella zoster) are all examples of viral infections. You should avoid direct contact with people who have active infections. 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 do get herpetic lesions, characterized by painful reddened fluid-filled blisters, it is important to notify the transplant coordinator for treatment.

Other Common Infections

1. Oral Thrush. Yeast infections (Candida) characterized by white patches on the tongue, which cannot be brushed away and may be painful.

2. Urinary tract. Symptoms may include pain, burning, and difficulty in starting your urine stream, feeling of urgency or frequent urination.
3. Vaginal. Yeast infection (Candida) characterized by discharge, odor, itching and pain.
4. Gastrointestinal. Nausea, vomiting, diarrhea, and abdominal pain are all signs of a possible gastrointestinal infection. If these signs persist for more than 24 hours, you must contact the transplant coordinator so that you can receive your immunosuppressive medications by another route as well as to try to identify the cause of the symptoms.

ALL OF THE ABOVE INFECTIONS MUST BE TREATED.

ADDITIONAL COMPLICATIONS

HYPERTENSION

High blood pressure is a major risk factor for both heart disease and stroke. Transplant patients have a higher incidence of high blood pressure due to immunosuppressive medication side effects. Even if you do not have a personal or family history of hypertension pre-transplant, you may develop this complication after liver transplant.

If you are diagnosed with high blood pressure, your transplant doctor will prescribe one or more anti-hypertensive medications to control your blood pressure. A diuretic (water pill) may also be used to lower your blood pressure, increase your urine output, and remove extra fluid. To help keep your blood pressure under control you should:

- Monitor blood pressure daily and report abnormal to your transplant coordinator or doctor.
- Take your anti-hypertensive medications exactly as prescribed.
- Maintain a well-balanced diet, low in salt and cholesterol.
- Follow a regular exercise program; i.e. daily walking.
- Do not smoke or drink alcohol.

POST-TRANSPLANT DIABETES

Just as some transplant recipients develop hypertension, some may also develop diabetes (high blood sugar). The major contributing factor for diabetes post-transplant is immunosuppressive medication side effects, especially from prednisone and Prograf.

High blood sugars (greater than 200) may lead to wound infections, dehydration, and kidney and heart disease long-term. As with non-transplant diabetes, effective management begins with lifestyle modification (diet and exercise), and, if necessary, medications in the form of pills and/or insulin injections. The good news is that as the immunosuppressive medication doses are weaned, most patients are able to achieve good blood sugar control without the need for such medication.

All patients developing high blood sugars post-transplant are referred to a dietician and a Diabetes Clinical Nurse Specialist for teaching and support.

HIGH FAT AND CHOLESTEROL LEVELS

Over the long-term, some transplant recipients may experience hyperlipidemia (high fat and cholesterol levels). High pre-transplant cholesterol levels, diabetes, high fat diet, obesity, age, and anti-rejection drug therapy all contribute to post-transplant hyperlipidemia.

Because hyperlipidemia is a major risk factor for atherosclerosis ("hardening of the arteries") it is imperative that cholesterol levels be kept under control with diet, exercise, and, if necessary, the use of cholesterol-lowering medications. Regular, long-term laboratory tests for cholesterol will enable your transplant doctor to determine if cholesterol-lowering medications are indicated.

ANXIETY AND DEPRESSION

It is not uncommon for transplant patients to experience anxiety and even some depression following their surgery, hospitalization, and return home. The long awaited event of receiving your new liver not always brings the anticipated exhilaration. Pain, mood-swings from Prednisone, potential complications, family and/or financial stresses can all lead to both transient feelings of anxiety and depression. Maintaining open communication with family and friends can help alleviate some of these feelings.

If necessary, consult with your transplant team social worker or nurse coordinator for information regarding services available to help you resolve stressful concerns or situations. Remember, the Liver Transplant Support Group is available twice a week for both pre and post-liver transplant patients to share concerns.

CANCER

Due to the effects of anti-rejection medications, transplant recipients are at greater risk for developing certain types of cancer, including skin cancer. For this reason it is important that you:

- Have routine cancer screening procedures regularly, including yearly mammograms, Pap smears, stool samples, and exams for skin, testicular and prostate cancer.
- Examine yourself regularly for any indication of cancer, including skin exams and monthly breast self-examinations for women.
- Be aware of moles, birthmarks and beauty marks, and report spots on the skin that change color, or increase in size or thickness.
- Report sores that continue to itch, hurt, crust, scab, bleed or do not heal within 3 weeks.
- Report continually swollen lymph nodes (glands) anywhere in your body.
- Wear a hat and sunscreen with sun protective factor (SPF) rated at least 15-30.
- Avoid midday sun when the UV rays are strongest.

BATHING/SHOWERS

Showers can be taken after the last JP drain has been removed and the bile catheter has been clamped. This is usually 6-7 days after the surgery.

If you have a central line (CVP), check with your nurses prior to showering. They will help you cover the area to protect it.

Here are some things to remember while showering:

1. Protect your Bile catheter! You will want to remove the dressing that covers the bile catheter before showering, but it is a good idea to tape the tube to your body to prevent it becoming dislodged accidentally.
2. Lightly soap the incision areas and carefully rinse. Do not use alcohol or Betadine to clean the bile catheter area.
3. Gently pat the incision and bile catheter area dry after you have finished showering. Towel drying by rubbing can cause accidental removal of staples from the incision or dislodgment of the bile catheter.
4. Sitting in bathtubs to soak is not advisable while the bile catheter is in place; this can promote infection and weaken the sutures holding the bile catheter to the skin.
5. Bubble baths, saunas, jacuzzis and swimming pools are not recommended until the bile catheter is removed.

WHAT DIET DOES STANFORD HEALTH SERVICES RECOMMEND?

Nutrition and your transplant:

Good nutrition is an important part of your medical treatment. Eating well can help to speed your recovery after transplantation by providing your body with energy and protein for wound healing. During the first few weeks after transplantation, your energy needs are extremely high. However, it is common to feel a loss of appetite, taste changes, or early satiety/fullness at a time when you most need to eat.

Here's what to do:

1. Eat frequently; small snacks and optional supplements help you to meet your needs for healing, while avoiding that bloated feeling.
2. Drink ample amounts of liquids - at least 8 to 10 cups (2-3 liters) each day.
3. Select nutrient dense fluids (such as milk, juice, supplements/shakes) in addition to plain water.
4. Stand and walk whenever possible - it will help get your appetite back on track, and help you get rid of that weak bloated feeling.

After a couple of weeks, or when you return home, your appetite will begin to improve. Paying attention to the quantity, quality, and variety of foods you eat will help you lessen the side effects of your transplant medications.

To stay healthy, experts at Stanford Health Services recommend five proven strategies after transplant:

1. Lose excess weight. An average of 10-40 pounds of weight gain as early as six months following transplant can mean that it is time to take action. Dropping as few as ten pounds can make a difference.
2. Cut back on saturated fat.
3. Eat at least five servings of fruits and vegetables daily.
4. Do not consume alcoholic beverages.
5. Include regular exercise, at least one hour in a week.

SPECIAL CONSIDERATIONS THAT MAY AFFECT YOUR BASIC DIET:

- *A diet low in cholesterol and saturated fat can lower the risk of heart disease.*
Transplant medications can cause high blood cholesterol. The American Heart Association recommends limiting your intake of foods high in saturated fat such as fatty cuts of meat, poultry skin, whole milk dairy products, lard, butter, palm oil and coconut oil. Saturated fat raises your blood cholesterol level more than anything else that you eat. The best way to reduce your blood cholesterol level is to choose foods such as fruit, vegetables, and whole-grain foods naturally low in fat and high in starch and fiber.
- *Adequate calcium and vitamin D intake can help Prevent osteoporosis.*
Transplant medications interfere with the absorption of calcium. Furthermore, as you age, your bones become more fragile and break easily. If you are not able to take 2 - 3 servings of dairy products daily or calcium fortified juices, you should consider supplementing your diet with calcium and vitamin D.
- *Preventing High Blood Potassium.*
High blood potassium due to medications or rejection may require a temporary low potassium diet. Limit such high potassium foods as oranges/orange juice, potatoes, bananas, and avoid salt substitutes.
- *Preventing Diabetes.*
Transplant medications such as steroids may cause your blood glucose (or blood sugar) levels to go up. Untreated, long term high blood glucose can delay wound healing and damage the blood vessels leading to vital organs. By controlling your carbohydrate and sugar intake, you may continue to eat well and enjoy a variety of food choices without developing diabetes, or high blood sugar.
- *Eating the right foods can lower blood pressure significantly.*
This was shown by a recent landmark study called DASH (Dietary Approaches to Stop Hypertension). Better yet: It is the same diet that may help cut your risk of cancer, heart disease, osteoporosis, and diabetes. Lower blood pressure can also help to prolong the function of your transplant.
- *Preventing High Drug Levels.*
Grapefruit juice will change the absorption of some transplant immunosuppressive medications and may lead to Prograf toxicity. Avoid both grapefruit juice and grapefruits after transplant. Unless otherwise specified, water is the best liquid to use to take medications.
- *Preventing Low Magnesium Blood Levels.*
Transplant medications may interfere with absorption of magnesium. Magnesium is essential for the normal metabolism of calcium and phosphorus and plays a major role in bone metabolism. It is also important in neuromuscular activity and impulse transmission. It is an activator for enzymes and amino acid metabolism. You may refer the following list to choose foods higher in magnesium for your daily meals.

MAGNESIUM CONTENT OF SELECTED FOODS

Recommended Dietary Allowances:

Adult Males: 270 to 400 mg

Adult Females: 280 to 300 mg

<u>Food</u>	<u>Amount</u>	<u>Magnesium(mg)</u>
Cereal, 100% Bran	1 oz. (1/2 cup)	134
Almonds, dry roasted	1 oz. (24 nuts)	86
Filbert/Hazel nuts, dried	1 oz. (20 nuts)	84
Spinach, cooked	½ cup	79
Swiss Chard, cooked	½ cup	75
Cashews, dry roasted	1 oz. (18 med. Nuts)	74
Bran Flakes	1 cup	71
Brazil Nuts, dried shelled	1 oz. (8 med. Nuts)	64
Figs, dried	½ cup (6 each)	60
Flour, soy bean	¼ cup	60
Peanut Butter, smooth	2 tbsp	56
Beans, Lima, cooked	½ cup	50
Beet Greens	½ cup	49
Peanuts, dry roasted	1 oz.	49
Walnuts, dried	1 oz. (4 halves)	48
Broccoli, cooked	½ cup	47
Okra, cooked	½ cup	46
Cereal, wheat germ, toasted	¼ cup	45
Avocado	½ med.	45
Spinach, raw, chopped	1 cup	44
Pecans, dry roasted	1 oz.	38
Pistachio, dry roasted	1 oz.	37

Magnesium Content of Selected Foods Continued:

<u>Food</u>	<u>Amount</u>	<u>Magnesium(mg)</u>
Macadamia Nuts, dry roasted	1 oz.	33
Milk, low fat	1 cup	33
Seeds, sesame, dried	1 Tbsp	32
Tofu, soybean curd	1 oz.	31
Oatmeal, cooked	½ cup	28
Bread, whole wheat	1 slice	26
Meat, beef, poultry, fish	3 oz.	24
Potato, baked	1 med.	19

BLOOD PRESSURE,TEMPERATURE, AND DAILY WEIGHT MONITORING

It will be necessary to take your blood pressure twice a day when you are discharged from the hospital. Prograf and Neoral can cause hypertension (high blood pressure), which can lead to strokes, so it is essential that you take your antihypertensive medications as instructed and that you monitor your blood pressure carefully.

Blood pressure (BP) is the measure 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).

If your insurance authorizes use of Chronimed or ProCare mail-order pharmacies, you will receive a free blood pressure cuff with your first medication delivery. Patients not eligible for either of these pharmacies will need to have their support persons purchase a blood pressure cuff prior to discharge.

The following brands have been found to be accurate and reliable blood pressure cuffs and can be purchased at any pharmacy such as Longs, Walgreens and Rite-Aide:

OmChron: Marshalls: Sunbeam:

Prices range from \$40-\$110

You will be instructed in the use of the blood pressure cuff as well as how to recognize a blood pressure that is too high or too low before leaving the hospital. Use your blood pressure cuff once a day while in the hospital to learn your blood pressure trends and to check the accuracy of the cuff.

After you are discharged from the hospital, you will need to check your blood pressure twice daily. The best time to do this is first thing in the morning and in the evening. It is normal to have higher blood pressure readings in the evening. It will be important for you to record your blood pressures in your transplant diary. If you notice that your top number (systolic) is more than 160 or your lower number (diastolic) is more than 95 for 24 to 48 hours notify your transplant coordinator.

You will also need to check your temperature twice daily at home. You should continue to check your weight each morning when you are home. This should be done first thing in the morning (along with the blood pressure and temperature check) before eating breakfast. Always keep a record of your weights, temperatures, and blood pressures and bring this record to your transplant clinic visits for review.

ACTIVITY AND EXERCISE

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

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

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. Check with your transplant physician regarding when it is safe to drive. If you are experiencing blurry vision as a result of your medications, **DO NOT DRIVE**.

Avoid lifting more than 10 pounds for three months after your surgery. This allows time for the wound to heal well before you gradually resume normal lifting. Also avoid excessive physical strain from pushing or pulling large objects such as furniture.

Most patients can return to work 2-3 months after surgery. However, this will depend upon 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.

Anal intercourse is not recommended for transplant patients as Prednisone causes the rectal tissues to be easily irritated or torn. Female patients may experience some degree of vaginal discomfort, irritation or dryness also caused by Prednisone. Use of a lubricant such as KY-Jelly may relieve those 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, cervical caps, condoms and diaphragms. These methods are safe and effective birth control measures when used correctly. Birth control pills should not be used unless their use 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 after surgery. All anti rejection medicines must be taken throughout pregnancy to prevent rejection. At this time, little is known about the effects of Neoral or Prograf on a developing fetus.

After transplantation, women should continue to have a yearly PAP smear and gynecological exam.

Always practice "safe sex" and use condoms for all sexual activities.

ALCOHOL

Alcoholic beverages should not be consumed after liver transplantation. Alcohol is processed by the liver and may produce changes in your liver. These changes can be confused with signs of rejection or liver infection.

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

OVERGROWTH OF HAIR

Overgrowth of hair, known as hirsutism, is a temporary side effect of Neoral. Although this may be great for bald patients, facial hair is disconcerting for women. Excessive facial hair can easily be removed by the use of depilatories, such as Surgi-cream or other facial hair removers. Some cosmetic manufacturers, such as Merle Norman or Revlon, produce special facial hair removers. Products designed to remove body hair from legs and underarms, such as NEET or NAIR, should not be used on your face.

SUN

Prednisone may increase your sensitivity to the sun, making you more prone to sunburn. To guard against overexposure to the sun, even if you were never prone to sunburn previously, you should always use a sunscreen with a high Sun Protection Factor (SPF) such as #15. As a general guideline, the higher the SPF number the greater the protection offered by the cream or lotion.

VACCINATIONS

Flu shots are recommended but are not mandatory. These injections are given during 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. Tetanus shots are acceptable vaccinations.

YOU SHOULD NOT RECEIVE ANY LIVE VIRUS VACCINES (these include polio and MMR).

PREPARATION FOR DISCHARGE

Once you are eating, are able to walk without assistance, are off all intravenous medications, and your liver tests and anti-rejection drug levels have stabilized, it is time for discharge.

The following is a check list of things that are essential to be completed prior to discharge:

1. Read your teaching booklet.
2. Know the signs of rejection.
3. Know the signs of infection.
4. Know all of your medications including:
 - Names
 - Dosages
 - Frequency
 - Actions of the drug
 - Side effects
5. Know how to take your blood pressure and know your blood pressure parameters for when to call your transplant coordinator.
6. Identify the person who will stay with you when you are discharged.
7. Identify where you will stay.
8. Know where and how often you will have your blood work drawn after discharge.
9. Obtain a clinic appointment.
10. Know how you will obtain your medications prior to discharge. You will need to obtain all of your discharge medications 1-2 days prior to your discharge from the hospital. Your transplant surgeon will order your discharge medications either from Chronimed or ProCare mail order pharmacies. If your insurance does not authorize use of either of these, your support person will need to obtain your discharge medications from a local pharmacy and bring them in to the hospital for review
11. Note being prepared for your discharge, such as not knowing your medications or how to take your blood pressure, can and will delay your discharge from the hospital.

CLINIC INSTRUCTIONS

Liver Transplant Clinic is held on Monday 9 AM to 4 PM and Thursday from 9 AM to 12:30 PM in the Blake Wilbur Medical Specialties Clinic, second floor. All clinic appointments are scheduled by calling the Liver Transplant Office at 650-498-7878.

Be sure you have a scheduled appointment before you are discharged from the hospital. Initially, you must have your lab work drawn on Sundays and Wednesdays, from 8:00am to 9:00 AM.

If you are having your blood work drawn at Stanford, please note the following:

- You will need to register in Admitting to pick up your lab stickers before going to the lab. Sunday labs are done in the Inpatient Clinical Lab on the first floor of the main hospital in Room H1524.
- Don't forget to bring your lab orders! Wednesday labs are done in the Outpatient Lab located on the first floor of the Boswell Clinic near the information booth or in the Blake Wilbur Clinic Lab on the first floor of the Blake Wilbur Building.

If you are having your blood drawn at your local lab near your home, please note the following:

- You will need to register at the Outpatient Registration desk at the lab.
- You will need to have your standing lab orders with you.

NOTE: NEVER GIVE THE LAB YOUR STANDING LAB ORDERS WITHOUT KEEPING A COPY FOR YOURSELF.

The morning you have your blood drawn **DO NOT EAT BREAKFAST** and **HOLD YOUR PROGRAF** until after your blood work is done. You may hold your other morning medicines until you eat if you wish.

Please check in with the clinic receptionist when you arrive at the Transplant Clinic. If for any reason you cannot come for your clinic visit, please call 650-498-7878 to reschedule.

Bring your Medication Sheet and Vital Sign Log with you to all clinic appointments.

Bring your Medi-Cal stickers, Medicare and/or any other insurance cards to clinic with you each time.

THINGS TO REMEMBER

When to call the Transplant Coordinator

The liver transplant coordinators are available Monday through Friday from 8:30 AM to 4:30 PM in the transplant office to answer questions, re-order medications, review laboratory results, and address any other medical concerns. After 4:30 PM and on weekends, the Liver Transplant Hepatologists are "on-call" for PATIENT EMERGENCIES ONLY (i.e., fever). Please do not call for matters that can be managed during office hours (i.e., prescription refills).

The Liver Transplant Program number from 8:30 AM - 4:30 PM on Monday- Friday is 650-498-7878. After 4:30 PM the on-call hepatologist can be reached by dialing 650-723-6661 and asking the Stanford page operator to contact the on-call Liver Transplant Hepatologist.

DO NOT take any medications unless a physician has prescribed them for you. This includes over-the-counter (OTC) medications such as:

- Ibuprofen (i.e. Advil, Motrin). These may harm your kidneys.
- Aspirin or aspirin products (i.e., Alka Seltzer, Bufferin). These may increase stomach irritation.
- Alcohol-containing products (i.e., Nyquil).

If at any time you start a new medication, always check with the Liver Transplant Program. Many medications interfere with the immunosuppressive medications, especially Neoral and Prograf.

Nausea, Vomiting, Diarrhea

If you are nauseated or have been vomiting and cannot take your medications, please call us immediately so that we can arrange to treat the nausea and/or admit you to the hospital, if appropriate.

If you have diarrhea, which persists longer than 24 hours, please notify the transplant coordinator. If, on the other hand, you are troubled with persistent constipation also contact the 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 indicate that you have had a liver transplant and are taking steroids and Neoral/Prograf, as well as any other underlying health problems (i.e., diabetes, allergies, hypertension) you may have.

Vacations

Because of the increased risk of infection and rejection episodes during the first 6 months after transplantation, out-of-state travel is not recommended without checking with your transplant physician or coordinator.

When leaving home for any substantial length of time, such as a vacation, let us know and we will help you arrange your blood tests appropriately.

The Liver Transplant Program can give you the name of the nearest transplant center, so that if you require any help while you are away you will know who to contact.

NOTE: We may not be able to call in prescriptions across state lines, so please remember to take plenty of medications with you and carry them on your person when traveling.

If you are planning a trip to a foreign country that requires immunization for smallpox, measles, German measles, or any other vaccine containing a live virus, ask your transplant team for advice at least 6 weeks before your departure. Vaccinations with "live viruses" are not recommended for those on immunosuppressive medication, and it may not be safe for you to travel to these countries without immunization.

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 these is during your clinic appointment or during regular office hours. NOT DURING NON-OFFICE HOURS OR WEEKENDS.

FOLLOW-UP MEDICAL CARE

Ophthalmologist

Routine eye examinations are very important. Prednisone and Prograf may cause changes in your eyesight such as blurry vision. These visual changes may be related to the dosage of the drugs you are taking. You should alert your eye doctor to all of your medications. You should check with your ophthalmologist regarding any necessary changes in your eyewear.

Cataracts and glaucoma are eye problems, which may develop as a result of the steroids. Since routine screening for these problems may not be a part of all routine eye examinations you may have to request that these examinations be performed.

Dentist

Routine dental care must be maintained. Be sure to inform your dentist of your medications. Neoral may cause overgrowth of your gums (gingival hyperplasia). This will decrease as the dose of Neoral you are taking is lowered. If your gums become swollen and painful, your dentist may suggest oral hygiene measures, which may temporarily relieve this discomfort. Some home remedies, such as gargling with warm water, may be effective.

If you require ANY type of dental work, including routine cleaning, you will need antibiotics to prevent infection. We recommend the following protocol:

- Amoxicillin 2.0 gm (four 500 mg tablets) 1 hour prior to the procedure.

The drug of choice is amoxicillin. If you are allergic to amoxicillin or penicillin, 600 mg of clindamycin one hour prior to the procedure may be substituted.

RESEARCH PROJECTS

Research is a vital part of science and medicine. It opens new doors that enable doctors to offer you better options in treatment. Stanford University Hospital, like all state-of-the-art medical centers, often participates in various research projects. If you are eligible for a study, your physician will give you a written consent form that will explain the research project in detail, as well as a verbal explanation of the project. Research studies at Stanford University Hospital are confidential and participation is voluntary.

HOW TO WRITE A LETTER TO THE DONOR FAMILY

Many of you have expressed the desire to thank the family of the donor from whom you received an organ transplant. Please follow these simple guidelines. The family will be happy to hear from you.

1. You may write a letter or message of any length.
2. Do not put your name on the letter; it must be anonymous.
3. Give your letter to a transplant coordinator, who will identify you or your donor and forward your letter to the California Transplant Donor Network.
4. Even if the organ you received was from another region, the local donor network will forward your letter to the appropriate agency to be sent to the family.
5. Or you may send your letter directly to the donor network with your name clearly printed only on the return address part of the envelope and send to:

California Transplant Donor Network
1611 Telegraph Ave. Suite 600
Oakland, CA 94612

FINANCIAL COUNSELOR

Insurance concerns can arise anytime before and after transplant.

After your liver transplant, you will need sufficient insurance to cover the immunosuppressive (anti-rejection) medications, which you will need to take for the rest of your life.

Although you may have Medicare, it will not cover all the costs and will only cover your medications for three years after your transplant.

You are encouraged to learn as much as possible about your insurance. The financial counselor welcomes your questions and will assist you in explaining your current coverage as well as make suggestions for additional coverage if needed.

The role of the financial counselor includes:

- Liaison to patients with billing issues
- Managing authorizations
- Providing information regarding COBRA, Medicare, pre-existing conditions, contracted pharmacies, and issues due to changes in insurance policies.

If you become aware of any changes in your coverage, please notify the Financial Counselor immediately.

LIVER TRANSPLANT NURSE COORDINATOR

Each liver transplant patient has an assigned liver transplant nurse coordinator that is in charge of managing their care through the entire liver transplant process, from referral through to post-transplant follow-up.

As an integral part of the transplant team, your liver transplant coordinator has many responsibilities. You have become familiar with many of these responsibilities since the time of your referral to the Liver Transplant Program and while waiting on the liver transplant list. Post-transplant, the primary role of your coordinator includes the following:

- Patient and family education regarding medications, follow-up medical care, self-care, and general health practices, and signs and symptoms to monitor for.
- Communication liaison for you and the transplant team and for the transplant doctors and your local healthcare providers.
- Long-term surveillance for complications via regular laboratory and symptom monitoring.
- Individual referral to community resources as needed.

It is imperative that you maintain good communication with your transplant coordinator at all times throughout the liver transplant process and especially after your transplant. For example, your coordinator needs to be notified immediately if you have any symptoms of possible infection or rejection so that quick intervention can be taken.

By working together with your transplant coordinator and transplant doctor and following their recommendations, you can optimize your chances for the continued lifelong success of your liver transplant.

TRANSPLANT SOCIAL WORKER

Your liver transplant social worker obtains a psychosocial history from you at your first interview with her. This enables your social worker and the team to best understand who you are and how we can help you during the very stressful times before and after your transplant.

In the period immediately after the transplant surgery, emotional support for your family is provided by the social worker, individually and in the semi-weekly support groups. If you live more than fifty miles from Stanford local housing may be a need for you and your family. Your social worker can help you locate the best housing for your needs. Because some housing costs are based on ability to pay, detailed income information must be obtained in the initial interview with the social worker.

In the initial interview you learn that you will not be able to drive a car for three months after your transplant surgery, so it is expected that your transportation arrangements are made prior to your hospital admission. During the first month after discharge from the hospital you will need to return to clinic every Monday and Thursday and make trips to the lab for blood draws every Sunday and Wednesday, so having a plan in place for someone to drive you to your appointments is crucial.

Your social worker can help with housing, vocational rehabilitation, writing the very important letter to the donor family, and counseling. The social worker can also often help you frame questions that you would like to ask the doctors. Good communication with the liver transplant team will enable you to feel more in control over your life and the important things that are happening to you. Good communication also helps the team better help you.

Your social worker on the liver transplant team is a good resource to help you and your family deal with feelings or concerns that may arise during this very exciting, but stressful, time. Some of the stressful issues that often arise during the post-transplant period relate to marital and family stress, finances, and sexual issues, and body-image changes. These may lead to feelings of depression, guilt, anxiety, and mood swings. Through individual and group counseling, or referral to community resources, your social worker can help you adjust to life after transplant.

You are expected to attend the liver transplant support group as soon as possible after your surgery. Those who attend this support group usually adjust more easily to their new life because they have learned from those who have gone before. They also feel a kinship with the other patients and are helpful to those who come after.

These support services are provided to help you adjust to a new, exciting life. Take advantage of all that is offered. The more you know, the easier your adjustment will be.



Adult Liver Transplant Support Group

At

Blake Wilbur Conference Room

Time: 10:30AM-12:00PM

Every Monday

Blake Wilbur Building
900 Blake Wilbur Drive
1st floor, Blake Wilbur Conference room.

If you are planning to attend support group and need a wheel chair, please obtain this from the front desk at the Blake Wilbur Building.

For additional information please call:

Jenny Kwak, LCSW (650) 498-5831

Kimberly Averett, MSW (650) 498-5428

Miriam Beinin, LCSW (650)-725-8636



DEFINITIONS

Abscess:	Localized infection.
Anemia:	A condition in which the blood is deficient in red blood cells or oxygen-carrying proteins..
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 yellowish or greenish fluid secreted by the liver. it aids in digestion and absorption of fats.
Biliary atresia:	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, an abscess, tissue damage or bleeding in the body.
Cholangiogram:	Injection of dye into the bile ducts directly or through the 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.
Cross matching:	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 inhibit 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 heart beating pattern traced on paper by the use of electrodes (EKG, ECG) placed on the chest; used to determine the type of heart rhythm and any injury to the heart tissue.
Encephalopathy:	Change in consciousness, thinking abilities and behavior occurring in advanced liver disease by the accumulation of wastes from protein breakdown.
Endoscope:	A small telescope”-like instrument that can be inserted into the esophagus to examine the lining of the esophagus, stomach and part of the small intestine.
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 the liver's ability to function by removing a radioactive dye from the blood stream and passing it into the intestine.
Hypertension:	This 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 the transplant recipient has the new liver. It helps prevent the recipient's own 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, AL T, alkaline Phosphatase and GGT that are released by the cells of the liver and other parts of the body.
Noncompliance:	Failure to take medicine as prescribed or making daily decisions that may shorten the lifetime of the patient.
Petechiae:	Small spots of blood leakage in the skin of membranes frequently seen with poor blood clotting.
Portal hypertension:	Elevated blood pressure in the portal vein. It is a complication of cirrhosis of the liver and is the cause of varices.
Prednisone:	A steroid hormone taken by most transplant recipients to help prevent rejection.

Prograf:	Formerly called FK506, relatively new and potent immunosuppressive medication.
Pruritus:	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, which 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:	Transjugular intrahepatic portacaval shunt. X-ray procedure performed to decrease portal hypertension.
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, which can cause gastrointestinal bleeding.
Vena cava:	The largest vein in the body, returning blood to the heart.

Patient Vital Sign Record Log

The week of _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Weight							
Blood Pressure	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Temperature	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Blood Sugar	am	am	am	am	Am	am	am
	noon	noon	noon	noon	noon	noon	noon
	pm	pm	pm	pm	pm	pm	pm

List of questions and concerns for my doctor: _____

Patient Vital Sign Record Log

The week of _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Weight							
Blood Pressure	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Temperature	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Blood Sugar	am	am	am	am	Am	am	am
	noon	noon	noon	noon	noon	noon	noon
	pm	pm	pm	pm	pm	pm	pm

List of questions and concerns for my doctor: _____

Patient Vital Sign Record Log

The week of _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Weight							
Blood Pressure	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Temperature	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Blood Sugar	am	am	am	am	Am	am	am
	noon	noon	noon	noon	noon	noon	noon
	pm	pm	pm	pm	pm	pm	pm

List of questions and concerns for my doctor: _____

Patient Vital Sign Record Log

The week of _____

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Weight							
Blood Pressure	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Temperature	am	am	am	am	am	am	am
	pm	pm	pm	pm	pm	pm	pm
Blood Sugar	am	am	am	am	Am	am	am
	noon	noon	noon	noon	noon	noon	noon
	pm	pm	pm	pm	pm	pm	pm

List of questions and concerns for my doctor: _____

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www.liverfoundation.org

www.unos.org

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January 1995 by Candice Gettys, R.N., Nurse Manager
Revised 05/1998, 08/2001, 01/2004 by Fatima Rosa, R.N.