

Liver Transplant Patient Handbook



UCSF Medical Center

Liver Transplant Phone Number

1 (800) LIVER TX
(548-3789)

Leave your **name, date of birth, phone number, and a brief message.**

Your message will be returned within
one business day.

Frequently Asked Questions

Medication questions:

- What do I do if I forget to take my anti-rejection (immunosuppressive) medication? **See page 8 under "missed dose" listed under each medication description.**
- What do I do if I need a prescription refill? **Call your pharmacy who will contact the Transplant Office for refill authorization.**
- What do I do if my pharmacy hasn't received prior authorization for a medication? **Call (800) 548-3789 and leave a non-urgent message.**
- What over the counter medications can I take? **See page 46.**
- What should I do if am prescribed a medication by another provider? **See page 46.**

Vaccination information:

- Which vaccines can I receive and which should I avoid? **See page 28.**
- What if I am traveling out of the country? **See page 45.**

Labs:

- What do I do when my standing order expires? **Call (800) 548-3789 and leave a non-urgent message. Kaiser insured patients call (888) 551-2740 and leave a message for your Kaiser coordinator.**
- How often will I need to have labs drawn? **Frequently right after transplant, then once per month for a lifetime.**
- How can I get my lab results? **Ask your lab how you may also receive lab results. Some labs/providers have ways you can access your labs on-line.**
- Do my labs need to be drawn while fasting? **No, but you must draw labs first thing in the morning before taking medications.**

Low Potassium diet:

- What foods should I limit to keep my potassium level in range? **See page 33.**

Illness and infection:

- What over the counter medications can I take? **See page 46.**
- When and who should I call when I am not feeling well? **See page 46.**

Dentist:

- Do I need antibiotics before going to the dentist? **See page 42.**

Medical records

- How do I receive a copy of my medical records? **Call medical records (415) 353-2885. The transplant office is not authorized to send medical records.**

Disability and FMLA forms and work release forms: (See page 45.)

- How do I get my forms filled out and signed for medical leave? **Call (800) 548-3789 and leave a message for the Social Worker.**
- When can I return to work? **See page 45.**

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Introduction

Liver Transplant Service Phone Numbers

The Liver Transplant Office is open from 8am to 5pm, Monday through Friday. The Liver Transplant answering service will accept emergency phone calls before and after office hours, on weekends, and all holidays.

Urgent Calls Only

The 24 hour **urgent** transplant number is **(415) 353-1888**. This number is answered 24 hours a day, 7 days a week. If you experience an urgent health concern during non-business hours, please use the urgent transplant phone number. If you feel your concern can wait until the next business day, please call during business hours and ask that your transplant nurse practitioner be paged.

Leave the following information when you call the 24 hour urgent transplant number:

- Your name (spell it for the service) and date of birth
- Your phone number(s), including area code
- Brief reason for call

National Emergency Number Is 911

- Call 911 or have a family member or friend take you to the nearest emergency room if you have any of the following:
 - Chest pain
 - Bleeding
 - Trouble breathing
 - Unconsciousness

Non-Emergency Calls

- Reporting lab values is not an emergency.
- Prescription refills are not an emergency.
- Call **1 (800) LIVER TX** (548-3789) with questions, or messages for the transplant team. Messages may be left 24 hours a day. Your message will be returned within one business day.
- Requests for routine prescription refills should be called in by your pharmacy to the above number.
- Pediatric patients should call **1 (800) UC KID GI** or (415) 476-5892 or (415) 476-8636.

Consulting Other Specialists

You may be sent to specialists in other departments at the Medical Center and clinic, so you need to keep a record of the provider's name in each department in order to make an appointment. Keep a list of these providers and their departments for future reference.

Your primary care provider may refer you to specialists within your insurance plan. Include these providers on your list, also.

Providers in Other Departments

- Cardiologist (Heart)
- Dentist (Teeth)
- Dermatologist (Skin)
- Endocrinologist (Diabetes)
- ENT (Ear/Nose/Throat)
- Ophthalmologist (Eye)
- Gynecologist (Women's issues)
- Orthopedist (Bone)
- Primary Care/Internal medicine
- Other

**All UCSF Clinic Phone Numbers
are in the (415) Area Code**

Dental	476-1891
Dermatology	353-7800
Eye.....	353-2800
ENT	353-2757
Gastroenterology	
Adult.....	353-2318
Pediatric.....	353-5892
Gynecology/Obstetrics	353-2223
Adult Post Liver Transplant Clinic appt	353-9130
Pediatric Liver Transplant Clinic appt	353-2813
Medicine	353-4624
Neurology.....	353-2273
Orthopedic.....	353-2808
UCSF Pharmacy	353-1544
Urology	353-2555

Other Services:

Financial Counseling	353-8776
Social Work (message line)	(800) 548-3789

Now That You Have Your Liver Transplant

This booklet was prepared to help you learn what you need to know about your new liver. Although we are here to help you, it is **your responsibility** to learn how to take care of yourself and your new liver. You are the most important person in your health care team so you need to know your medications, lab values, and the routine follow-up care needed.

In the hospital, your nurses will begin to teach you as soon as you are able to learn. At first it may seem like a lot of information, but it will get easier. It's normal to have questions after you are discharged from the hospital. This handbook is a quick reference guide and a "starting point" for answering your questions. Always ask your nurse or the transplant team any questions you might have. We are here to help you.

Write your questions down so you do not forget them. There is space to write your questions at the end of this handbook.

Your Local Health Care Provider, The Transplant Team, and Your Insurance

Your local health care providers and the transplant team are committed to providing care for you in the best way possible. This commitment includes providing care within the guidelines outlined by your insurance company. After the first hospital discharge and follow-up appointment, you may need to get pre-authorization from your primary care provider for clinic visits or procedures with the transplant team. **It is your responsibility to get any necessary authorizations have been requested and obtain these from your primary care physician or you may be billed for some charges.** You may be able to have some testing such as liver biopsies done in your local area. Know as much as you can about the pre-authorization requirements of your insurance company, as well as any special features about your coverage. *Examples: when do you need a pre-authorization? Which pharmacies are "preferred" within your insurance system?*

Medications and Diagnostic Tests

General Information

You will take several medications after your liver transplant for the rest of your life. Each medication has been individually prescribed for you, and it is very important that you take your medications as you are taught. We want you to be responsible for taking your own medications. We also want children to be involved in taking their own medications. There is more information about these medications follow later in this chapter.

Self Medication Schedule

After your transplant your nurse will set up a medication schedule for you. This medication schedule is set up to help you learn about the medications you are taking, when to take them, what they look like, how much to take, what they are for, and their side effects. When you begin to take your own medicine after surgery, your nurse must always check your pills before you take them. When you go home from the hospital you may be taking 10–14 different medications. These include medications you will take for the rest of your life and other medications that will stop in weeks to months.

Your Medicine Schedule

You will be given a copy of your medicine schedule with a list of all your medications to keep at your bedside. Record any changes on this schedule in pencil.

- Never follow the directions on the bottle as these directions may change.
- Write **any** dosage changes, medication changes, or new medicines on your schedule.
- Remember to bring your medicine schedule when you come to the clinic or to the hospital. Also bring the medication bottles if you have any questions; pediatric patients always bring medication bottles in addition to your schedule.
- Never take any new medications without letting the Liver Transplant Office know. Many medications change the effects of your immunosuppressive medications. These include but are not limited to: Erythromycin (Pediazole®), Azithromycin (Zithromax®), Clarithromycin (Biaxin®), Voriconazole, Fluconazole, Ibuprofen (Advil®, Motrin®), Dilantin®, Phenobarbital, and herbal supplements.

Medicine Times

You must take your pills at the same time every day. In the hospital, we use standard times of 9am, 12 noon, 6pm, and bedtime. When you go home, you should use times that fits your lifestyle but the medications should be taken at the same time each day. Your tacrolimus or cyclosporine should be taken 12 hours apart from each other, example 9am and 9pm. Your nurses will help you set up a system.

Warnings About Medications

Never:

- Never change or stop any immunosuppressive medication the transplant team has prescribed without checking with us first.
- You must never forget to take your medications.
- Never take Motrin, Ibuprofen, Advil (Non Steroidal Anti-inflammatory drug also called NSAIDS) as the combined effect with Tacrolimus (Prograf) or Cyclosporine (Neoral, Gengraf) can cause kidney damage.

Always:

- Use acetaminophen (example: Tylenol®) **only** for headache or pain (maximum dose 2000 mg/day). Parents should be sure the dose is correct for their child's weight. Remember, Tylenol is also in some narcotics, for example Vicodin and Norco. The total maximum dose of 2000 mg/day includes prescription and over the counter medication.
- Check with your pharmacist or transplant team if you have any questions about any of your medications.
- Store your medicine out of the reach of small children. Remember that your medicine could be deadly if accidentally taken by a child. Pharmacies put all prescriptions in child proof containers. If you do not want child proof containers, ask your pharmacist for regular containers.
- Plan ahead: always call for prescription refills at least 1–2 weeks before you run out of medication.
- Call **1 (800) LIVER TX** with any questions you have about medications. We make all attempts to get back to you within 24 hours. Office hours: Monday–Friday, 8am–5pm.

Immunosuppressive Medications

Because your new liver is a “foreigner,” your immune system will try to reject it. Therefore, it is necessary to suppress your immune system to protect your new liver. The drugs described in this chapter prevent and/or treat rejection of your new liver. Immediately after your transplant, when you are most likely to reject your new liver, you will be taking very high doses of these medications. As the risk of rejection decreases, the doses will be reduced. When the doses are high, you may experience some side effects.

Remember that not every patient experiences all of these side effects, but they occur often enough that you should know about them. Do not hesitate to tell the transplant team about any side effects or problems you may have. We can often help to lessen the side effects.

Cyclosporine (Neoral[®], Gengraf[®]), Tacrolimus (Prograf[®]), Mycophenolate Mofetil (CellCept[®] Myfortic), Prednisone, Sirolimus (Rapamune[®])

These are the immunosuppressive drugs prescribed to prevent rejection of your transplanted liver. You will be on a combination of these drugs at different times after your transplant. The drug or the dose of each of these drugs may change depending on your particular condition. Your transplant team will help you with changes in your medications while you are in the hospital. After you leave the hospital, you will receive phone calls to adjust the dosages based on your lab results. Write these changes on your medication schedule immediately along with the date of the change.

Cyclosporine (Neoral [®] or Gengraf [®]):	
Purpose	<ul style="list-style-type: none">▪ Cyclosporine is an immunosuppressant medication that helps prevent rejection.
Dose	<ul style="list-style-type: none">▪ Cyclosporine capsules are available in 25 mg and 100 mg strengths; liquid is 100 mg/ml. Do not combine the types of cyclosporine you take. In other words, prescriptions for both 25 and 100 mg capsules should be consistently filled with the same brand of cyclosporine microemulsion. Call the transplant team with any questions. The dose is adjusted by your laboratory values. It is very important to have your labs drawn 12 hours after your last Cyclosporine dose and before you take your morning medications for proper adjustment of this medication.

Cyclosporine

(Neoral® or Gengraf®):

When to Take	<ul style="list-style-type: none">▪ AM Dose: take with your breakfast after your lab work is completed (usually around 9am).▪ PM Dose: 12 hours after your AM dose (Usually around 9pm).▪ For children who take these drugs three times a day, the additional dose should be taken at noon with lunch.
Missed Dose	<ul style="list-style-type: none">▪ If you miss a dose, make it up as soon as you remember. But, don't take two doses at one time without contacting the transplant office.
Precautions	<ul style="list-style-type: none">▪ Cyclosporine can be altered by some medications. Before you take any new drugs including over the counter medications and medications prescribed by your local provider please contact the transplant office. It is recommended that mothers do not breast feed when taking this medication. Grapefruits and grapefruit juice can interfere with your cyclosporine level. You should avoid grapefruit and grapefruit juice.
Common Side Effects	<ul style="list-style-type: none">▪ Headaches▪ Loss of Appetite▪ Tremors▪ Diarrhea▪ Seizures▪ Nausea/vomiting▪ Nightmares▪ Rash▪ Memory loss▪ Hair growth▪ Fluid retention▪ Gum swelling▪ Decreased kidney function▪ Increased risk of infection▪ Elevated potassium levels▪ Joint discomfort▪ High blood pressure▪ Leg cramps▪ Hot flashes

Tacrolimus

Prograf®

Purpose	<ul style="list-style-type: none">Tacrolimus is an immunosuppressant medication that helps prevent or treat rejection.
Dose	<ul style="list-style-type: none">The tablets are available in 0.5 mg, 1 mg, and 5 mg strengths; liquid is 0.5 mg/ml. The liquid must be specially made by your pharmacist. The dose is adjusted by your laboratory values. It is very important to have your labs drawn 12 hours after your last Tacrolimus dose and before you take your morning medications for proper adjustment of this medication.
When to Take	<ul style="list-style-type: none">AM Dose: take with your breakfast after your lab work is completed (usually around 9am).PM Dose: 12 hours after your AM dose (usually around 9pm).
Missed Dose	<ul style="list-style-type: none">If you miss a dose, make it up as soon as you remember. BUT, don't take two doses at one time without contacting the transplant office.
Precautions	<ul style="list-style-type: none">Tacrolimus (Prograf) can be altered by some medications. Before you take any new drugs including over the counter medications and medications prescribed by your local provider please contact the transplant office. It is recommended that mothers do not breast feed when taking this medication. Grapefruits and grapefruit juice can interfere with your level. You should avoid grapefruit and grape fruit juice.
Common Side Effects	<p><i>The side effects of Tacrolimus are similar to those of Cyclosporine.</i></p> <ul style="list-style-type: none">HeadachesDiarrheaSeizuresHigh blood pressureTremorsRashMental status changesDecreased magnesiumInsomniaHigh blood sugarAnemiaHigh potassiumNausea/vomitingDecreased kidney functionDecreased appetiteLeg crampsHair Loss

Mycophenolate Mofetil

Cellcept® or Myfortic®

Purpose	<ul style="list-style-type: none">▪ Mycophenolate is an immunosuppressant medication that helps prevent rejection. Myfortic is enteric coated form of Mycophenolate that can have less stomach and bowel side effects.
Dose	<ul style="list-style-type: none">▪ Mycophenolate is available in 250 mg strength and 500 mg tablets. Note that tablets are also available in 500 mg strength, but we will write your prescriptions using 250 mg strength so it will be easier to make dosage changes. Myfortic is available in 180 mg and 360 mg tablets. Liquid comes in 200 mg/ml strength. Be sure to check the bottle you get from your pharmacy to make sure you have the right dose. Do not crush or chew Myfortic tablets. <p><i>Note: the doses of Mycophenolate and Myfortic are not the same due to the way they are absorbed in the system.</i></p>
When to Take	<ul style="list-style-type: none">▪ AM Dose: Take with your breakfast (usually around 9am).▪ PM Dose: 12 hours after your AM dose (usually around 9pm).
Missed Dose	<ul style="list-style-type: none">▪ If you miss a dose, make it up as soon as you remember. But, don't take two doses at one time without contacting the transplant office.
Precautions	<ul style="list-style-type: none">▪ Antacids such as Maalox® and Mylanta® decrease the absorption of Mycophenolate. You should not take these while on Mycophenolate. We do recommend that you continue to take a medication such as Omeprazole (Prilosec®), Pantoprazole (Protonix®) or Lansoprazole (Prevacid®), etc. while you are on Mycophenolate. You should not take Mycophenolate (Cellcept® or Myfortic®) for at least 3 months before conceiving children, so check with the transplant office if you are considering adding to your family.
Common Side Effects	<ul style="list-style-type: none">▪ decreased white blood count▪ diarrhea▪ abdominal pain▪ ulcers▪ inflammation of the pancreas

Sirolimus

Rapamune®

Purpose	<ul style="list-style-type: none">▪ Sirolimus is an immunosuppressant medication that helps prevent or treat rejection
Dose	<ul style="list-style-type: none">▪ The tablets are available in 1 mg and 2 mg strength. This is a once per day dosing schedule. The dose is adjusted to your laboratory values. It is important to have lab drawn 24 hours after your last dose prior to your next dose. Liquid is available as 1 mg/mL and should be mixed with orange juice or water only in a glass or plastic container.
When to Take	<ul style="list-style-type: none">▪ If you also take Cyclosporine (Neoral® or Gengraf®) as another immunosuppressant medication, you must take the Sirolimus 4 hours after the Cyclosporine dose as these drugs should NOT be taken at the same time.▪ If you take Tacrolimus (Prograf) it is ok to take Sirolimus at the same time.
Missed Dose	<ul style="list-style-type: none">▪ If you miss a dose, make it up as soon as you remember. But, don't take two doses at one time without contacting the transplant office.
Precautions	<ul style="list-style-type: none">▪ Please check with the transplant office before you consider becoming pregnant.▪ It is recommended that mothers do not breast feed when taking this medication.
Common Side Effects	<p>The most common side effects of Sirolimus are changes in blood counts: anemia (low red blood counts), low platelets, low white blood cells. Other side effects may include:</p> <ul style="list-style-type: none">▪ Mouth sores▪ Rash▪ Poor wound healing▪ Headaches▪ Diarrhea▪ Tremors▪ Swelling▪ Kidney damage <p><i>*Alert: you will need to be taken off of Sirolimus approximately one month prior to any surgery due to delayed wound healing. Please inform your transplant team of any upcoming surgery.</i></p>

Prednisone

Purpose	<ul style="list-style-type: none"> ▪ This is an immunosuppressant medication that is used to prevent or treat rejection.
Dose	<ul style="list-style-type: none"> ▪ Adults: Use only 5 mg and 10 mg tablets unless first contacting the transplant office. ▪ Children: Prednisone solution is available in the following concentrations: 1 mg/ml; 5 mg/ml; and 15 mg/5 ml. Be sure you read the label. If you have questions, call the transplant office. Also, Prednisone is available in 1 mg and 5 mg tablets for older children who are able to swallow pills.
When to Take	<ul style="list-style-type: none"> ▪ Prednisone is taken once per day in the morning. You will be given a schedule to follow that tells you how much prednisone to take every day. You will be on a higher dose right after transplant and will decrease the daily amount by following the written schedule. By the time you are two months post transplant you will usually be on 5 mg once a day taken in the morning. Take with food to avoid upset stomach. ▪ The dose for children varies depending on their weight.
Missed Dose	<ul style="list-style-type: none"> ▪ If you miss a dose, make it up as soon as you remember. But, don't take two doses at one time without contacting the transplant office.
Precautions	<ul style="list-style-type: none"> ▪ It is important that you never stop taking your Prednisone abruptly. This could cause severe side effects. ▪ If you are a diabetic it is important to remember that as your Prednisone dose decreases, your insulin requirements will also decrease.
Common Side Effects	<ul style="list-style-type: none"> ▪ Mood changes or mood swings ▪ Depression ▪ Euphoria ▪ Irritability ▪ Vision changes ▪ Thrush ▪ Acne ▪ Increased risk of infection ▪ Stomach upset ▪ High blood sugar ▪ Moon face ▪ Cataracts ▪ Sensitivity to the sun ▪ High blood pressure ▪ Joint discomfort ▪ Nausea/vomiting ▪ Muscle wasting ▪ Ulcers ▪ Increased appetite

Other Medications You May Take After Your Transplant

Anti Fungal Medications

Fluconazole (Diflucan®)

Purpose	<ul style="list-style-type: none"> Prevents or treats fungal (Candida) infections often found in the mouth.
Dose	<ul style="list-style-type: none"> This medication is taken one time weekly. The dose is generally 100 mg. This medication will be discontinued once your prednisone dose reaches 5 mg daily, usually two months after your transplant.
When to Take	<ul style="list-style-type: none"> Once per week.
Missed Dose	<ul style="list-style-type: none"> If you miss a dose, make it up as soon as you remember. But, don't take two doses at one time.
Precautions	<ul style="list-style-type: none"> Never take this medication more than once per week unless under specific instruction with the transplant department due to the interaction with your transplant medications.

Antivirals

Valgancyclovir (Valcyte®) and Acyclovir (Zovirax®).

Purpose	<ul style="list-style-type: none"> Prevents or treats viral infections such as CMV, cold sores, herpes zoster, and chicken pox.
Dose	<ul style="list-style-type: none"> Valgancyclovir is available in 450 mg tablets. The adult dose is usually 900 mg per day for the first three to four months after transplant but depends on your kidney function. Acyclovir is available in 200 mg capsules, 800 mg tablets or in liquid form (200 mg/5 ml). The adult dose is usually 800 mg 4 times a day for 3 to 4 months after transplant. The children's dose is based on body weight. Adults are usually treated for 3 months after transplant. Children are usually treated for 4 to 6 months after transplant.
Missed Dose	<ul style="list-style-type: none"> Take as soon as you remember. Never double dose.
Side Effects	<ul style="list-style-type: none"> May include decreased white count. Dosage may be decreased for people with kidney problems.

Antibiotics

Trimethoprim/sulfamethoxazole (Bactrim® or Septra®), dapsone, pentamidine

Purpose	<ul style="list-style-type: none">▪ Treats or prevents bacterial infections, such a pneumocystis pneumonia.
Dose	<ul style="list-style-type: none">▪ For Trimethoprim/Sulfamethoxazole (Bactrim® or Septra®) the adult dose is 1 tablet every Monday, Wednesday, Friday; Dapsone is 50–100 mg once a day; Pentamidine is a once a month inhalation treatment. Pediatric doses are based on body weight.
Missed Dose	<ul style="list-style-type: none">▪ Take as soon as you remember. Never double dose.
Side Effects	<ul style="list-style-type: none">▪ Side effects of trimethoprim/sulfamethoxazole include a rash, decreased white count, nausea, vomiting, diarrhea, sun sensitivity.▪ Side effects of Dapsone include decreased red blood cell count, fatigue, shortness of breath.▪ Side effects of pentamidine include coughing.▪ You will be on this medication as long as you are on Prednisone.
Precautions	<ul style="list-style-type: none">▪ Some patients may not be able to take Septra/Bactrim® (sulfa medications). For those patients dapsone will be prescribed. Another alternative is pentamidine which is given monthly as a respiratory inhalation treatment.

Diuretics – “water pills”

Furosemide (Lasix®)

Purpose	<ul style="list-style-type: none">▪ To remove excess fluid from your body and sometimes for blood pressure management.
Dose	<ul style="list-style-type: none">▪ Varies according to your weight, kidney function, potassium level, urine output, and blood pressure. Try to take doses in the morning or early afternoon to avoid frequent urination in the middle of the night.
Missed Dose	<ul style="list-style-type: none">▪ Take as soon as you remember. Never double dose.
Side Effects	<ul style="list-style-type: none">▪ Weakness, muscle cramps, light-headedness, dizziness.

Anti Ulcer Medications

Omeprazole (Prilosec[®]), Esomeprazole (Nexium[®]), Pantoprazole (Protonix[®]), Lansoprazole (Prevacid[®])

Purpose	<ul style="list-style-type: none">▪ To prevent ulcers. Ulcers can develop with high doses of prednisone and while taking Mycophenolate (Cellcept[®] or Myfortic[®])
Dose	<ul style="list-style-type: none">▪ Dose and type of medication is based on individual need and body weight.
Missed Dose	<ul style="list-style-type: none">▪ Take as soon as you remember. Never double dose.
Side Effects	<ul style="list-style-type: none">▪ Side effects are uncommon.

High Blood Pressure Medications (Anti-hypertensives)

Nifedipine (ProcardiaXL[®]), Metoprolol, Amlodipine (Norvasc[®])

Purpose	<ul style="list-style-type: none">▪ To control your blood pressure.
Dose	<ul style="list-style-type: none">▪ Dose and type of medication is based on individual need and body weight.
Missed Dose	<ul style="list-style-type: none">▪ Take as soon as you remember. Never double dose.
Side Effects	<ul style="list-style-type: none">▪ Dizziness, nausea, headache, flushing, changes in heart rate.

Diagnostic Tests

The list below describes the purposes of a variety of diagnostic procedures you may undergo after you have had your liver transplant.

Ultrasound

Sometimes done the day after transplant to be sure the main blood vessels leading to the liver are functioning normally. An ultrasound can also be used to check for abnormal fluid collection (blood, bile) in the abdomen and to localize position for biopsies in children. A gel is put on your abdomen and a transducer (a wand like instrument) is passed over the abdomen. Images of your liver appear on a monitor.

ERCP/PTC

There are different types of x-rays that check bile ducts for leaks, blockages, or other potential problems. ERCP (endoscopic retrograde cholangiogram) is done by placing a tube down your throat through which a catheter is inserted into a bile duct. PTC (percutaneous transhepatic cholangiogram) is done by inserting a needle into the liver through the abdomen, then placing the catheter in the bile ducts. You will be given medication to relax you before the ERCP or PTC. Children usually have these tests done under anesthesia.

CT Scan

A type of x-ray that looks at your liver from several angles to check for infection or fluid collections.

After you drink a liquid dye, pictures are taken while you lie still. Children are usually given something to relax them before this procedure is performed.

Liver Biopsy

A liver biopsy checks for rejection, hepatitis, and other possible problems. You may need a liver biopsy if your liver numbers go up. The right side of the abdomen is numbed, a biopsy needle is inserted, and a small piece of liver tissue removed. You must lie on your right side for at least 1 hour and stay in bed for 4 hours after this procedure. You may not take food or fluids during this time.

You must have transportation arranged by a friend or relative. Public transportation (cabs, buses) is not allowed. Your procedure will be cancelled if you do not have adequate supervised transportation.

You must be off blood thinners, such as coumadin or aspirin or Ibuprofen prior to biopsy.

See page 19 for guidelines.

Infants and children are given mild sedation during the biopsy.

When You Go Home

Outpatient Care Guidelines

Call the Transplant Emergency phone number, (415) 353-1888, or your local healthcare provider for temperatures over 100.4° (38°C). The most important thing you can do to ensure your long term health is to recognize and report any changes in the way you are feeling. Please do not try to “self diagnose.” Because of the immunosuppressive medications you take, symptoms may need urgent treatment.

Liver Transplant Clinic

You will be followed by a Transplant Center for the rest of your life. You will be seen on a regular basis in the Liver Transplant clinic. Children will be followed in the Pediatric GI/Transplant clinic.

Please bring your medicine schedule, and medications for the entire day with you. Remember to check in at the clinic desk when you arrive. Return appointments may be made at the desk when you leave or you may call (415) 353-9130. Pediatric patients call (415) 353-2813.

Labs

You need to have your blood drawn twice weekly the first month after your transplant and once weekly the next month following your transplant. After that you will probably have your labs done twice a month, then once a month. You can have your blood drawn at a local laboratory who will fax your lab results to the Liver Transplant Office. *Fax for adults: (415) 353-2102. Fax for children: (415) 476-1343.*

Adult Clinic

The adult Liver Transplant Clinic is on the 6th floor of the Ambulatory Care Center (ACC) and meets every Tuesday morning from 8am–12pm. Call (415) 353-9130 to make appointments at the adult clinic. You will be given a specific time for your appointment. If your insurance requires authorization for clinic visits, it is your responsibility to arrange with your primary care physician and have this approved prior to the visit.

Pediatric Clinic

The Pediatric GI/Liver Clinic is on the second floor of the Ambulatory Care Clinic and meets Thursdays from 8am–12pm. Call (415) 353-2813 to make appointments at the pediatric clinic. Pediatric patients alternate their weekly clinic visits between the adult transplant clinic and the pediatric clinic for the first 4–6 weeks after transplant.

Outpatient Liver Biopsy

The frequency of outpatient liver biopsies will depend on what types of problems you have. Biopsies may be done to evaluate for rejection or hepatitis. Do not eat or drink anything after midnight before the biopsy, except for your medications. You must have a current set of labs drawn one week prior to your biopsy. You will be instructed to stop taking aspirin (also don't take Motrin, Advil or Ibuprofen) 5 days before and 5 days after your biopsy. If you are taking any other blood thinner (such as coumadin) your biopsy will require careful coordination. Be sure to take your morning medications the day of the biopsy. If you are diabetic, ask about adjusting your insulin dosage for that morning. You will stay in the surgery center for about 6 hours after the biopsy is performed.

You must have transportation arranged by a friend or relative. Public transportation (cabs, buses) is not allowed. Your procedure will be cancelled if you do not have adequate supervised transportation.

Infants and small children may have liquids up until 4 hours before the biopsy. Infants and small children are always admitted to the hospital for this procedure. Check with your physician or transplant nurse practitioner for questions.

Location

Adult outpatient liver biopsies are performed at the Surgery Center, 400 Parnassus Avenue. It is located on the Plaza Level. You should report there at 7:45am the morning of your biopsy.

Your local gastroenterologist may perform this procedure at your local hospital and the slides will be sent to our pathology department for review.

Pediatric liver biopsies are generally done in the hospital. Most children are admitted in the morning of the procedure and spend the night. If rejection is seen on the biopsy children may remain hospitalized for a couple days to a week, depending on the treatment. Pediatric outpatient liver biopsies are performed in the Surgery Center at 400 Parnassus Avenue. General anesthesia is often used. An ultrasound to mark the spot for biopsy will be performed either the day before or at 8:30am the morning of the biopsy. Be sure to check with your transplant nurse practitioner as to when this is scheduled. When you bring your child for an outpatient biopsy you must bring: 1) a history and physical performed by your pediatrician not more than 2 days before the scheduled biopsy and, 2) lab work performed within 48 hours of the scheduled biopsy.

After the first few months, your local gastroenterologist may perform this procedure at your local hospital and the slides will be sent to us for review.

Daily Routine

Follow a daily routine similar to the one outlined below after you go home.

Mornings

1. Weigh yourself each morning after going to the bathroom. Record your weight in your handbook.
2. Take and record your temperature.
3. Take and record your blood pressure if you are taking anti-hypertensive medications.
4. Take your morning medications, except as described in number "5" below.
5. Bring your Cyclosporine (Gengraf® or Neoral®) or Tacrolimus (Prograf®) or Sirolimus (Rapamune®) with you to the lab on the days you have your Cyclosporine, Tacrolimus or Sirolimus level drawn; then take your morning Cyclosporine, Tacrolimus or Sirolimus dose **after** your blood is drawn.

Noon

6. Take your medications as ordered by the Transplant Team.

Nights (between 7–9pm):

9. Take your bedtime medications.
10. Set out your medications for the next day. Use of a multi-chambered plastic pill box may be helpful.

Routine Follow-up Care

The first 60–90 days after your transplant are the time of highest risk for rejection and infection. You will need to have frequent blood tests. Your vital signs (pulse, blood pressure, temperature) must be checked often during the first three months then your vital signs can be checked as needed. The risk of rejection usually decreases after the first 60–90 days. The frequency of blood tests and vital signs can also be reduced. Your transplant team will let you know when you can decrease the frequency of your laboratory tests.

Be sure to keep the Transplant Office informed of your correct address and phone number(s), and any changes in your health care provider's name, address, or phone number(s).

It is also important to tell us whom to contact in case of an emergency. You will be given a form to complete. Be sure to return the completed form to us.

If you are an outpatient and need urgent medical care or need to see a health care provider at UCSF, call (415) 353-1888 (days, evenings, and holidays) or go to your local emergency room.

Pediatric patients should call (415) 476-5892

Do not come to the Patient Care Unit or Clinic unless told to do so by the Transplant Team.

Your Local Health Care Provider's Role

Your local health care provider may be the one who took care of you before you came to UCSF for your liver transplant, or who referred you to us. Your visit to this provider is very important and should occur no later than one month after you return home. You should also continue seeing those specialists who were involved in your care before you received a liver transplant. For example: your pediatrician for children, your cardiologist for heart disease, your gynecologist for women, your ophthalmologist for eye care, and/or your family provider for general health care needs, etc.

After the immediate post transplant period (in other words, more than 6–12 weeks after your release from the hospital) , your first contact for illnesses should be with your local provider. After he or she has seen you, your provider should contact the Transplant Office with any questions.

Remember – Contact the Transplant office during business hours if a new medication is prescribed by your local health care provider. Many medications have significant interactions with your antirejection medications. Inform the Transplant Office of any changes in your health care provider's name, address, or phone number(s).

Laboratory Tests and Lab Letters

Blood tests need to be done frequently for about 90 days after your transplant. They are done every day while you are hospitalized and twice weekly after you go home.

Preferred lab locations are Kaiser, Lab Corp or Quest labs as we receive these results promptly.

Infants and small children are often discharged after transplant with a central line for blood draws. The central line is an intravenous catheter placed at the time of transplant in the front of the chest. Your nurse will show you how to take care of it before you go home, and you will have a home health nurse checking in with you after you are discharged from the hospital. When blood draws are decreased to once a week, the central line is typically removed. This requires a “come and go” surgical procedure which is done in the surgery center. *See page 19.*

Regular laboratory days after you go home are Mondays and Thursdays. You will take home a Laboratory Letter (*see example on the next page*) that lists all the tests that need to be done and how often. Give this letter to your laboratory.

Your lab should fax or mail results to the Transplant Office and to your local provider. Ask your lab or provider for a copy of your labs.

Lab results should be faxed to the Transplant Office at (415) 353-2102 (adult) or (415) 476-1343 (pediatrics)

6-Month Standing Order

Effective Date: _____

Account numbers: Quest Sacramento: **6006480** Quest San Jose: **76164** Labcorp: **04336680**

Ordering Provider:

- John Roberts, MD 41192 NPI#1437113446 Claudia Praglin, NP 56755 NPI#1255355616
 Carolyn Nguyen, NP 99829 NPI #1578762902 Jennifer Cademartori, NP 72437 NPI#1770504300

FAX RESULTS TO:

- Post Liver Transplant Clinic (415) 353-2102 Patient
 Additional Physician: _____ Fax # _____

To report **CRITICAL LABS** call: **415-353-1888**

Patient Name _____ DOB _____ UC MRN _____

Please perform the following **checked-off** laboratory tests:

Twice weekly Once Weekly Twice monthly Once Monthly Other _____

Routine Lab Tests	ICD-9 Codes	Drug Levels	ICD-9 Codes
CBC with diff	996.82, V42.7	Cyclosporine	V42.7, V58.83
Electrolyte Panel	996.82, V42.7	Tacrolimus (Prograf)	V42.7, V58.83
BUN /Creatinine	996.82, V42.7	Sirolimus (Rapamune)	V42.7, V58.83
Glucose	790.29, V58.6		
Magnesium	275.2		
AST, ALT, Alkaline Phos	996.82, V42.7	Other Tests	ICD-9 Codes
Total Bilirubin	996.82, V42.7	Calcium	996.82, V42.7
PT/INR	996.82, V42.7, 790.4	Phosphorous	275.3, 794.4
		Albumin	996.82, V42.7,
		Direct/Indirect Bilirubin	996.82, V42.7
		GGT	996.82, V42.7

Once Weekly Twice Monthly Once Monthly Every 3 Months Other _____

Specialty Lab Tests	ICD-9 Codes	Specialty Lab Tests	ICD-9 Codes
Hemoglobin A1C	250.00	HCV RNA Quantitative viral load by bDNA	790.4, 070.54
Triglycerides	272.4, V58.83	HCV RNA Qualitative viral load by PCR	790.4, 070.54
Lipid Panel: Chol, Trig, HDL, LDL	272.4, V58.83	HBV DNA	790.4, 070.32
Uric Acid	790.6, V58.83	HBsAg	790.4, 070.32
TSH	244.90, 242.90	Ferritin	285.9
CMV PCR	078.5	Iron	285.9
AFP	155.0	Transferrin/ %saturation	285.9

Twice weekly Once Weekly Twice Monthly Once Monthly Other _____

Other Tests	ICD-9 Codes	Other Tests	ICD-9 Codes

Signature _____

(pediatric lab slip)

UCSF Medical Center

UCSF Post Liver Transplant Clinic
400 Parnassus Ave, 6th Floor
San Francisco, CA 94143

6-Month Standing Order

Effective Date: _____

Account numbers: Quest Sacramento: 6006480 Quest San Jose: 76164 Labcorp: 04336680

Ordering Provider:

Philip Rosenthal, MD NPI 1417066242

FAX RESULTS TO:

X Peds GI/Hepatology/Liver Transplant (415)476-1343

X Patient

Additional Physician: _____

Fax # _____

To report CRITICAL LABS call: 415-476-5892

Patient Name _____ DOB _____ UC MRN _____

Please perform the following checked-off laboratory tests:

Table with columns: Routine Lab Tests, ICD-9 Codes, Drug Levels, ICD-9 Codes. Includes tests like CBC with diff, Electrolyte Panel, BUN/Creatinine, Glucose, Magnesium, AST, ALT, Alkaline Phos, Total Bilirubin, PT/INR, Cyclosporine, Tacrolimus (Prograf), Sirolimus (Rapamune), Calcium, Phosphorous, Albumin, Direct/Indirect Bilirubin, GGT.

Table with columns: Specialty Lab Tests, ICD-9 Codes, Specialty Lab Tests, ICD-9 Codes. Includes tests like Hemoglobin A1C, Triglycerides, Lipid Panel: Chol, Trig, HDL, LDL, Uric Acid, TSH, CMV PCR quantitative, AFP, HCV RNA Quantitative viral load by bDNA, HCV RNA Qualitative viral load by PCR, HBV DNA, HBsAg, Ferritin, Iron, Transferrin/ %saturation.

Table with columns: Other Tests, ICD-9 Codes, Other Tests, ICD-9 Codes. Includes EBV PCR Quantitative.

Signature _____

Laboratory Records and Vital Signs

Date:

Hematocrit (Hct)							
Hemoglobin (Hgb)							
WBC							
Platelets (Plts)							
BUN							
Creatinine (Cr)							
Sodium (Na)							
Potassium (K)							
Glucose							
Bili - Total							
SGOT/AST							
ALK P'tase							
SGPT/ALT							
Cyclosporine or Prograf level							
Weight							
Temp							
Blood Pressure							

Laboratory Records and Vital Signs

Date:

Hematocrit (Hct)							
Hemoglobin (Hgb)							
WBC							
Platelets (Plts)							
BUN							
Creatinine (Cr)							
Sodium (Na)							
Potassium (K)							
Glucose							
Bili - Total							
SGOT/AST							
ALK P'tase							
SGPT/ALT							
Cyclosporine or Prograf level							
Weight							
Temp							
Blood Pressure							

Laboratory Records and Vital Signs

Date:

Hematocrit (Hct)							
Hemoglobin (Hgb)							
WBC							
Platelets (Plts)							
BUN							
Creatinine (Cr)							
Sodium (Na)							
Potassium (K)							
Glucose							
Bili - Total							
SGOT/AST							
ALK P'tase							
SGPT/ALT							
Cyclosporine or Prograf level							
Weight							
Temp							
Blood Pressure							

Medication Levels

If you are taking Cyclosporine (Neoral[®], Gengraf[®], Sandimmune), Tacrolimus (Prograf[®]) or Sirolimus (Rapamune[®]), your blood must be tested frequently to measure the drug level in your blood. Do not take your morning dose of medication before your labs. Take your Cyclosporine, Tacrolimus or Sirolimus with you to the lab and take your morning dose after your blood is drawn.

Immunization and Immune Protection

It is extremely important for pediatric liver transplant patients and children of transplant recipients to receive appropriate immunizations to prevent disease. However, after transplant the recipient's immune system is compromised due to the immunosuppressive medications that must be taken to prevent rejection.

Therefore, **liver transplant patients should not receive any live virus vaccines**, such as measles, mumps, rubella (MMR), small pox, chicken pox, shingles (Zostavax[®]), nasal flu mist and oral polio vaccine (OPV).

Transplant patients can receive other vaccines including diphtheria, tetanus toxoid, pertussis (DPT), and inactivated polio virus vaccine (IPV), or human papilloma virus (HPV).

The following highlights important information about immunizations and the liver transplant patient and family.

Immunizations

If you are planning a trip to a foreign country that requires any immunizations, you may need to have your health care provider write a letter to the Passport Bureau stating that you cannot receive certain vaccines. If you have questions about vaccinations or precautions to take, ask your primary care provider. You may be referred to a travel clinic. Another resource you may contact is the Overseas Medical Center, phone (415) 982-8380.

Diphtheria/tetanus toxoid/pertussis vaccine (DPT)

Inactivated virus: Transplant patients and household members may receive vaccine.

Human Papillomavirus (HPV)

Inactivated Virus: Transplant patients and household members may receive vaccine.

Hemophilus B (HIB)

Polysaccharide: Transplant patients and household members may receive HIB.

Hepatitis A (Hep A)

Inactivated virus: Transplant patients and household members may receive Hep A.

Hepatitis B (Hep B)

Inactivated virus: Transplant patients and household members may receive Hep B.

Oral Polio Virus Vaccine (OPV)

Live virus: Transplant patients and household contacts with patients should not receive OPV. Vaccine strains are transmissible. Because OPV is shed in the stool, it is recommended that IPV be given instead to transplant patients and those in frequent contact with them. Transplant patients **should not** change diapers of children given OPV!

Inactive Polio Virus Vaccine (IPV)

Inactive virus: Transplant patients and household members may receive IPV instead of OPV (oral polio vaccine).

Measles, Mumps, Rubella (MMR)

Live Virus: Liver transplant patients should NEVER receive MMR after transplant. It may be given to siblings and other household members.

Flu Shots

Polysaccharide: Liver transplant patients and household members may receive flu shots including the H1N1.

Never receive the nasal flu mist—this is a live vaccine.

Tetanus

Toxoid: Generally given every 10 years. Liver transplant patients and household members may receive tetanus shots.

Tuberculosis (TB) testing using purified protein derivative (PPD)

TB testing using PPD may be performed on liver transplant patients and household members.

Varicella (Chicken Pox)

If the family member breaks out with vesicles (pox), the transplant patient should not touch them. Rarely, a child who has received the vaccine may break out with a few vesicles. If this occurs, the pox should be covered with a band-aid and contact the transplant team for further guidance.

Varicella Zoster (Shingles)

Live virus: Transplant patients should not receive this vaccine. Family members may receive the vaccine.

Nutrition Following Liver Transplantation

Nutrition plays a key role in your recovery after liver transplantation. As with any surgery, adequate calories, protein, vitamins, and minerals are needed for wound healing. Also, your nutrient and diet needs may change if you have complications and/or side effects from your medications after your transplant.

Once you have successfully recovered from the early stage after transplant (e.g. your appetite is back to normal, your weight is stable, and your wounds are healing well), then you should change to a diet that is low in saturated fat and high in fiber, fruits, and vegetables. This type of diet will help reduce risks for other chronic diseases including heart disease and diabetes. Always discuss your individual dietary needs and concerns with your dietitian or doctor.

It is important to maintain a healthy weight. Obesity, gaining an unhealthy amount of excess fat, increases your risk of chronic diseases and can damage your new liver.

Short Term Nutrition Management

In the first month after your liver transplant, you will be recovering from the stress of surgery. It is important to take in enough protein, calories, vitamins and minerals to help your wounds heal and prevent muscle loss. Limit concentrated sweets or foods high in salt to reduce stress on your recovering body functions. If you have nausea, poor appetite or abnormal bowel functions, ask your health care team for suggestions. It is common for patients to feel full after eating a portion of the meal. If this happens, you should try eating smaller portions 6 times a day rather than larger portions 3 times per day.

Calories

You should eat enough calories to prevent muscle wasting and allow for gradual regaining of lean body weight that is often lost with severe illness before transplant and during hospitalization (bed-rest) after transplant. Choose nutrient dense foods (dairy, whole grains, plant foods) instead of foods considered “empty calories” (e.g. sodas, candy). If appetite is poor, broaden your scope of food choices to allow for food preferences. Fruits and vegetables need to be part of your diet to provide enough vitamins and minerals.

Protein

Protein is important to promote healing and muscle gain. Extra protein is needed to overcome muscle breakdown caused by the high doses of prednisone given right after transplant.

Every day you should eat some foods that are highest in protein. Meats and fish have the highest concentrations of proteins, but many vegetarian sources are also excellent healthy choices that can add variety.

Animal-based products high in Protein	Plant-based products high in Protein
<ul style="list-style-type: none">• Fish• Poultry (chicken, turkey)• Egg whites (egg substitute)• Eggs (no more than 4 yolks per week)• Dairy products (milk, cheese, yogurt)• Red meat (beef, pork, veal)	<ul style="list-style-type: none">• Unsalted nuts• Peanut butter (or other nut butters)• Soy products (tofu, soy milk, tempeh)• Dried beans, lentils (split peas, kidney, black, pinto, navy beans, etc.)• Seitan (wheat gluten)

Choose lean protein foods more often and prepare them using lean cooking methods (i.e. grill or bake meats rather than frying).

Sugar

Prednisone can decrease the uptake of sugar from your blood into your body's cells. This may cause your blood sugar (glucose) level to rise. This condition is called "hyperglycemia" (high blood sugar) or "steroid-induced diabetes". You can help manage this side effect by avoiding foods that are concentrated with carbohydrate (sugars).

Foods High in Simple Sugars and should be limited:	
<ul style="list-style-type: none">• Sugar• Molasses• Doughnuts, pastries, sweet rolls• Pies, cakes, cookies• Candy, chocolate candy• Ice cream, frozen yogurt, sherbet	<ul style="list-style-type: none">• Honey• Syrups (corn, maple, etc.)• Jam, jelly, marmalade (small amounts OK)• Soft drinks (diet sodas OK)• Other sweetened beverages (fruit juices, teas: diet OK)• Jell-O

If you develop high blood sugars, your diet may need to include the following guidelines:

- Eat at least three meals each day at regular, evenly spaced times. Avoid skipping meals. Each meal and snack should include some high quality protein. For example, turkey sandwich on whole grain bread with salad. A snack could be ½ cup 1% cottage cheese with fresh fruit or berries.
- Carbohydrate foods should be high in fiber. Choose to eat more whole grain products, legumes, and vegetables instead of refined white breads and cereals.
- Limit fruit to one serving per meal. One serving = ½ cup chopped or canned fruit, or one medium piece of fruit.
- Read food labels. Avoid foods with added sugars listed in the ingredients. Different names for sugars include: fructose, maltose, dextrose, corn syrup, high fructose corn syrup, honey, raw sugar, brown sugar, etc.

There are many resources available to learn how to best manage blood sugars. Ask your dietitian or health-care provider for reading and education materials. Many healthcare providers or insurance plans provide diabetes management classes. Ask if they may be appropriate for you.

Sodium (salt)

Surgery and medications such as prednisone can cause your body to “hold on to” (retain) sodium and water. This can then cause increased blood pressure. To help avoid this, it is best to restrict salt intake. The “No Added Salt” diet, which is usually recommended, suggests eating less than 3000 mg of sodium each day. To follow these recommendations, you should:

1. Limit salt when cooking. Use herbs and spices for flavor.
2. Do not add salt after food is prepared.
3. Avoid or limit the following foods:

High salt soups

Most canned, dehydrated, and bullion soups are high in salt. Read labels to choose those lowest in salts. Many popular brands now carry low sodium versions of soups.

Processed meats

Ham, bacon, sausage, frankfurters, cold cuts (bologna, salami, pastrami), corned beef, smoked or dried meat or fish, canned meat (unless labeled “no salt added”), salt pork.

Processed / canned food products

Cheese, packaged meals /dinner, most canned foods (except those labeled “no salt added”), frozen vegetables with sauces, pickles, sauerkraut, canned vegetable juice.

Restaurant items

Average amount of sodium per entree is 3000 mg.

Salted snacks

Salted crackers, pretzels, potato chips, corn chips, tortilla chips, popcorn, nuts, seeds, etc.

Condiments and miscellaneous:

Use in moderation: catsup, prepared mustards, horseradish, sauces (barbecue, chili, steak, Worcestershire, etc.), MSG (monosodium glutamate), soy sauce, meat tenderizers, pickle relish, olives, garlic salt, onion salt, salad dressings.

Note: salt substitutes are high in potassium and should only be used with your healthcare provider's permission.

Potassium

Some drugs such as Cyclosporine or Tacrolimus can increase your blood potassium levels. Other drugs such as Furosemide (Lasix®) can decrease blood potassium. Abnormal blood potassium levels can cause problems with muscle and heart function. Your health care team may change your medications and/or diet to help manage your blood potassium levels.

Below is a list of common foods high in potassium. You may be asked to either increase or decrease your intake of these foods. Remember that these are general guidelines and do not include all foods that contain potassium. If your diet needs to be stricter, ask your dietitian for a more complete list.

Fruits	Vegetables	Juices	Other Foods
<ul style="list-style-type: none">• Apricots• Avocados• Bananas• Dried fruit• Melons• Nectarines• Oranges• Peaches	<ul style="list-style-type: none">• Leafy greens• Pumpkins• Potatoes• Split peas• Dried beans• Lentils• Tomatoes	<ul style="list-style-type: none">• Orange juice• Prune juice• Tomato juice• V-8 juice	<ul style="list-style-type: none">• Milk and dairy• Peanut Butter• Nuts• Chocolate

Nutrition for Pediatric Patients Following Liver Transplant

Children and adolescents who receive liver transplantation may have had weight loss or delayed weight gain and growth before surgery. You probably had to make adjustments in your child's diet to reduce the complications or discomfort of chronic liver disease. After surgery, however, the emphasis is to provide enough calories, protein, and other essential nutrients to promote healing, weight gain and growth. Encourage your child to eat a variety of foods and try to limit the amount of dietary restrictions you put on your child. However, your child's diet should be somewhat low in sodium (salt) and concentrated sweets to reduce the body's stress from medications and recovery from surgery. This may be difficult when children's diets often include fast food favorites.

The dietitian will work with you and your child to identify wholesome and tasty foods that are easily tolerated and good substitutes for fast food. Some infants and children may need tube feedings after transplant for normal growth and development. If nasogastric tube feeds are necessary, your healthcare provider will prescribe them and you will receive instructions on how to manage the feedings at home.

Long Term Nutritional Management

Transplant patients have increased risks for excessive weight gain, heart disease, diabetes, and low bone mineral density (osteopenia or osteoporosis) in the months and years following surgery. Some medications can be involved in the development of these complications, but researchers and healthcare providers believe diet and activity behaviors are very important. Risks can be reduced by adopting a low fat, low saturated fat, low cholesterol, high fiber "Heart Healthy" diet as outlined:

Foods	Choose more often	Choose less often
Vegetables	Minimum 3 servings each day. Try fresh or frozen that are prepared plain or with small amounts of unsaturated fats.	Vegetables prepared with butter, cheese or cream sauce.
Fruits	Minimum 2 servings each day. Fresh, frozen, canned, or dried.	Fruit juice; fruit served with butter or cream sauce.
Breads, Cereals, Grains, Dry Peas, Beans, and Soy	Whole grain bread, cereals, pasta and rice; dried peas, beans; baked goods made with unsaturated oil or margarine; soy foods.	Refined, white breads, cereals and baked good; white rice; dried peas or beans made with cream, butter, or cheese sauce.
Eggs and Dairy Products	Egg whites and substitutes; skim or 1% milk, yogurt and cottage cheese.	Egg yolks; whole or 2% milk, yogurt and cheese.
Meat and Poultry	Lean cuts with fat trimmed; turkey or chicken without skin; lean luncheon meat; cooking methods to help reduce fat.	Fatty cuts of meat; bacon and sausage; organ meats; any fried meat; high fat luncheon meat (salami)

Foods	Choose more often	Choose less often
Fish and Shellfish	All, cooked using low-fat methods.	Fish and shellfish cooked with butter, cheese or cream sauces.
Fats and Oils	Limit all fats to <30% of total calories. Margarine (made from unsaturated oils), including reduced- or non- fat varieties; reduced or non-fat salad dressings (including mayonnaise); liquid cooking oils; unsalted nuts and seeds.	Tropical oils (palm, palm-kernel, coconut); transfatty acids (hydrogenated fats); butter, lard, bacon fat, shortening, full fat salad dressings; coconut.
Sweets and Snacks <i>*Remember that while some of these products are low in fat, they still contain calories, mostly from sugars.</i>	Low- or non- fat frozen desserts and baked goods; flavored gelatins; candy such as gum drops; low salt pretzels and baked snack chips; air-popped popcorn.	Candy and baked goods made with butter, cream or tropical oils; high fat ice cream and frozen desserts; doughnuts; regular snack chips.

An easy way to think of this is to eat lots of vegetable/plant foods (whole grains, fruit, vegetables) and fish. Limit the amount of high fat animal foods. Read food labels carefully to avoid unnecessary fats and sugars.

It is also important to get enough calcium in your diet. Adults after transplant should have approximately 1200 mg of calcium (but less than 2000 mg) each day. This amount may be difficult to achieve if you don't eat dairy foods. Talk with your healthcare provider or dietitian about adding calcium supplements if you feel your dietary calcium is low.

Low-Fat Cooking Tips

- Microwave, broil, grill, or steam without adding fat.
- Use nonstick sprays or cookware.
- Trim all visible fat off meat and remove skin from poultry. (It is OK to remove skin **after** cooking)
- Experiment with reducing the amount of oil you use in baking. (Often recipes will taste just as good with less oil.)

There are many books and magazines devoted to health and nutrition. Enjoy trying new low fat, healthy recipes for the whole family.

Fitness For Life

At UCSF, we strongly feel that regular physical activity is necessary after transplant for you to become as healthy and physically fit as possible. Everything you do to improve your overall health increases your chances of having a long life with your transplant. With the increasing shortage of organs available for transplant, it is a good idea to make healthy lifestyle choices.... a second transplant may not come easily.

There is enough scientific evidence to say that regular physical activity:

- Decreases risk of death from heart disease.
- Prevents or delays the development of high blood pressure.
- Reduces blood pressure in people who already have high blood pressure.
- Keeps muscles and joints strong and functioning.
- Helps bones develop during childhood and helps adults prevent osteoporosis (thinning of the bones).

Special Importance of Physical Activity for Transplant Recipients

Long periods of inactivity and/or bed rest causes loss of muscle mass and strength (including strength of the heart) and limits your ability to perform exercise. A successful transplant does not automatically return you to normal physical activity. For muscles to regain their function and strength, they must be used regularly. Many people after transplant have high blood pressure, high cholesterol, and gain fat weight. All of these increase your risk of heart attacks or stroke.

The weight gain following transplant is **not** due to prednisone. The weight gain **is** a result of the balance between how much and what types of foods are eaten and how many calories are burned through physical activity.

How to Start an Exercise Program

When you decide to start your exercise or physical activity program, you should consider several things:

- type of exercise
- how often you will exercise (number of times per week)
- how long you will exercise each session (minutes per session)
- how you will continue to develop your program
- how hard you need to work or exert yourself

The key is to start slowly and increase gradually. That way your body will adapt to the exercise so you will feel comfortable and not get discouraged. You will definitely see progress as long as you stick with a program.

TYPE of activity:

The best activities use large muscle groups in a rhythmic manner: walking, aerobics, cycling, swimming, jogging, machines such as climbers, stationary cycles, ski machines. Choose an activity that is convenient and fun for you. There are no activities that are restricted for transplant patients.

If you have problems with your joints, an activity that supports your body weight and is not jarring will be best for you (such as cycling). If, after starting you feel discomfort in your joints, you may want to change your activity to one that is 'easier' on the joints such as swimming. Walking is easy, requires no special equipment other than comfortable, supportive shoes, and may be done anywhere, anytime.

FREQUENCY of activity:

You should try to schedule your activity so you are doing something at least 5 days per week. Planning activity into your daily schedule will help you stay with it on regular basis. There is no time of day that is better for exercise...it all depends on what works for you and when you will be able to do it regularly.

DURATION of Activity:

Start with your activity for 10 minutes and gradually increase by 5 minutes every week to a goal of 30 or more minutes per session. **If** you are working to reduce or control your weight you will need to burn more calories, which means that you must exercise for a longer duration each session....the longer you exercise, the more calories you will burn.

INTENSITY of Activity:

The question is "how hard must I work myself when I exercise?" You should work hard enough to:

- make your heart beat faster
- allow you to breathe in a way that you can talk with someone during your session
- make you feel warm (perspiration is ok)
- feel that the exercise is "somewhat hard" for you

The increased effort can be worked in for short times during your exercise session. For example: climb hills and then walk down, or walk much faster for a block or two then walking slower for a block or two, etc. This will add variety to your session as well as further improve your fitness.

PROGRESSION of Activity:

It is best to start slowly and increase gradually. Start with a short duration of activity and gradually increase the time of each session. Start with a comfortable, lower level of intensity (work) and gradually increase the exertion level as you get used to the exercise. People may have problems, such as injuries, when they do too much exercise too soon. Gradual progression will prevent those kinds of problems.

Resistance (Weight) Training

Exercises that can easily be done at home to strengthen muscles include:

- climbing stairs
- standing up and sitting down into a chair (repeat 10–15 times, using your hands as little as possible so your legs do the work)
- lifting soup cans
- push-ups against the wall or from a counter

As you become stronger, you may want to use free weights or weight machines at a gym. Start with a low weight that you can comfortably lift 10–12 times. Remember that the weight being lifted will increase the stress on the joint (such as elbow or shoulder), so if the weight is too heavy or the exercise is not performed correctly you may hurt yourself. Don't hold your breath when lifting weights.

The CHALLENGE = Sticking with it!!

1. You must work hard enough with your body (heart, lungs, muscles, etc.) so that changes can happen.
2. You must stay with the program.

The fact is: increased physical activity is a personal commitment. No one else can do it for you and your health over time is dependent on being physically active on a regular basis.

U.S. Transplant Games

The U.S. Transplant Games is a wonderful celebration open to all recipients of solid organ and bone marrow transplants in the United States. All transplant recipients are welcome, whether or not they are athletes. The Games provide competition for those interested in challenging themselves and is also a chance to meet others from all over the country who have the similar experience of transplantation. At the first event in 1990, there were 400 recipients, and it has grown to over 5,000 recipients, family and friends. It is an exciting, inspirational event for everyone. The UCSF Transplant Service encourages anyone who is interested in participating.

The National Kidney Foundation (NKF) organizes the U.S. Transplant Games every 2 years. All transplant recipients (heart, lung, liver, kidney, pancreas, and bone marrow) of all ages and all athletic abilities are welcome and encouraged to participate. This is your time to show your family, friends, donors, and donor

families that you're not "just" alive, but living life, too! Events include both team and individual races, swimming, golf, tennis, table tennis, bicycling, bowling and more.

There are also social events: opening and closing ceremonies, parties, workshops for donors, and a special tribute to all organ and tissue donors. For more information about the Transplant Games, please visit the National Kidney Foundation (www.kidney.org) or call the Northern California Chapter of the Kidney Foundation, (800) 622-9010. Contact the American Liver Foundation for liver walks (www.liverfoundation.org) 800-GO LIVER.

Health Maintenance

Skin Cancer

Transplant patients have an added risk of cancer, especially skin and lip cancers. This risk increases with time due to long term immunosuppression (Anti rejection medications).

Immunosuppressive drugs make your skin sensitive to the sun causing you to burn easier, faster, and to a much greater degree than before your transplant. Prolonged, repeated exposure to the sun produces permanent skin changes and damage. Remember that you can burn even if your skin is dark because your medications may make you more sensitive to the sun.

Your risk of developing skin cancers increases with time after transplant. These cancers are ten times more common in transplant patients than in the general population. It is therefore essential that you limit your exposure to the sun and that you protect yourself when you are outside.

Warning signs of skin cancers are any sores that bleed, scab, grow, or do not go away in a few weeks. Such sores are most likely to appear on the exposed parts of your body—face, neck, head (especially if you are bald), and your hands and arms. A mole that bleeds or changes color or size must be examined immediately. You must contact your local provider to be evaluated by a dermatologist. You should see a dermatologist yearly or more frequently if indicated. You may need to be referred to a “high risk” dermatologist. Contact your Transplant provider for more information.

The rays of the sun that are responsible for skin cancers are ultraviolet rays (UV rays) which are present even on cloudy days and in shady areas. We advise you to always protect your skin from exposure to these rays. Avoid the mid-day sun (10am–3pm) when ultraviolet rays are strongest. For extra protection from the sun wear sunscreen with SPF of least 30, lip balm, broad brimmed hats, long sleeves, and slacks every time when you go outdoors.

Routine Self Examination

Cancers are more common when people are on immunosuppressive medications. Because of this, we recommend a monthly self examination (ask your primary care provider if you need instruction how to do breast or testicular self-examination) and routine medical check ups. PAP smears and breast exams should be done every year. Reports should be sent to the Transplant Office. Your local physician can perform these tests.

Acne

Prednisone may cause acne on your face, chest, shoulders, or back. Cyclosporine can make your skin oily in these areas.

If your skin becomes excessively dry, temporarily stop using soaps on these areas to allow the skin to recover its natural moisture.

You may use over the counter preparations (such as Oxy-5 or Oxy-10) to treat acne. We recommend that you do not use Retin-A (a powerful acid form of Vitamin A). It causes increased sun sensitivity which should be avoided.

If acne remains a problem, tell us about it. Severe or infected acne must be treated by a dermatologist.

Dry Skin

If you have problems with dry skin, use a mild soap and apply body lotion after bathing. For severe dry, scaly skin you may need a good body lotion. There are many good products available from your local drug store without a prescription.

Cuts and Scratches

Keep minor cuts and scratches clean and dry by washing daily with soap and water. If you wish, you may apply an antiseptic such as Betadine solution. For large cuts, dog bites, etc., contact your doctor immediately.

You will not need any special skin care unless you have problems with acne or dry skin. You should take a bath or shower as often as necessary (daily or every other day) to keep your skin clean. Use any soap that you prefer.

IMPORTANT: Any persistent skin problem requires an evaluation by a dermatologist.

Increased Hair Growth

This problem is caused by Cyclosporine and is especially annoying to women. You can remove hair with a hair removal cream. There are several creams on the market made especially for your face. Be sure to follow bottle directions concerning testing. Hair removal cream causes severe irritation to the eyes, mucous membranes, and lips so apply carefully. A safer way to diminish the look of excessive hair is to bleach the extra hair growth with 50% peroxide solution. When your Prednisone dose is less than 20 mg per day, you may want to consider waxing or electrolysis for permanent hair removal.

Caution: Parents should be particularly careful when using these products on infants and young children since their skin tends to be more sensitive.

Hair Loss

Tacrolimus® (Prograf) can cause hair loss. This usually stops or slows down as you have your dose lowered.

Hair Care

Prednisone often affects the condition of your hair because it makes your hair weaker. Permanent wave lotion, tints, dyes, and bleaching may cause your hair to break. We recommend that you wait until your Prednisone dose is less than 20 mg per day to have a permanent or to color your hair.

Dental Care

Routine dental work should be done six months after your transplant. This includes having your teeth cleaned. However, if you have tooth or gum pain you should see your dentist immediately.

- You will not need to take an antibiotic when you have dental work done, unless your dentist deems necessary due to a possible infection.

We follow the American Heart Association (AHA) guidelines for prophylaxis. Your local healthcare provider and dentist are aware of these guidelines and should refer to them should they have questions regarding antibiotics for dental work in transplant patients.

It is extremely important that you practice good mouth care after your transplant to maintain healthy gums and teeth, as well as to avoid infection. Brush your teeth once or twice a day. Floss your teeth once a day; be gentle if you notice any bleeding. Contact your dentist or dental hygienist if your gums continue to bleed with flossing.

If your dental work was not completed before transplantation, you must see your dentist for evaluation within the first few weeks after you return home.

Follow the procedure outlined below when you visit the dentist:

- Make an appointment.
- Inform the dental office that you have had your transplant.

The Transplant Center will fax or mail a dental clearance letter as requested by the dentist or by you. See sample dental letter on the next page.



Liver Transplant Program

350 Parnassus Avenue
Suite 805
San Francisco, CA 94117
tel: 415/353-1888
fax: 415/353-2102

Date _____

Name _____

DOB _____

To Whom It May Concern:

Please be advised that this patient received a liver transplant on _____.

There are no contraindications for dental work at this time. Please see the following guidelines for post liver transplant patients.

Antibiotic prophylaxis: We follow the American Heart Association guidelines for antibiotic prophylaxis. Post liver transplant patients do not need prophylactic antibiotics for routine dental procedures. Antibiotics may be given at the discretion of the treating Dentist if required as standard of care for a particular procedure.

Local Anesthetic: This patient may receive local anesthesia such as Novocain as needed.

Pain Medications: The patient should not receive products containing aspirin or ibuprofen. He/She may receive products containing Tylenol as long as the total daily dose does not exceed 2 grams per day. Patients may receive a short course of narcotics if needed.

We can be reached at (415) 353-1888 for any additional questions.

Thank you,

UCSF Transplant Service

Prednisone Dose and Routine Dental Care

Your Prednisone dose should be 5 mg once/day (or less) when dental work is done to reduce the possibility of infection and bleeding, and to increase the healing process. But, do not avoid dental care if your Prednisone dose is high and you have tooth or gum pain. It is better to have healthy teeth and gums than to allow them to become infected.

If your dentist has any questions or if you have any questions, contact the Liver Transplant Office for further information.

Smoking

Don't smoke. You stopped smoking (or were supposed to) prior to transplant. Now there are even more reasons not to smoke.

Smoking damages the lungs, putting you at great risk for lung infections including bronchitis, emphysema, and pneumonia. It also increases your risk of cancer (especially after transplant). Smoking lessens the ability of your red blood cells to carry oxygen, so less oxygen goes to all of your tissues decreasing your ability to heal. Smoking narrows your blood vessels, especially those in your legs, arms, and heart. Smoking also increases acid in your stomach that can delay or prevent the healing of any ulcers that may occur. All of these problems are more serious in someone taking immunosuppressive medications.

Talk with your primary care provider about short term medications or smoking cessation programs that may be available if you need help to stop smoking.

Alcohol and Illegal drugs

Do not drink alcoholic beverages or take drugs, including marijuana. This includes non-alcoholic beers and wines. (They still contain small amounts of alcohol). Alcohol is metabolized (broken down) by the liver and causes liver damage as well as liver failure. Almost all medications are metabolized by the liver. The combination of these medications with alcohol could seriously harm your liver.

Smoking marijuana exposes your lungs to harmful fungi that can lead to life threatening infections.

If you are having trouble living without alcohol or drugs, you need to know that this can be a life threatening problem. Help is available. Contact your local primary care physician or the transplant social worker.

Sexuality

You may resume sexual activity when you feel like it. Remember to always practice safe sex if you are not in a monogamous relationship. Contact the transplant team to review immunosuppressive medications before becoming pregnant or fathering children. Contact your gynecologist to discuss methods of birth control.

Family Planning

Some people want to have children after they have had a liver transplant. For many women this is possible, but there are also risks to the mother and fetus. It is important to discuss these risks with the Transplant

Team so that you can make the right decision for you and your family. Male transplant recipients should also review medications with the transplant team before fathering children. Some immunosuppressive medications may need to be changed or discontinued prior to pregnancy to protect the baby from potential birth defects.

Return to work/school/disability: frequently asked questions

1. When can I return to work / school?

Most patients are able to return to work 3–6 months after transplant with no restrictions. Generally, there are no weight lifting or activity limits approximately 3 months after transplant. Most people start planning about a month after transplant for their return to work. Of course, this depends on your particular recovery.

Children may be ready to return to school approximately 3 months after transplant.

2. How long will I be on disability?

Disability benefits depend on your physical condition. If you were on disability at the time of your transplant, your continued eligibility for benefits will be reviewed some time after your surgery. The timing of this review will depend on your particular disability plan. If your liver function is good and your condition is stable, the liver transplant team will not be able to say that you continue to be disabled. Generally, by 6 months after transplant, patients are no longer disabled because of transplantation.

3. What should I do with disability forms?

The transplant team will be able to complete your disability forms within the first 3 months after transplant. You may bring the forms to your clinic appointments or mail them to the transplant social worker. Generally, after 3 months, your primary care provider will be seeing you more often than the transplant team and is the appropriate person to complete any disability forms.

4. What if I don't have a job?

If you have been off work prior to transplant, there is help available to assist you in finding a job. The Department of Vocational Rehabilitation can help you identify your skills and options. They can also help you with job finding skills, re-training or schooling. Call the transplant social worker for more information.

Call 1 (800) LIVER TX (548-3789) with non urgent questions, or messages for the transplant team. Messages may be left 24 hours a day. Your message will be returned within one business day.

Travel

There are no travel restrictions after transplant if your condition is stable. *See page 28 for additional information about immunizations.* Contact your local health care provider or travel clinic for questions. When traveling, remember to plan to take enough medication plus extra so you will be prepared if you have unexpected changes in plans. Always carry medication on board rather than checking with your luggage.

More information can be found at www.cdc.gov. Remember that you may **NOT** receive live vaccines.

Other Health Care Concerns

Illness and Infection

You need to protect yourself from infection because your immune system is suppressed. Wash your hands with soap and water often to wash away bacteria and viruses. Keep your hands away from your face and mouth. Wash hands after using the bathroom and before eating. Avoid sick people. Ask sick friends to visit when they are well. If you have a wound and do your own dressing changes, wash your hands before and after you change the dressing. When you cough or sneeze, use tissues, discard them in the trash, then wash your hands.

Even when taking all possible precautions, there are times when you may get an infection anyway. If you have a fever over 100.4° F (38° C) or you do not feel well, see your local healthcare provider and call the transplant office. You may need to have blood drawn and a chest x-ray. You will be prescribed an antibiotic if you have a bacterial infection. Sometimes you may need to be admitted to the hospital for treatment.

Remember that stomach pains, problems with your heart, problems with breathing, or fevers cannot be diagnosed over the phone. See your own healthcare provider for any treatment. Your healthcare provider or you may call us at (415) 353-1888 if there are any questions about your care.

Call 1 (800) LIVER TX (548-3789) with non urgent questions, or messages for the transplant team. Messages may be left 24 hours a day. Your message will be returned within one business day.

Colds and Flu

You will get colds and flu. If you get a cold, you may take over the counter medications (ex: Sudafed, Dimetapp, etc.). Avoid cold remedies that contain aspirin and Ibuprofen. Limit Tylenol (acetaminophen) to 2000 mg per day. Read labels and prescriptions—Tylenol is contained in many medications. If you have a cough, you may take cough medicine (ex: Robitussin). However, if your cough becomes productive and you run a fever, call your local healthcare provider. You may need a chest x-ray and antibiotics.

For Children: Please check with your pediatrician.

Inform the Transplant Office whenever you are exposed to any communicable disease that you have not previously had. This is particularly important for liver transplant children.

Adults: 1 (800) LIVER TX

Monday–Friday, 8am–5pm

Children: 1 (800) UC KID GI

Herpes Zoster (Shingles)

Shingles appear as a rash or small water blisters usually on the chest, back or hip. They may also occur on other areas. The rash may or may not be painful. You should notify the transplant office if this rash appears.

Persistent Headaches

Cyclosporine and Tacrolimus can cause headaches. Please inform your transplant nurse practitioner for adjustments. If they become persistent you may need to see a neurologist.

Skin Eruptions

If you develop warts, persistent sores, or moles you must see a physician, preferably a dermatologist. If a skin eruption requires medical treatment, have your health care provider call the transplant office 1 (800) LIVER TX to discuss the treatment.

Thrush

This is an infection caused by fungus that usually affects the mouth. It can also affect the esophagus (the tube to your stomach), the vagina in women or the diaper area in infants. With oral thrush, your mouth may be very tender and you may notice that your tongue is covered by a white film. Mycelex Troche or Nystatin (a yellow liquid) can help clear up this infection. It is helpful to eat soft foods or drink liquids. With vaginal thrush, you will notice an increase in vaginal discharge and possibly a change in its color. Your genital area may also itch. Vaginal creams and other medicines are available. Talk with your primary care provider or the Transplant Team if you think you have thrush. Do not take oral antifungals (fluconazole) without checking with your transplant team first. Antifungals can cause a drastic elevation in your tacrolimus or cyclosporine blood levels.

Chicken Pox, Measles, and Mumps:

Chicken pox is a virus that causes a mild fever and small red bumps on the skin and can be very itchy. It is spread by coming in contact with another person infected with the virus. Being in the same room with an infected person can transmit the virus. If you had chicken pox as a child, you most likely will not get it again. However, if you have not had chicken pox or you are not sure, let the Transplant Team know. This is a relatively mild disease in children. In adults chicken pox is more severe—especially in immuno compromised adults. If you suspect you have been exposed to chicken pox, call the Transplant Team immediately.

Emergency Medical Identification

You should wear a medical identification bracelet or necklace at all times after your transplant. You may obtain a form to order one at your local pharmacy. Indicate on the form that you have had a liver transplant, and are “immunosuppressed.” Include the 24 hour hotline number (415) 353-1888 to be printed on the tag. It is a good idea to also have your local health care provider’s phone number printed on the tag. If the transplant patient is a child, you may want to print the parents’ first names and home phone number(s) as well.

Guidelines for Visiting Transplant Children

- Brothers and sisters (siblings) may visit in single rooms. When visiting in shared, double rooms, the other patient's family must give permission. Special arrangements can be made for patients in 4 bed rooms and monitored rooms.
- Each family may bring only two children under 12 at one time.
- As soon as the family arrives in the Family Lounge, one parent must notify the nurse of your arrival.
- The nurse will come to the waiting room to complete the screening for the visit.
- A screening form must be completed by the nurse on each child for each visit before the visit occurs.
- If the visit is approved, the nurse will put a sibling visitor sticker on the child's clothing and bring him/her to the patient's room. If the child visitor is not approved, he/she and a responsible adult will need to wait in the lounge until arrangements can be made for the sibling to leave the hospital.
- If there is any doubt about a possible infection of one or both children visitors, neither will be allowed to visit. Please do not bring children visitors with colds, sore throats, runny noses, etc.
- All children must wash their hands thoroughly before entering the patient's room.
- No visiting children may be allowed in the playroom or other patient rooms except for pre arranged special occasions (birthdays, holidays, etc).
- No children visitors may receive treatments or medications of any kind while they are visiting.
- Parents are responsible for continuous supervision of their own children visitors under 12. The staff may ask you to take your child/children home if they are unsupervised or disruptive.
- There are no accommodations for visiting children under 12 to spend the night.
- If there are any falls, bumps, cuts or accidents, a parent must notify the nurse promptly. You may be asked to take the visitor to the emergency room for treatment.
- Visiting children must leave the Pediatric floor immediately when the visit is over.

Thank you for being careful and following these guidelines. If you have any questions, please feel free to ask any of the nurses.

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Resources

Getting Back Into Life!

A serious illness can create many personal and family stresses. After your transplant, there will be different types of adjustments. You and your family can expect some ups and downs related to your physical condition as well as emotional reactions to this new phase in your life. For example, you may feel somewhat anxious when you get your labs drawn or when you need to have tests if your lab values change. You or your caregivers may have mixed feelings as you become more independent and responsible for your own care. These are normal reactions.

If you have been sick for a long time, you may have had to give up some of your normal life such as child care, work, and activities with friends. You and people close to you may have some ups and downs as you get back to your normal activities and roles. Your illness may also have changed your relationship with your significant other. Sometimes it may help to talk to someone else who knows what you are going through. In most communities, there are transplant support groups. The transplant social worker is available to talk with you about these transitions. The social worker also has lists of the community support groups and other resources which may help you.

If you had a sudden, unexpected transplant, you may experience some sadness or depression as you start to feel physically better. Remember, you did not have a chance to plan or prepare for the changes in your life and you will need to do that as you recover. Again, please speak with the transplant social worker or the transplant team if you are having difficulty.

No one can predict exactly what your recovery will be like. Complications, minor and serious, may occur any time. Remember that the transplant team will work with your primary health care providers and you to take care of you.

There may also be some practical problems after transplant such as insurance or financial issues. Your medical care following transplantation is very expensive. Therefore, you must keep current with your insurance. Know what it covers, how it works, and what your responsibilities are. You must check with your insurance company to find out which laboratories and pharmacies you may use with your plan. Most insurance companies will only pay when you use the health care providers they approve. Remember, it is your responsibility to make sure any visits to UCSF have been approved (authorized) by your insurance. If your insurance coverage changes, please call the UCSF Financial Counselor, phone (415) 353-8776 to update your records.

Some people, as they recover after transplant, lose eligibility for disability based insurances like Medi-Care and Medi-Cal. If you think you are going to lose your insurance, talk with either the financial counselor or transplant social worker about what other coverage may be available. Do not wait to call until you have no insurance. You must plan ahead.

Other practical issues that you should continue to keep updated include advance directives, wills, and power of attorney, especially if you have no legal next of kin.

There is light at the end of the tunnel!!

Life after transplant can be a real roller coaster ride for patients, families, and friends. The goal of transplantation is to help you return to good health and your usual lifestyle. Most patients are able to return to work, raise families, and lead full, physically active lives after transplantation.

Your transplant team looks forward to helping you in whatever way we can. Talk to us.

Adult Support Group

The Liver Transplant Support Group is held on Tuesdays after the adult Transplant Clinic on 9 Long in the solarium from 1–2pm. It is open to all present and future liver transplant recipients and their families and friends.

Pamphlets and Organizations to Help You

Pamphlets available at www.liverfoundation.org:

- Biliary Atresia
- Decide to Make a Difference (organ donor)
- Diet and Your Liver
- Facts About Liver Transplantation
- Hemochromatosis
- Liver Disease: A Problem for the Child
- Viral Hepatitis: Everybody's Problems
- Your Liver Lets You Live

Organizations:

- **American Liver Foundation**
75 Maiden Lane
New York, New York 10038
1-800-GO-LIVER (465-4837)
www.liverfoundation.org

Northern California Chapter
One Sansome Street, Suite 2100
San Francisco, CA 94104
(415) 984-3169
- **Centers for Disease Control**
<http://www.cdc.gov>

(See travel guidelines)
- **Transplant Recipients International Organization (TRIO): Your voice of the transplant**
(800) TRIO-386
info@trioweb.org
- **United Network for Organ Sharing (UNOS)**
www.unos.org
- **California Transplant Donor Network**
(888) 570-9400
www.CTDN.org
- **Children's Liver Disease Foundation**
www.childliverdisease.org
- **Children's Organ Transplant Association**
(800) 366-2682
www.cota.org

Notes

