6th Edition
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Dumont-UCLA Liver Transplant Center
The Pfleger Liver Institute
Division of Liver and Pancreas Transplantation
Ronald Reagan UCLA Medical Center Department of Surgery

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Dumont-UCLA Liver Transplant Program.

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Congratulations on receiving your liver transplant at Ronald Reagan UCLA Medical Center! You now may look forward to regaining your health and returning to a productive life.

To ensure your success in caring for your new liver, it is very important that you read and understand the information presented in this booklet.

An outpatient transplant coordinator will conduct at least one teaching session with you before you are discharged to review the information in this manual and to assist you and your caregiver/s in fully understanding it.

It is required that at least one family member or significant other must be present for the teaching session. You are encouraged to write down any questions you have about the material before you meet with your coordinator. **You will not be discharged from the hospital until at least one family member or significant other has read this booklet and has participated in the teaching session.**

Success after your liver transplant depends on your understanding and compliance with regard to the topics in this booklet and good communication with your outpatient transplant coordinator.
WELCOME TO RONALD REAGAN
RONALD REAGAN UCLA MEDICAL CENTER

We are the LIVER units: 8 North and 8 ICU

We are pleased to assist you with your health care needs. Ronald Reagan Ronald Reagan UCLA Medical Center is a teaching hospital, so unlike community hospitals, a team of doctors (not a single doctor) will take care of you. Some doctors on your team may change during your hospital stay because your physicians may “rotate” on and off the service. You may require a physician consultation from a service other than your primary team. Medical Students (doctors in training) may also be involved in your care. These are some reasons why you may see many doctors during your stay. Our team will ensure that you receive excellent care to address your needs. Let us describe for you our team members:

**Attending Physician:**
An Attending Physician is a Board Certified/Eligible physician who supervises every team member involved in your care.

**Fellows:**
Fellows are fully trained surgeons that are completing additional training in organ transplants. They directly oversee the members of our transplant team and report to the attending physician.

**Residents:**
First and Second year residents are completing their training as physicians. Residents rotate through the liver transplant service to gain experience with transplant patients. Residents help to supervise your care in the ICU and on the floor. They work under direct supervision of the Transplant Fellow.

**Interns:**
Interns are first year physicians who rotate through the liver transplant floor to learn how to care for liver transplant patients. Interns are under the direct supervision of the Nurse Practitioners, Residents, Fellows and Attendings.

**Hepatologists:**
The Hepatologists are medical service physicians who specialize in caring for liver related diseases. The Hepatologist is an Attending physician on the medicine service who collaborates with the Surgeons in managing your care in the hospital. Once you are discharged from the hospital and surgery clinic the Hepatologist will manage your care as an outpatient.

**Pharmacists:**
The Pharmacist is a physician who specializes in medications. Pharmacists work with the transplant team on drug clinical trials and help with issues related to the management of medications.
Nurse Practitioner (NP): A Nurse Practitioner is a Registered Nurse with advanced education and training. Nurse Practitioners are responsible for the majority of your daily care after you have been transferred out of the ICU. Nurse Practitioners are under the direct supervision of the Fellows.

Registered Nurse (RN): An RN will be assigned to you each shift. Your RN will assess you and the effectiveness of your medical care every time they interact with you during your hospitalization. Your RN will supervise other members of your transplant team. Your RN will administer your medications. Your RN is your main resource to use if you need to communicate with other members of the transplant team.

Case Manager: An RN Case Manager is assigned to you immediately upon admission to UCLA. The 8N Case Managers coordinate home discharge medications, order prescribed medical equipment and home nurse visits that you will require at home. They provide your insurance company and your referring physicians with daily updates of your care and progress.

Licensed Vocational (LVNs): LVNs provide direct patient care under the supervision of your RN and may also give medications.

Care Partner: Care Partners are supervised by the RN or LVN and assist with your personal needs such as bathing, taking vital signs, and helping you out of bed, etc.

Social Workers: Social workers assist you with a variety of needs. They provide emotional support to you and your families, assist you to complete Insurance, Disability and FEMLA forms, and help troubleshoot with family problems or other issues that will affect your ability to be discharged home.

Physical Therapist: The Physical Therapist will see you after your transplant to assess your equipment needs for discharge such as a walker or bedside commode. They will work closely with you to improve your strength and endurance. They may recommend that you go to a rehabilitation facility after you are discharged from the hospital if you are unable to safely go home without additional physical strengthening and conditioning.
In-house Transplant Coordinator: Your In House Transplant coordinator is a registered nurse with specialized training who is responsible for coordinating your post transplant care while you are in the hospital. Your In House Transplant Coordinator will focus on educating you and your caregiver on how to best care for you after you leave the hospital. You and your caregiver will be taught how to manage your medications and how to make changes in your lifestyle that will ensure a safe and healthy outcome for you after you leave the hospital.

Outpatient Transplant Coordinator: Your Outpatient Transplant Coordinator is a registered nurse who has specialized training in caring for liver transplant patients. Your Transplant Coordinator will coordinate your care after you leave the hospital. Your relationship with your Transplant Coordinator will last for as long as you are under the care of the UCLA transplant team. Your Transplant Coordinator is your most important point of contact after you leave the hospital.

Caregiver: Your Caregiver is the person you have identified before your transplant as the family member, significant other or friend you have designated as the person who is responsible for taking care of you after your transplant. Your Caregiver is a necessary part of your transplant team. Your Caregiver will need to take care of all of your needs when you are at home until you are able to safely take care of yourself.

Other: Our dieticians, respiratory therapists, chaplains, and unit secretaries are other important team members available to help you and your family during your hospital stay.
Telephone List: Post Transplant Service
Office hours are 8:00am - 5:00pm

EMERGENCY: call (310) 825-6301 option #1 and ask for the “liver coordinator” on-call

Program Director
Ronald W. Busuttil, M.D., Ph.D (310) 825-5318

Hepatologists
Assistant for Dr. Han and Dr. Durazo (310) 794-5970
Assistant for Dr. Saab (310) 206-6705
  • Francisco Durazo, M.D. (310) 794-7788
  • Steven Han, M.D. (310) 794-7888
  • Sammy Saab, M.D. (310) 794-7788

Assistant for Dr. Goldstein (310) 208-2355
  • Leonard Goldstein, M.D. (310) 208-2355

Clinical Nurse Coordinators, Outpatient
Assistant for Kevin and Scott Ernest Johnson (310) 794-3180
Assistant for Katherine and Anna Natalie Coles (310) 794-3141
Assistant for AJ and Diana Nick Oceano (310) 794-3317

You are assigned to an Outpatient Transplant coordinator according to the first letter of your last name:
  • A - Cas: Kevin King, RN (310) 794-3182
  • Cau – Gham: Scott Kaufman, RN (310) 794 3199
  • Gheo – K: Katherine Meneses, RN (310) 794-3269
  • L – N : Anna Zafar, RN (310) 794-3286
  • O – Shi: AJ Maxfield, RN (310) 794-3316
  • Shu – Z: Diana Radler, RN (310) 794-3115
  • In House Coordinator: Oonagh Sankar, RN Page Number 95803
  • Supervisor Gregg Kunder, RN (310) 794-3188

Living Related Donors and Living Related Donor Recipients

Clinical Pharmacist Curtis Holt, Pharm.D. (310) 206-4952

Social Workers
You are assigned to a Social Worker according to the first letter of your last name:
  o A-F Inpatients: Peggy Stewart, MSW, CSAC (310) 267-9728; pager 97456
  o G-Z Inpatients: Shiraz Gewirz (310) 267-9766; pager 95167
  o All Out-patients: Elisa Geraci (310) 825-5921; pager 94472
Financial Counselors
You are assigned to a Financial Counselor according to the first letter of your last name:

- **A-L:**  
  Michelle Barrow  
  (310) 794-3260

- **M-Z:**  
  Beverly Mitchell  
  (310) 794-3491
HOW TO CONTACT YOUR TRANSPLANT TEAM 
AFTER YOU LEAVE THE HOSPITAL

Your outpatient transplant coordinator
Please refer to the telephone list to determine who your outpatient transplant coordinator will be, based on the first letter of your last name.

Contacting your outpatient transplant coordinator
During business hours (Weekdays from 8 a.m. to 5 p.m.) call your outpatient transplant coordinator at the phone number listed on the phone list for all non-urgent concerns. Your call will be returned within 24 hours.

FOR AN EMERGENCY DURING WORKING HOURS or DURING NIGHTS, WEEKENDS AND HOLIDAYS:
If you have an urgent problem or emergency that requires immediate attention you must contact your outpatient transplant coordinator or the coordinator on call by calling the UCLA page operator at (310) 825-6301. Ask the page operator to page your outpatient transplant coordinator or the liver transplant coordinator on call. If your page is not returned within 15 minutes, you must call the page operator again and repeat the page.

DO NOT PAGE YOUR TRANSPLANT COORDINATOR FOR NON-URGENT OR NON-EMERGENCY SITUATIONS.

YOU SHOULD NOT PAGE A COORDINATOR FOR NON URGENT ISSUES such as medication refills, making, changing or canceling a clinic appointment or finding out about laboratory test results. These questions should be dealt with during business hours by calling (not paging) your outpatient transplant coordinator.

Emergency Department or Re-Hospitalization
If you are hospitalized at an outside hospital, you or your family member must notify your transplant coordinator (or the on-call coordinator during non business hours) immediately so that we can guide your medical management and involve the transplant team in your care.
POSSIBLE COMPLICATIONS

Complications usually happen during the first year after transplant. Many patients are hospitalized for a complication at least once during the first year after their transplant. Rejection and Infection are the two most common complications. Your ability to recognize the danger signs of rejection and infection and to promptly alert your transplant coordinator (or the on call coordinator) will increase your chance for a successful outcome. With early recognition and treatment, most episodes of rejection and infection resolve with a brief hospital stay.

REJECTION

We monitor your blood work for any signs of rejection at each lab draw.

DANGER SIGNS OF REJECTION - Contact your transplant coordinator IMMEDIATELY!
You may be scheduled for blood tests and a liver biopsy after notifying us of your symptoms.

- Fever of 100.5 degrees Fahrenheit or higher
- Discomfort on the right side of your abdomen, where your liver is located
- Jaundice “the whites of the eyes” look yellow in sunlight; skin looks yellow
- Dark urine color of tea or Coca-Cola
- Stool is pale or chalk-colored

Your body's immune system is designed to destroy foreign cells such as bacteria and viruses. Your immune system cannot tell the difference between a foreign bacteria cell and the foreign cells that make up your new liver.

Rejection happens when your immune system is triggered to attack and kill cells in your "foreign" liver. As the liver cells die, they release proteins called enzymes into the bloodstream. We measure the levels of these enzymes when we test your blood. If your liver enzyme levels are high, it tells us that you may be rejecting your new liver. Rejection can be without signs or symptoms and that is why you will have regular blood draws so that we can look at your liver test results. Even though you are taking medications to prevent rejection, your immune system can still attack your new liver.

Approximately 20% of liver transplant recipients have at least one episode of rejection.

If you do not take your medication properly, you will have a higher chance of experiencing rejection.

Over time, your liver becomes less "foreign" to your immune system, but you can still have rejection any time, even years after your transplant. If found early rejection rarely leads to retransplantation and can be successfully reversed by adjusting your medications or by treating you with more powerful medications during a one to two week hospital stay.
INFECTION

We monitor your blood work for any signs of infection at each lab draw.

DANGER SIGNS OF INFECTION - Contact your transplant coordinator IMMEDIATELY so that a prompt work up and treatment can be started.

- Fever of 100.5 degrees Fahrenheit or higher
- Redness, swelling and/or cloudy or foul smelling drainage from any wound or drain site
- Cough: a persistent cough that lasts longer than 2 days with or without trouble breathing or shortness of breath
- Rash or sores on your skin, in your mouth or on your genital area
- Urinating frequently or burning upon urination or an unusual drainage from your genitals
- Diarrhea (5 or more LIQUID stools) over 24 hours without improvement

Infections are caused by tiny microorganisms called bacteria, fungi, viruses and protozoa. Because you are immunosuppressed, you have a higher risk of getting infections from these germs that lived happily in your body and did not make you sick before your transplant. Some of the infections you might get are called opportunistic infections. Cytomegalovirus (CMV) and Pneumocystis jerovici are two opportunistic organisms that cause infections in transplant recipients. You are taking medications to reduce your risk for opportunistic infections.

You can help to prevent an infection by avoiding close contact with people who have a cold or the flu, washing your hands before touching your face, and treating all minor cuts and abrasions with an antibiotic ointment. Other tips in preventing infection are given in the "Lifestyle and Activity" section of this booklet.

Take your temperature daily for the first month
You are required to check your temperature every morning for the first month after discharge and whenever you don’t feel well. Please use a GLASS THERMOMETER.

Fever
Do not mask fevers by taking Tylenol or other medications. You should immediately notify your transplant coordinator or the on call coordinator for any fever of 100.5 degrees Fahrenheit or higher. If you took Tylenol, let it wear off AFTER 6 HOURS and take your temperature again. Call us for any fever of 100.5 degrees or higher.
HOW YOU WILL BE DISCHARGED FROM THE HOSPITAL

MEDICATIONS AT DISCHARGE (we will coordinate everything for you).

**Mail Order Pharmacy:** A Mail Order pharmacy is a pharmacy that is familiar with transplant medications and the insurance paperwork associated with these medications. You will be receiving your medicines from a mail order pharmacy that will take your insurance plan.

**Co-Pays:** Every patient has a different medication insurance plan. We do not know the details of your plan. You can call your Mail Order Pharmacy to determine your co-pay. The co-pay cost is USUALLY approx $50 - $1500 per month.

- Kaiser Permanente patients receive 3 months of medications at discharge.
- Both Kaiser and Mail Order pharmacies can deliver right to your door at home or can mail your medicines to you through UPS.

If you have KAISER insurance your pharmacy is the Kaiser Sunset Pharmacy: 323-783-9078

For all other insurances your pharmacy is A-Med/MODERN Pharmacy: 800-228-3643

**Medications will be delivered to the hospital BEFORE you leave:** Your pharmacy will deliver all of your medications to the hospital. A transplant coordinator will teach you and your caregiver about your medications before you leave the hospital. After the class, take these medicines home. These are for use once you go home. Do not give these medicines to any nursing homes or rehabilitation facilities. Take these medicines home.

**Refills once you return to home:** Call the pharmacy (the phone number is on each bottle) to order your refills!! You should contact your pharmacy fourteen days before you will run out of your medications. If you call a few days prior to running out of your medicines you can miss doses of some very important medications.

**We will teach you AGAIN before you go home.** BEFORE you go home, a transplant coordinator will meet with you and your caregivers in your hospital room to review all of your medications and follow-up appointments. A detailed medication list will be provided to you and your caregiver that this time
**Equipment & Home Nursing Visits – we will coordinate this for you BASED ON YOUR DOCTOR’S ORDERS**

**We will order equipment and nursing visits if the doctors orders them:** The 8N Case Managers will coordinate and order any medical equipment and home nursing visits you will require at home. Insurance only pays for a limited number of home nursing visits, each will last about 50 minutes. Your insurance will not pay for 24/7 or hourly care once you are home.

**RN CASE MANAGERS on Liver Service:**
For last names A -L ask your nurse for your case manager’s contact information.
For last names M-Z contact Anna Sokal, RN, MSN at 310-267-9771; Anna may be paged through the page operator 310-825-6301, option 1, then ask for pager 94352

**Not everything may be covered by your insurance:** If a wheelchair, walker, shower/commode chair or cane is prescribed by your physical therapist, it MAY be covered by your insurance. If it is covered it can be delivered to your hospital room or to your home. The delivery location and date depends on which insurance you have and when the insurance company’s preferred provider is able to fill the order.

**If your insurance won’t cover something:** If recommended equipment is NOT covered by your insurance, you may rent or purchase these items at most pharmacies like Walgreens, CVS or Rite-Aid. You may also rent or purchase this equipment through one of UCLA’s pharmacies. Your 8N case manager will help you with this.
LIVER SURGICAL CLINIC – Four Weekly Surgical Appointments

After you go home, you MUST attend the surgical clinic EVERY THURSDAY for 4 weeks. If you are readmitted to the hospital, you will return to clinic on the first Thursday after you return to your home, until you have attended a total of four Thursday clinics.

**Blood Tests**
- EVERY TIME you come to clinic, you will have your blood drawn.
- Report to the lab **before 6:30 a.m.** to have your blood drawn.
- Then take your medications.
- If you do not have your blood tests done early enough before your clinic appointment your lab results will not be available by the time you are seen by your doctor in the clinic.

**Eating Breakfast**
If you like, you may eat a light breakfast and then take all of your medication EXCEPT YOUR IMMUNOSUPPRESSANT medications before your blood is drawn. Or you may wait until after your blood is drawn and then take ALL of your medications with food.

**Your appointments are ALWAYS at 8 AM, no matter what! Do not be late!**

After your blood is drawn, go upstairs to your clinic appointment. Please check in at the front desk of the clinic.

You will be seen by an outpatient transplant coordinator and a surgeon on a first come, first serve basis. Please notify the clinic nurses if you have not seen both a surgeon and an outpatient transplant coordinator.

Use this as your “before clinic” check list:
1. Bring your morning and afternoon medications.
2. Bring your updated medication list.
3. Bring your daily temperature and blood pressure log.
4. If you are diabetic, bring your blood sugar log book.
5. If you are on insulin, bring your insulin with you.
6. Bring a WRITTEN list of any questions you have.
7. Bring something to eat and drink for everyone who is with you. Bring extra snacks and drinks because the appointments can take a long time.
8. Bring a book or something to occupy you as there is sometimes a long wait.
HEPATOLOGY CLINIC – Lifetime Hepatology Appointments

Scheduling Clinic Appointments
Your outpatient transplant coordinator will make your first appointment but YOU are responsible for making ALL your future appointments at the front desk of the clinic as you check out.

Contact (310) 794-7788 or your transplant coordinator to make, change or cancel an appointment.

If you receive HBIG shots, you must also make your next appointment for a shot at the front desk of the clinic as you check out. The clinic staff will give you a colored piece of paper to give to the clinic front desk to help you schedule your future appointments.

After you complete your four Thursday surgical clinic appointments you will transition to the “post-hepatology” clinic.

Your appointments are ALWAYS in the morning, no matter what! Do not be late! You must arrive to the lab no later than 6:30AM and the clinic no later than 9:30 AM.

- EVERY TIME you come to clinic, you will have your blood drawn.
  - You can have your blood drawn at UCLA on the morning before your appointment.
  - You can have blood drawn at UCLA the weekend before your appointment.
  - You can have your blood drawn at a non-UCLA lab near your home no later than the Wednesday before your scheduled appointment.

- The “Hepatology” appointments are located at the same clinic location as your Thursday clinics: same building, same suite. (200 UCLA Medical Plaza, Suite 214.)
- You will be in either a Tuesday or Wednesday clinic based on your assigned hepatologist.
- You will be seen every 2 weeks and slowly transition to monthly, quarterly, semi-annual and then annual hepatology appointments.
- You appointment frequency may change, based on your current medical condition.
- In addition, you will have blood drawn on a regular schedule so that we can monitor your liver status BETWEEN clinic appointments. We will provide you with a “standing lab order” to have your blood drawn near your home. The results of these lab tests should be faxed to 310-983-3570 so that we can examine them IMMEDIATELY. If you have not received a call within one week regarding your lab results contact your transplant coordinator.

Lab results
Your outpatient transplant coordinator will contact you by Friday afternoon of the week of your clinic visit if there are any medication changes or if any additional follow up is needed.
Primary Medical Doctor (PMD)
Your primary physician will eventually resume responsibility for your health care needs that are unrelated to your liver transplant, so it is important that you resume your relationship with a primary care physician. If you do not have a primary physician, your insurance company can identify one in your insurance network and geographical area. If you would like to see a UCLA primary care physician you may choose one by calling the UCLA physician referral line at 310-825-2631.

Consults – Physicians and Specialists
You may require a follow-up appointment with various physician specialists over your lifetime such as diabetes specialist or cancer specialists.

Cancer
If your transplant was for cancer of the liver, you will require LIFETIME follow-up and surveillance diagnostic tests. Please make sure you track your schedule and maintain all follow-up visits. Contact your Outpatient Transplant Coordinator if you are unsure about your testing schedule.

Medications prescribed by other doctors
Always talk to your transplant coordinator before taking any medicines prescribed by other doctors as some medicines can have harmful interactions with your immunosuppressants and your liver.

- NEVER take erythromycin, biaxin or aminoglycoside antibiotics because they can cause kidney damage.
- NEVER take Aldactone unless instructed by your transplant team as it can cause the potassium in your blood to rise too high.
- NEVER take Aspirin (unless our MD ok’s it) or NSAIDS as these will cause kidney damage. NSAIDS include Naprosyn, Advil and Ibuprofen. Always ask your Outpatient Transplant coordinator if it is OK to take ANY medication that the UCLA transplant team did not prescribe for you.

Stay near UCLA after transplant
- If you live too far away to drive to clinic every week or have to come here from another state to have your liver transplant, you must stay in the local area (near UCLA) for the first two to four weeks after you are discharged.
- You may want to make arrangements to stay at the UCLA Tiverton House or in a hotel near UCLA. Contact your insurance company to see if they will pay for any part of your room and board following the transplant.
- Your transplant physician will let you know when it is safe for you to return home.
- If you have come to here from another country we recommend that you remain in Southern California for about 4-6 months.
INSURANCE

- If you CHANGE your insurance: Please contact us immediately. We do not recommend that you change your insurance for at least one year after your transplant.

- If you LOOSE your insurance: Please contact us immediately. You are must not miss taking your medications, having your blood drawn or coming to clinic. If you lose your insurance you are in a very dangerous situation that must be fixed as soon as possible.

- If you have Medi-Cal: Please do not assign your Medi-Cal to an HMO. If you allow your Medi-Cal to be assigned to an HMO you will not be allowed to come to UCLA for any medical care.
ACTIVITY AND LIFESTYLE

1. **Exercise / Driving / Sexual Activity**

You must protect your abdomen to prevent an injury to the wound that was made during your operation. Do not participate in any activities that will result in damage or strain to your surgical area for at least six months after your last abdominal surgery. It will take one year for your surgical wound to completely heal.

Straining or hitting your stomach can make your surgical wound open up and create a HERNIA.

- Do not lift objects weighing over 15 pounds. Two 1 gallon milk cartons weigh about 15 pounds.

- Do not perform sit-ups.

- Do not push or pull heavy items.

We encourage you to walk as much as possible. You can walk up and down stairs. When your Prednisone dose is 5 mg. a day or less you may use a treadmill or stationary bicycle.

You may be cleared to drive after 6 weeks if your transplant doctor gives you permission.

Sexual activity may be resumed in six weeks if you are feeling well.

2. **T-tube Care / Showering is Permitted at Home**

You may shower while your T-tube is in place, once you have returned home. Some patients will have a t-tube in their right abdomen after they are discharged home.

The t-tube may be “capped” closed or may be attached to a drainage bag.

The purpose of the T-tube is to support your bile duct while it heals from the surgery. Your bile duct drains bile out of your liver. Bile is the substance that can make you turn yellow if you have liver disease.

Your T-tube will be removed about 3 to 5 months after your liver transplant.

You will be spending the night in the hospital during the T-tube removal procedure.

You may need to stay longer if there are any complications like fever or stomach pain.
DO NOT Submerge your t-tube in water:
DO NOT take baths, go into a Jacuzzi or go swimming in a pool or the ocean. You will get an infection if you submerge your T-tube in water.

YOU NEED TO DO DRESSING CHANGES DAILY AFTER YOUR SHOWER
Change your t-tube dressing everyday after your shower. Let the dressings get wet in the shower as they will be easier to remove. After the shower, clean the site daily as we have taught you with alcohol and betadine. Place a clean gauze dressing over the tube. Do not allow any part of the tube to dangle out of the dressing. Do not allow the tube to become dislodged or pulled. Always check to be sure the stitch that holds the tube to the skin is still intact. If the stitch is broken the tube will come out of the skin and a dangerous infection will happen.

DANGER SIGNS: Notify us immediately if:

Your t-tube becomes dislodged or gets pulled out even an inch.

You notice yellow or cloudy drainage coming out onto your skin.

Or if THE STITCH HOLDING THE TUBE IN YOUR SKIN BECOMES LOOSE OR COMES OUT.

3. **Staples**

Your staples will be removed about three weeks after your last surgery at one of your clinic visits. Staple removal does not hurt but if your staples are causing you discomfort you should take a pain pill before you come to clinic if you are three to four weeks after your transplant operation. You may take a shower if you have staples. Steri-strips are small pieces of tape that will be placed over your wound when the staples are removed. Please let the steri-strips fall off on their own; if they do not fall off within 10 days after your staples are removed you may peel them off.

4. **Gardening and Plants**

Please avoid any contact with houseplants, flowers and gardening for the first 3 months after transplant. Plants and soil may contain organisms, bacteria and fungus that you could inhale, increasing your risk for infection. When your transplant coordinator has cleared you to garden you must wear gloves in addition to shoes and socks when gardening.

You may have indoor plants, but have someone else care for them for the first 3 months. If you have fresh cut flowers in your house, they should be discarded after two days and someone else should change the water each day. The plant water may contain bacteria and fungus that you could inhale, increasing your risk for infection.
5. **Drinking Water**

City water is OK to drink. You may drink water from your sink that has been treated at a water purification plant and has been appropriately chlorinated.

Don’t drink well water that has NOT been treated, or water at campgrounds. You may drink bottled water or use a filter.

6. **Pets**

It is safe for you to have contact with a cat or dog. Always wash your hands after touching your pets. Avoid feces (poop) from cats, dogs and other animals. Poop may harbor harmful microorganisms. You must not clean cat litter boxes.

Exotic animals such as reptiles are not allowed.

Pet birds are not allowed in your immediate living area. Bird droppings harbor organisms that can cause serious infections. Birds should be kept outside of the home or in a room that you will not enter. Your caregiver will need to care for any birds in your home.

You will need to check with your coordinator if you have or plan on having any other kind of pet.

7. **Smoking and Alcohol**

**If you destroy your transplanted liver by using drugs or alcohol, you will not receive another liver transplant.**

Smoking is strongly discouraged following liver transplantation. Smoking destroys the lining of the airways that bring air into your lungs. When this lining is destroyed potentially harmful organisms and particles will settle into your lungs. Smoking can cause life threatening infections and lung cancer. Smoking will also affect the amount of immunosuppressant level in your blood. Smoking reduces your blood's ability to carry oxygen to your liver, which can result in increased liver cell death.

Smoking marijuana and other substances can introduce harmful fungus into your lungs that can give you a deadly pneumonia.

Alcoholic beverages are not allowed. Use of alcohol can cause liver cirrhosis and result in liver failure. If you have Hepatitis C, use of alcohol can speed up the damage the Hepatitis C virus can do to your transplanted liver.
8. **Dental Visits**

As you are now immunosuppressed, you will need to take antibiotics EVERY TIME you undergo any type of dental work, including cleaning.

Having regular dental check ups and maintaining good mouth care is very important after liver transplantation.

You will take antibiotics 1 hour before every procedure to assure that an adequate amount of the antibiotic is in the blood stream.

Your transplant coordinator or your dentist can also prescribe the correct medicine for you.

Call your outpatient transplant coordinator AT LEAST ONE WEEK prior to your dental appointment to obtain a prescription for the correct antibiotic.

9. **Travel**

Please stay near UCLA after your transplant. We prefer that you not travel for the first 3 months. If your physician permits, and your condition is stable:

- you may travel within California, Nevada and Arizona after 3 months
- you may travel within the Western portion of the US within 6 months
- you may travel all over the US after 6 months
- you may travel internationally after 12 months.

Always take EXTRA MEDICATION with you in case your trip back home is delayed!

We highly recommend not traveling to DEVELOPING COUNTRIES for the first year. If you are traveling to a third world country, drink only bottled water and avoid eating foods sold on the street or at food stands. Only eat well cooked meat when abroad, and if you are in a third world country, avoid raw fruits and vegetables. They are usually washed in tap water that may be contaminated. Cooked vegetables are generally safe to eat.

10. **Sun Exposure**

**Your risk for skin cancer rises after your liver transplant due to the immunosuppression medications you take.** Your immune system is less able to detect and destroy cancer cells.

ALWAYS wear sunscreen with a sun protection factor (SPF) of 15 or higher whenever you are outdoors, even on cloudy days. Wear a hat and a long sleeved shirt if you expect to be outdoors a long time. Avoid staying outside during the peak sun hours of 10 am – 4 pm.
11. **Pregnancy and Birth Control**

Pregnancy is possible after liver transplantation, but women who have had a liver transplant should wait at least one year after their transplant before conceiving. Men are able to father children after liver transplantation.

Let us know if you are planning to start a family. Your immunosuppressant medications must be adjusted WELL IN ADVANCE of conception. Close follow-up by an obstetrician specializing in high risk pregnancies is required.

Birth control pills must be avoided after transplantation due to the increased risk for blood clots in the blood vessel that carries blood to the liver. Oral contraceptives may cause blood clots, bile to clog up in the liver and may contribute to hypertension (high blood pressure).

Intrauterine devices (IUDs) are not advised due to the increased risk for infection.

Barrier methods such as condoms and diaphragms are a safe and acceptable alternative to birth control pills and IUDs.

10. **Contacting Your Donor Family** (excerpted from www.transplantliving.org)

Use this as a checklist if you choose to write a letter to your donor family:

- Use your first name only
- Use the state where you live but not the county or city
- Recognize the donor family's generosity and thank them for their gift
- Describe how long you waited for a transplant and how the wait affected you and your family
- Explain how the transplant has improved your health and changed your life
- Describe the impact of your transplant on your own family
- Explain what has happened in your life since the transplant
- Mention if you are married, have children, grandchildren, etc.
- State your hobbies or interests
- Do not include your address, city or phone number
- Do not include the name or location of the hospital where your transplant surgery was performed, or the names of your transplant health care providers
- Use caution when including religious comments, as you do not know the religion of the donor's family
When your letter is completed: Place your card or envelope in an unsealed envelope. Include a separate piece of paper with your full name and date of transplant. Place these items in another envelope and mail them to your transplant coordinator.
Your coordinator’s mailing address is:
   Name of your coordinator
   UCLA Liver Transplant
   924 Westwood Blvd. Suite 740
   Los Angeles, California 90095

Once UCLA receives your letter: we will forward your letter to your organ procurement agency “OPO.” Your OPO will review it to ensure confidentiality. The OPO will then contact the donor family to ask if they wish to accept correspondence from recipients. If the donor family does not wish to communicate, the OPO will inform your transplant center accordingly. If the donor family does wish to communicate, the OPO will forward your letter.

Confidentiality: Although there is no law that a donor's family and the organ recipient cannot meet and know each others' names, all OPOs have policies to protect the privacy of both parties.

Will I hear from the donor's family?

You may or may not hear from your donor's family. Some donor families may feel that writing about their loved one and their decision to donate helps them in their grieving process. Others choose not to write to the organ recipient. If the donor family chooses to respond, they will send a letter to the OPO. The OPO will then forward the response to you.
MEDICATIONS

1. **Immunosuppressants**

For the rest of your life, you will take 1-4 immunosuppressants to prevent rejection of your liver. Without these medications you will reject and lose your liver. Immunosuppressants weaken your immune system by interfering with how your white blood cells work. These medicines prevent your white blood cells from attacking and destroying your liver. This causes an increased chance for infection because your white blood cells will not be as likely to attack bacteria, viruses or fungus within your body.

Only your UCLA liver doctors can change your liver medications or doses. Never stop or change the dose of any liver related medication without asking your transplant physicians or your transplant coordinator.

The most common immunosuppressants you may encounter are described in the next pages. Combinations of these drugs are effective in preventing (or reversing) rejection. Your transplant physicians will decide which one is best for you.

A. **Prograf (Tacrolimus)**

*We monitor the level of this drug at each lab draw and will always notify you if you need to make any changes in your doses.*

Tacrolimus (Prograf) comes in 5 mg, 1 mg and 0.5 mg capsules. It must be taken twice a day, 12 hours apart, usually at 8 a.m. and 8 p.m.

You must AVOID all Grapefruit products (and possibly Starfruits & Pomegranates.)

Patients who take Tacrolimus / Prograf may experience the following side effects:

<table>
<thead>
<tr>
<th>Effects on Nervous System</th>
<th>Effects on Stomach and Intestines</th>
<th>Effects on Kidneys</th>
</tr>
</thead>
<tbody>
<tr>
<td>** Tremors</td>
<td>** Diarrhea</td>
<td>** Increased potassium in bloodstream</td>
</tr>
<tr>
<td>** Headaches</td>
<td>** Nausea</td>
<td>(If kidneys not able to filter out enough potassium -- this can lead to an irregular heartbeat.)</td>
</tr>
<tr>
<td>** Seizures</td>
<td>** Decreased appetite</td>
<td>** Fluid retention</td>
</tr>
<tr>
<td>** Numbness, tingling and/or pain in extremities (arms, legs, hands, feet)</td>
<td></td>
<td>** High blood pressure</td>
</tr>
<tr>
<td>** Numbness around mouth</td>
<td></td>
<td>** Increased magnesium loss via urine</td>
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<tr>
<td>** Change in taste of food</td>
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<td></td>
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<tr>
<td>** Confusion</td>
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<td>** Drowsiness</td>
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<td>** Difficulty speaking</td>
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<tr>
<td>** Itching</td>
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<tr>
<td>** Hair loss</td>
<td></td>
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<tr>
<td>** Increased risk of infection</td>
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</tbody>
</table>

** High blood sugar occurs in about 20% of patients who take Prograf and half of these patients will require insulin injections. If you are already diabetic, you may require more insulin while taking Prograf. If you are not diabetic, but have other blood relatives who are, you may develop diabetes (high blood sugar) while taking Prograf.
B. **Cyclosporine-modified (Neoral / Gengraf)**

_We monitor the level of this drug at each lab draw and will always notify you if you need to make any changes in your dosing._

Cyclosporine-modified (Neoral / Gengraf) comes in 100 mg and 25 mg capsules. It must be taken twice a day, 12 hours apart, usually at 8 a.m. and 8 p.m.

*You must AVOID all Grapefruit products (and possibly Starfruits & Pomegranates.)*

Patients who take Cyclosporine-modified / Neoral may experience the following side effects:

**Nervous System** (same effects as Prograf)

**Effects on Kidneys** (same effects as Prograf)

**Other Side Effects**

- **Enlargement or overgrowth of gums**
- **Increased hair growth (often on face, arms and legs)**
- **Elevated blood sugar (not as common as with Prograf)**
- **Increased risk of infection**
- **Elevated cholesterol levels**
- **Oily skin**
- **Muscle and joint pain**
- **Diarrhea**
- **Runny nose**
- **Hot flashes**
- **Sweating**

C. **Prednisone**

Prednisone is a steroid that reduces inflammation in your tissue and your new liver. All liver transplant patients take Prednisone with their other medications to prevent liver rejection. Prednisone causes breakdown of muscle and bone tissue, (unlike the steroids that athletes sometimes take to build muscle) therefore, it is carefully monitored.

You may eventually be taken off this medication.

Prednisone can cause lack of sleep and should be taken in the morning to prevent you from having trouble sleeping at night. We will also prescribe an anti-ulcer medicine for you since this is a side effect of Prednisone.

**Side effects improve or disappear as the dose of Prednisone is reduced.**

**Side-Effects**

- **Acne**
- **Insomnia**
- **Facial puffiness**
- **Slow wound healing**
- **Increased risk of infection**
- **Weak muscles/muscle loss**
- **Weak bone/bone loss (osteoporosis)**
- **Ulcers in stomach/stomach irritation**
- **Fluid and salt retention (bloating, swollen ankles)**
- **Blurry vision/cataracts (usually occur after long-term Prednisone use)**
- **High blood pressure (due to sodium and fluid retention)**
- **Fluid and salt retention (bloating, swollen ankles)**
- **Mood swings (irritability, emotionality)**
- **Increased appetite/weight gain**
- **High blood sugar (diabetes)**
- **Easy bruising/thin skin**
D. **Cell-Cept** (Mycophenolate Mofetil) or **Myfortic** (Mycophenolate Mofetil EC)

Taking Cell-Cept allows us to decrease your doses of other immunosuppressants while still preventing liver rejection.

This medication can cause your white blood cell count to lower, increasing your risk for infection.

**Side Effects**
- **Nausea**
- **Diarrhea**
- **Poor appetite**
- **Increased risk for infection**
- **Low white blood cell count**
- **Increased risk for certain cancers affecting lymph nodes, blood cells and skin.**

E. **Sirolimus (Rapamune)**

*We monitor the level of this drug at each lab draw and will always notify you if you need to make any changes in your dosing.*

You must **AVOID** all Grapefruit products (and possibly Starfruits & Pomegranates.)

Sirolimus comes in 1mg and 2 mg capsules or 1mg/cc elixir (liquid) and is taken at 8 AM.

**Side Effects**
- **High blood pressure**
- **Rash**
- **Acne**
- **Anemia**
- **Joint pain**
- **Diarrhea**
- **Slow wound healing**
- **Increased cholesterol and triglyceride level**
- **Low potassium in bloodstream**
- **Low platelet level**

Only your UCLA liver doctors can change your liver medications or doses. Never stop or change the dose of any liver related medicines without consulting your transplant physicians or your transplant coordinator.
7. **Hepatitis B and C**

You may have received your liver transplant due to viral hepatitis.

**Removing your old liver does not cure your hepatitis.**

The hepatitis viruses live in your blood stream, lymph nodes, spleen and other places in your body besides the liver.

The medications we will prescribe for you may prevent your immune system from fighting off the hepatitis viruses and may even stimulate the viruses to grow in number and damage your new liver.

**Hepatitis B**

If you have hepatitis B, you will be given 1 or 2 oral drugs to prevent the virus from damaging your liver. Some of these medicines are Lamivudine (Epivir), Hepsera (Adefovir), Entecavir (Baraclude), Tenofovir (Viread).

You will also be receiving Hepatitis B Immune Globulin injections (HBIG). **HBIG** supplies antibodies against the hepatitis B virus. After HBIG is given monthly for 15 months, you may be able to convert to two oral medications. **YOU ARE RESPONSIBLE FOR MAINTAINING YOUR HBIG APPOINTMENT SCHEDULE!**

**Hepatitis C**

**If you have hepatitis C, you can expect it to infect your new liver at some point after your transplant.**

In most cases, hepatitis C has only mild effects on the liver and causes minimal liver damage. Most patients will feel and look well and their only evidence of re-infection may be slightly abnormal lab tests. It may take many years for the hepatitis C virus to create enough liver damage for you to experience symptoms of liver disease.

Your hepatologist will advise you of your best treatment plan to treat the damage done by Hepatitis C. Currently the usual treatment for Hepatitis C consists of injectable Interferon and oral Ribavirin. Promising new drugs that kill the virus completely have been developed and tested on patients who have had a liver transplant.

**Hepatitis Precautions**

We check your blood levels of hepatitis B and/or hepatitis C. If your have hepatitis B, your family members should be tested and vaccinated against it. Safe sex (proper use of condoms or abstinence) should be practiced until the vaccine has taken effect because hepatitis B is often transmitted sexually.

Since hepatitis C is transmitted through blood, we recommend that family members not use the same scissors, razors and toothbrushes as the patient and that they practice safe sex using a condom.
F. General Rules About Taking Your Immunosuppressants  
(Anti Rejection Medications)

i. Absorption
Immunosuppressants are absorbed in your stomach and intestines. Any situation that impairs the absorption of your immunosuppressants, such as persistent vomiting or diarrhea, increases your risk for liver rejection.

You must AVOID all Grapefruit products (and possibly Starfruits & Pomegranates.)

Vomiting
If you vomit within one hour of taking your immunosuppressant medications or you can see the pills and capsules in your vomit, you must repeat the doses and take them again.

If you vomit more than one hour after taking your medications, and do not see the pills and capsules in your vomit, they have most likely been absorbed and do not need to be repeated.

If you continue to vomit and are unable to hold down your medications, and you miss 2 doses, you must page your transplant coordinator or the on-call coordinator IMMEDIATELY.

Diarrhea
Diarrhea is four to five WATERY bowel movements in a 24-hour period. If you have Diarrhea you must IMMEDIATELY page your transplant coordinator or the on-call coordinator. Diarrhea can be a side effect of your medications or could indicate that you have an infection.

ii. Blood Levels
Whenever you come to the lab or clinic to have blood drawn, you must wait until after the blood is drawn to take your Tacrolimus (Prograf), Cyclosporine (Neoral) or Sirolimus (Rapamune). We measure the trough levels (valley level or lowest level in a 12-hour period) of these medications in your bloodstream. If you take these medications prior to the blood draw, your blood level will not be accurate and you may be over or under dosed.

The amount of Tacrolimus (Prograf), Cyclosporine (Neoral) or Sirolimus (Rapamune) you take may change from week to week, and the dose that we prescribe for you is determined by how high or low your trough level is. Therefore, it is crucial that you wait until after the blood draw to take these medications.

Always bring your Prograf, Cyclosporine/Neoral, or Sirolimus with you to the lab/clinic so you can take your dose after your blood is drawn.
If you accidentally take your Tacrolimus (Prograf), Cyclosporine (Neoral) or Sirolimus (Rapamune) before your blood is drawn, do not proceed with the blood draw until speaking with your coordinator. You may request the lab page your coordinator.

iii. Missed Doses

Missing even one dose of your immunosuppressants can trigger a rejection episode. If you miss a dose of any of your immunosuppressants you must notify your outpatient transplant coordinator (or the on-call coordinator). Your transplant coordinator may want you to have blood drawn to check the level of immunosuppressants in your bloodstream and to be sure that your liver is working well.

You should NEVER double up on any of your immunosuppressants to make up for missed doses. Doubling up on doses can result in life-threatening side effects.

iv. Late Doses

If you take your immunosuppressants late, you should always leave at least eight hours between your current dose and your next dose to minimize severe side-effects. For example, if you normally take Prograf at 8 a.m. and 8 p.m., but today you forgot to take your morning dose until 1 p.m., you should wait until at least 9 p.m. to take the second dose of the day.

Ideally, immunosuppressants should be taken 12 hours apart to maintain steady levels in your blood stream.

2. Drugs That Prevent Infection

Your highest risk for infection is during the first year after your liver transplant because you are taking higher doses of the immunosuppressant medications during that time. Therefore, you will take several medications during your first post-transplant year to protect you against various infections.

a. Antivirals

For 100 days after your liver transplant, you will be given an antiviral medication.

You will be discharged home on Valganciclovir (Valcyte), taken once daily.

This drug prevents infections resulting from CMV (cytomegalovirus), a virus that most of us are exposed to by the time we are adults that does not cause infection in people who are not immunosuppressed.

These medications also prevent infections from the viruses that cause fever blisters, cold sores, chicken pox and shingles. Side effects of Valcyte include a low white blood cell count, a low platelet count and anemia.
b. **Anti fungals**

You are at risk to have infections from fungus. You will be given a medication called **Fluconazole (Diflucan)** for 42 days after your transplant to prevent fungal infections.

Side effects of Fluconazole include raising the levels of your immunosuppressant medications in your blood. When your Fluconazole is discontinued, we will obtain blood tests and may increase your immunosuppressant dosing. This will require blood tests every 2-3 days for 2-3 weeks.

Fungal infections can cause skin rashes, vaginal discharge, a white coating on the tongue, inside the cheeks or on the back of the throat. Fungus can also cause a thickening and discoloration of the nails.

Serious fungus infections can cause lung, blood or brain infections. If you have lived in the Southwestern United States and have tested positive for Valley Fever (coci or coccidioides) you will need to take Fluconazole for several years or for life.

c. **Preventing Pneumocystis Pneumonia**

You are taking an antibiotic called **Bactrim DS** (double strength) for one year after your liver transplant; you may also need to take Bactrim DS longer if you are treated for rejection. Bactrim DS prevents a pneumonia caused by a protozoan called **Pneumocystis jerovici**. This organism normally does not make people sick if they are not immunosuppressed. One tablet is taken every day. Side effects include low white blood cell and platelet counts, anemia, rash, nausea, and sensitivity to sunlight. Bactrim DS should be taken with a large glass of water and with food to prevent nausea and to aid in absorption.

If you are allergic to sulfa drugs, you will receive an different medication to prevent Pneumocystis pneumonia. **Dapsone or Atovaquone (Mepron)** will be substituted.

3. **Medications to prevent Ulcers and Stomach Irritation**

Because you take Prednisone to prevent rejection, you are at risk for developing stomach ulcers or stomach irritation (gastritis). You will be taking one of the following medications to protect your stomach from getting ulcers (based on your insurance coverage): **Pepcid** (Famotidine), **Prilosec** (Omeprazole), **Prevacid** (Lansoprazole), **Nexium** (Esomeprazole) or **Protonix** (Pantoprazole).

When you are off Prednisone, your transplant physician may discontinue the anti-ulcer medications.
4. **Supplements (Vitamins and Minerals)**

Supplements are generally not covered by insurance, therefore, you MAY need to purchase any supplements from a grocery, vitamin or drug store.

a. **Magnesium**
Magnesium pills replace the magnesium lost in your urine as a result of taking Prograf or Neoral. If the magnesium in your blood falls too low, you are at risk for experiencing seizures or other problems like tremors and headaches. The magnesium pills you may receive include **Magnesium Protein Complex**, 133 mg tablets, or **Magnesium Oxide**, 250 or 400 mg tablets. The usual dose is three tablets three times a day with meals. Although the milligram amount is different, the amount of actual magnesium in a 133 mg Magnesium Protein Complex tablet and a 400 mg Magnesium Oxide tablet is about the same. High doses of magnesium may cause diarrhea.

b. **Fish Oil (Omega-3-Fatty Acids)**
You may be asked to take Fish Oil to improve the blood flow to your kidneys. Fish oil may cause loose stools. Fish Oil comes in 1000 mg capsules and patients generally take one or two capsules three times a day with each meal.

c. **Multi-Vitamins**
Multi-Vitamins are safe to take as long as you are not substituting vitamins for good nutrition through a well balanced diet. We recommend that you don’t take more than 100% of the RDA. Do not take vitamins with extra added iron. *If your potassium level is too high, you will need to find a multi-vitamin that is low in potassium.*

d. **Iron Supplements**
Your doctors may want you to take an iron supplement due to anemia. A low red blood cell count (anemia) is common for the first one to two months after your transplant because it takes time for your body to make up the blood cells you lost during the surgery. Poor kidney function and some of your medications can also contribute to anemia. You may also take **Vitamin C** to improve the way your body absorbs the iron. A B vitamin **Folate** may also be added for anemia. **Iron supplements** can cause constipation and dark stools, as well as nausea and upset stomach. *Be sure to take a stool softener!*

e. **Calcium Supplements**
If you are at risk for brittle bones (osteoporosis) you will need to take Calcium pills such as **TUMS**. You may also need to take **Myacalcin**, **Fosamax** and **Vitamin D** with the calcium to help strengthen your bones.
5. **Pain Medications**

Your surgical pain should improve within six weeks after your transplant and by then should be controlled with regular Tylenol. If it is not, you should contact your outpatient transplant coordinator so that the cause of your ongoing pain can be understood and treated.

When you go home from the hospital you will be given pain pills to reduce pain caused by the transplant surgery.

You will not be given for this pain medication after you have used it up unless you are continuing to experience a large amount of pain and have been examined by one of the transplant physicians.

**You must not take nonsteroidal anti-inflammatory drugs (NSAIDs) at any time after your transplant** because these medicines will damage your kidneys. **You may only take aspirin if told to do so by your transplant doctor.** AVOID all NSAIDS such as Motrin, Ibuprofen, Advil, Aleve, and Naprosyn.

6. **Medication for High Potassium**

Please see the information in the last half of this booklet for a list of foods you should avoid or limit if your blood potassium is too high.

High potassium in your blood is a COMMON side-effect of your immunosuppressant medications and is dangerous, affecting the way your heart beats and causing arrhythmias (irregular heart beat).

You may need to take a medicine called Florinef to lower your potassium. The side-effects of Florinef are sodium (salt) retention, swelling, and high blood pressure.

Review your potassium food list and adjust your diet so that you are not eating too many high potassium foods.

7. **Studies and Research**

As a University based hospital, UCLA does many research studies related to current treatments and therapies in the transplant field.

You may be asked to participate in a study that can benefit you as well as others. You may choose to participate or not to participate.
7. **Over The Counter Medications You May Take (Non Prescription)**

If any cold or cough symptom last longer than three days, notify your transplant coordinator.

Carefully read the labels of all over the counter medications.

Many medications are combinations of medications that will harm you.

Buy each medication in its “plain” form to treat the single symptom you are experiencing instead of a medication that contains 2-3 various active ingredients.

**No NSAIDS ever!**
- DO NOT EVER TAKE ASPIRIN, IBUPROFEN and any NSAIDS – non-steroidal anti-inflammatory: Motrin, Advil, Ibuprofen, Aleve, Naprosyn or Orudis. NSAIDS will damage your kidneys.
- Do not take Aspirin (unless a UCLA transplant doctor puts this on your medication list).

**Medications that contain Acetaminophen (Tylenol)** are safe only if they are not taken with other medicines that contain acetaminophen. Carefully read all labels for ingredients and instructions.

**Herbal remedies** are NOT safe for you.

**Mylanta and Metamucil** will cause poor absorption of your medicines and must be taken 2 hours before or 2 hours after your immunosuppressants.

**Cough**
- If you have a cough with chest congestion (tightness) take Plain Robitussin, or Plain Mucinex

- If you have no chest congestion take Robitussin DM or Mucinex DM

- Do not take Robitussin PE or Robitussin CF because these will increase your blood pressure.

**Sneezing / Runny Nose**
- Take plain Chlor-trimeton or take plain Dimetapp (Brompheniramine) or take plain Benadryl (Diphenhydramine) - this medication causes drowsiness. Plain Claritin, Allegra or Zyrtec are safe but may cause drowsiness.

Some Decongestants can make high blood pressure worse such as Sudafed (PSUEDOEPHEDRINE).

Plain Claritin, Allegra or Zyrtec are safe but may cause drowsiness.
Zinc Lozenges, Vitamin C, Occillococcinum, Echinacea and Golden Seal are safe to use but may or may not be effective.

AVOID ALL MEDICINES THAT HAVE A “D” AFTER THE NAME example: Claritin-D, Allegra-D.

Nasal / Sinus Congestion

Do not use nasal sprays for longer than three days.

Take 6-Hour Afrin Nasal Spray or 6-Hour Neosynephrine Nasal Spray or normal saline spray.

Avoid Sudafed / PSUEDOEPHEDRINE or PHENYLPROPANOLAMINE in any cold medicines or decongestants: Decongestants can cause or worsen high blood pressure.

Sore Throat

Take Chloroseptic lozenges or spray or NICE lozenges (sugar free).

Fever

We prefer you always take your temperature with a glass thermometer. Otherwise, have several digital thermometers available incase some of the batteries die. Immediately notify your transplant coordinator or the on call coordinator for any fever of 100.5 degrees Fahrenheit or higher.

You may take two REGULAR strength (not “extra-strength”) plain Tylenol (Acetaminophen) every six hours as needed after you have reported your fever to your coordinator. Allow the Tylenol to wear off every 6 hours and recheck your temperature with a thermometer. If your fever continues, call your coordinator!

- Do not take Aspirin or medicines containing aspirin.
- Do not take Motrin, Ibuprofen, Advil, Aleve, Naprosyn, Orudis or any other medication containing a non-steroidal anti-inflammatory (NSAID).

Body Aches & Headache

Take two REGULAR strength (not “extra-strength”) plain Tylenol (Acetaminophen) every six hours as needed. Call your coordinator if your pain persists.
8. Vaccines for Immunosuppressed / Liver Transplant Patients

You must check with your transplant coordinator or transplant doctor before receiving ANY immunizations. **YOU MUST BE SURE THAT ANY VACCINES YOU GET CONTAIN ONLY DEAD VIRUSES.** You are not permitted to have any vaccines that are made with live viruses.

Yearly flu shot: Some transplant physicians will let you get the flu shot 3 to 12 months after your transplant.

The Tetanus booster and/or hepatitis A and B vaccines can be taken 12 months after transplant.

Typhoid: ONLY the “Typherix” vaccine is allowed.

**You may NOT have the following vaccinations after your transplant:**

- DTaP (Dyptheria, Pertussis, Tetanus)
- Small Pox Immunization
- Yellow Fever Immunization
- Measles-Mumps-Rubella (MMR) immunization
- Oral Polio Immunization
- Shingles Immunization

People who have taken any of these vaccines may shed the virus in their body fluids (blood, urine, stool) for up to three months.

Avoid contact with body fluids of vaccinated persons for three months; this includes infants and small children (urine, feces, vomit, etc.). If you come in contact with these fluids, such as baby diaper changes, please use gloves and carefully wash your hands afterwards. You may need to shower and change clothes depending on the amount of contact the fluids made with your clothes and skin.

Because you are immunosuppressed these viruses, although weakened, can infect you.

If you plan a trip outside of the USA you can visit the UCLA Travel Clinic several weeks before your scheduled trip. Call to make an appointment:

Santa Monica Travelers and Tropical Medicine Clinic 310 319-4371
UCLA Westwood Travelers and Tropical Medicine Clinic 310 794-5583
DIETARY GUIDELINES

**Short Term Goals**

Your physician will identify your discharge diet goals. If you do not have kidney involvement, a high protein diet is recommended for the first six to eight weeks post transplant. Good sources of protein include lean meats, fish, poultry and low fat dairy.

**Long Term Goals**

Achieve and maintain a healthy weight. Try to avoid becoming overweight. Prednisone can continue to stimulate appetite, and if you're not careful, you may slowly gain excessive weight. Excess weight can contribute to high blood pressure, high cholesterol and high blood sugar. Avoid an abundance of fats, sweets and second helpings. Include aerobic exercise such as brisk walking in your daily activities.

**Food Safety**

Immunosuppressants reduce the body’s normal ability to fight infection, including food-borne illnesses, or food poisoning. The following food handling tips will help lower the risk of food contamination:

- Practice frequent and careful hand washing.
- Remember that eggs and some raw meats may contain Salmonella.
- Do not eat raw or undercooked meat, fish, poultry and eggs. This includes tasting batter or cookie dough containing raw eggs, Caesar salad dressing or drinking raw or unpasteurized milk or milk products.
- Do not thaw meat on the counter. Thaw meat in the refrigerator or use the microwave.
- Wash fresh fruits & vegetables with water before eating. You may scrub with a brush, but do not use regular soap.
- Keep food at safe temperatures:
  - Cook hot foods to at least 165° F.
  - Keep cold foods under 40° F.
  - Foods served in between 40-165° F should be eaten within 1-2 hrs.
- Do not refreeze defrosted foods.
- Leftovers should be eaten within 1-2 days or thrown away.
1. **Salt / Sodium**

Beware, sodium is “hidden” in many foods. Everyone needs some sodium, but most of us get much more than we need. Common table salt is made from two minerals: sodium and chloride.

Sodium is often responsible for the retention of fluid which can raise blood pressure. The recovering body may not process this excess sodium well and you may experience edema (swelling from fluid retention) and high blood pressure.

**Read package labels**
Avoid foods listing salt as one of the first ingredients. When there is a need to substitute for high sodium foods, you may occasionally use foods with the words "low sodium" or "no added salt" printed on the label.

The word "dietetic" may mean something other than "low sodium."

**Avoid fast food restaurants**
Fast food restaurants should be avoided or visited very infrequently due to the high sodium and high fat content of the foods served.

**Swelling / Edema**
Certain medical conditions and medications cause the body to retain sodium. This extra sodium stays in the tissues, causing swelling, high blood pressure or other problems.

To prevent / reduce the severity of swelling and high blood pressure, reduce the sodium in your diet to 3-4 grams per day, a “No Added Salt” diet.

**Greatly limit the following foods:**

- baking soda
- regular canned broth
- bouillon cubes
- monosodium glutamate
- Worcestershire sauce
- regular soy sauce
- meat tenderizers
- seafood seasoning
- fish sauce
- shrimp sauce
- barbecue sauce
- sauerkraut
- pickles
- horseradish
- meat sauces
- specialty sauces
- buttermilk
- lemon pepper
- seasoning salts
- garlic salt
- onion salt
- celery salt
- chili sauce
- olives
Processed foods
Avoid processed foods unless they are salt free. Foods that have been precooked, prepared, and packaged in ready-to-eat form when purchased (such as cured, aged and smoked meats, cold cuts, hot dogs, canned soups or vegetables, frozen entrees, salted nuts, chips and crackers) are usually FULL of sodium. If you avoid processed foods, then you may use up to 1/4 to 1/2 teaspoon of salt per day in cooking or at the table.

Cheese
Only use cheeses that are low in sodium and fat.

** Low Sodium/Fat: contains less than 150 mg of sodium per ounce and less than 6 grams of fat per ounce part skim mozzarella, part skim ricotta.

** Medium Sodium/Fat: contains 150-250 mg of sodium and 6 to 8 grams of fat per ounce: whole-milk mozzarella, brie, Swiss.

** High Sodium/Fat: greater than 250 mg sodium and 8 to 10 grams of fat per ounce: processed American sliced cheese, blue, grated parmesan and Roquefort.

Non-salt seasonings
Use natural herbs, spices and flavoring to enhance the flavor of your food. You may use any salt substitute containing herbs alone, such as tarragon.

- Do not use salt substitutes containing potassium chloride.
Increasing your potassium intake by using salt substitutes can make your blood potassium level too high, leading to irregular heart rhythms.

DO NOT CONSUME:
** Schilling salt substitute
** Adolph’s salt substitute
** Morton's salt substitute
** No Salt
** Nu-Salt
** Co-Salt
** Adolph's Seasoned Salt
** Lawry's Seasoned Salt
** Other seasoned salts
2. Potassium

Potassium is a mineral found in many of the foods you eat and it plays a role in keeping your heartbeat regular and your muscles working right. Potassium is located in almost all foods, especially in fruits, vegetables, and dried beans.

- **Limiting foods high in potassium** may be necessary if you are medications such as Prograf or Cyclosporine/Neoral.

- **Labs:** We monitor your potassium level on each lab draw. Your physician or transplant coordinator will let you know if you need to change your diet or if you need to take medication to alter your potassium level.

- **Potassium too high:** You may experience weakness, numbness, tingling, and a slow pulse. If your potassium becomes too high, it can cause an irregular heartbeat and become life threatening. Foods to avoid include: Bananas, Avocados, Nuts, like almonds and peanuts, Citrus fruits, Leafy green vegetables, Milk, Potatoes and tomatoes.

- **Low Potassium Vitamin:** If you are told that your potassium level is too high, you will need to find a multi-vitamin that is low in potassium.

- **Potassium too low:** You may experience muscle weakness, cramping, fatigue, confusion, problems with muscle coordination, irregular heartbeat, and heart failure.

- Healthy kidneys keep the right amount of potassium in your body. When your kidneys are impaired and/or recovering, they are unable to excrete excess potassium.

- **Reading labels** is also an important part of modifying potassium intake. Although, potassium content may not be listed on the front label, it is usually listed in the “ingredients” section.

- **How can you keep your potassium from getting too high?**
  - Remember that almost all foods have some potassium.
  - The size of the serving is very important.
  - Too many servings of a low potassium food turns it into a high-potassium food.
  - Eat a variety of foods but in moderation. Do not drink juice or use the liquid from canned fruits and vegetables, or the juices from cooked meat.
How to lower your potassium level:

- Watch your diet. Limit foods that are high in potassium.
- Limit fruits and vegetables to the amounts recommended by your dietitian.
- Limit milk and milk products or replace with nondairy substitutes.
- Discard liquids from canned fruits and vegetables.
- Avoid salt substitutes and other seasonings that contain potassium.
- Read labels on “low salt” or “low sodium” packaged foods to be sure potassium ingredients like potassium chloride are not added.
- Keep an eye on serving size. Almost all foods have some potassium, so even a low potassium food can turn into a high potassium food when eaten in large amounts.
- Do not skip dialysis. Stay on dialysis for the full treatment time. The full treatment time is necessary to clean the blood adequately.

When can you eat foods with HIGH potassium? If your potassium level is normal after 3 months then you can introduce ½ portion of a high potassium food 3 times a week if it has been through a leaching process.

Leaching process to lower potassium in foods:

For Potatoes, Sweet Potatoes, Carrots, Beets and Rutabagas:

1. Peel and place the vegetable in cold water so they won’t darken.
2. Slice vegetables 1/8 inch thick.
3. Rinse in warm water for a few seconds.
4. Soak for a minimum of two hours in warm water.
5. Use ten times the amount of water to the amount of vegetables.
6. If soaking longer, change the water every four hours.
7. Rinse under warm water again for a few seconds.
8. Cook vegetable with 5 x the amount of water to the amount of vegetable.
9. Limit portion to one serving, usually ½ cup.

For Squash, Mushrooms, Cauliflower and Frozen Greens:

1. Allow frozen vegetable to thaw to room temperature and drain.
2. Rinse fresh or frozen vegetables in warm water for a few seconds.
3. Soak for a minimum of two hours in warm water.
4. Use 10x the amount of water to the amount of vegetables, and change every 4 hours.
5. Rinse under warm water again for a few seconds.
6. Cook vegetable with 5 x the amount of water to the amount of vegetable.
7. Limit portion to one serving, usually ½ cup.
To keep your potassium levels normal try these suggestions:

**Food type**

**Fruit**
- Choose apples, berries or grapes, instead of bananas, oranges or kiwi.
- Select a small piece of watermelon, instead of cantaloupe or honeydew.
- Eat a peach, plum or pineapple, instead of nectarines, mangos or papaya.
- Choose dried cranberries, instead of raisins or other dried fruit.
- Use lower potassium canned pears, peaches or fruit cocktail, instead of fresh fruit.

**Vegetables**
- Choose green beans, wax beans or snow peas, instead of dried beans or peas.
- Prepare mashed potatoes or hash browns from leached potatoes, instead of eating baked potato or French fries. (Be sure to leach your potatoes to lower potassium content.)
- Use summer squashes like crookneck or zucchini, instead of winter squashes like acorn, banana or hubbard squash.
- Cook with onion, bell peppers, mushrooms or garlic, instead of tomatoes, tomato sauce or chili sauce.
- Drink ice water with sliced lemon and cucumber, instead of drinking vegetable juices.

**Dairy**
- Use nondairy creamer or un-enriched rice milk, instead of milk.
- Prepare pudding with nondairy creamer, instead of eating yogurt or pudding made with milk.
- Enjoy sherbet, sorbet or a Popsicle®, instead of ice cream or frozen yogurt.

**Miscellaneous**
- Choose vanilla- or lemon-flavored desserts, instead of chocolate desserts.
- Eat unsalted popcorn or pretzels, rice cakes, jelly beans or hard candies, instead of nuts or seeds.
- Season with pepper, lemon or low sodium herb and spice blends, instead of salt substitutes.
**High potassium foods**

Be sure to limit or avoid high potassium foods.

<table>
<thead>
<tr>
<th>Food type</th>
<th>High potassium foods – ½ cup unless specified</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fruits</strong></td>
<td>Avocados - ¼ of whole</td>
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<tr>
<td></td>
<td>Bananas, Plantains; ½</td>
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<tr>
<td></td>
<td>Cantaloupe</td>
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<td></td>
<td>Dates, figs</td>
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<td></td>
<td>Dried fruits</td>
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<tr>
<td></td>
<td>Honeydew</td>
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<td></td>
<td>Kiwi</td>
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<tr>
<td></td>
<td>Mangos, 1 medium</td>
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<tr>
<td></td>
<td>Oranges &amp; orange juice</td>
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<tr>
<td></td>
<td>Papaya, 1 cup</td>
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<tr>
<td></td>
<td>Prune juice or 5 prunes</td>
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<tr>
<td></td>
<td>Raisins ¼ c</td>
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<tr>
<td><strong>Vegetables</strong></td>
<td>Acorn Squash</td>
</tr>
<tr>
<td></td>
<td>Artichoke</td>
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<tr>
<td></td>
<td>Bamboo Shoots</td>
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<td></td>
<td>Baked or Refried beans</td>
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<td></td>
<td>Broccoli, 1 cup</td>
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<tr>
<td></td>
<td>Brussels Sprouts</td>
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<td></td>
<td>Chinese cabbage</td>
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<tr>
<td></td>
<td>Carrots, carrot juice</td>
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<tr>
<td></td>
<td>Dried beans &amp; peas</td>
</tr>
<tr>
<td></td>
<td>Greens, except Kale &amp; except mustard greens</td>
</tr>
<tr>
<td></td>
<td>Hubbard Squash</td>
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<tr>
<td></td>
<td>Kohlrabi</td>
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<tr>
<td></td>
<td>Lentils</td>
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<tr>
<td></td>
<td>Legumes</td>
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<tr>
<td></td>
<td>Mushrooms Canned</td>
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<tr>
<td></td>
<td>Parsnips</td>
</tr>
<tr>
<td></td>
<td>Peppers, sweet, red, green</td>
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<tr>
<td></td>
<td>Potatoes, French fries</td>
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<tr>
<td></td>
<td>Pumpkin</td>
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<tr>
<td></td>
<td>Rutabagas</td>
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<tr>
<td></td>
<td>Spinach (cooked)</td>
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<tr>
<td></td>
<td>Sweet potatoes</td>
</tr>
<tr>
<td></td>
<td>Soybeans</td>
</tr>
<tr>
<td></td>
<td>Tomatoes, tomato sauce</td>
</tr>
<tr>
<td></td>
<td>Tomato products</td>
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<tr>
<td></td>
<td>Tomato paste</td>
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<tr>
<td></td>
<td>Vegetable juices</td>
</tr>
<tr>
<td></td>
<td>Winter squash</td>
</tr>
<tr>
<td><strong>Dairy</strong></td>
<td>Milk, Soy Milk</td>
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<tr>
<td></td>
<td>Yogurt</td>
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<tr>
<td></td>
<td>Ice cream</td>
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<tr>
<td><strong>Miscellaneous</strong></td>
<td>Bran / Bran products</td>
</tr>
<tr>
<td></td>
<td>Granola</td>
</tr>
<tr>
<td></td>
<td>Peanut Butter</td>
</tr>
<tr>
<td></td>
<td>Sports Drinks (Gatorade)</td>
</tr>
<tr>
<td></td>
<td>Chocolate</td>
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<tr>
<td></td>
<td>Molasses</td>
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<tr>
<td></td>
<td>Salt substitute with potassium</td>
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<tr>
<td></td>
<td>Salt Free broth</td>
</tr>
<tr>
<td></td>
<td>Seeds and nuts - 2 tbsp</td>
</tr>
<tr>
<td></td>
<td>Trail Mix - 2 tbsp</td>
</tr>
</tbody>
</table>

**Disclaimer:** The above list does not include all foods high in potassium. Portion size also plays a role in the amount of potassium you get from the foods you eat.
### Food type

**Low potassium foods – ½ cup unless specified**

<table>
<thead>
<tr>
<th>Fruits</th>
<th>• Apples</th>
<th>• Peaches</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Berries</td>
<td>• Canned Pears</td>
</tr>
<tr>
<td></td>
<td>• Fruit Cocktail</td>
<td>• Pineapple</td>
</tr>
<tr>
<td></td>
<td>• Grapes</td>
<td>• Plums</td>
</tr>
<tr>
<td></td>
<td>• Lemon</td>
<td>• Watermelon</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Vegetables</th>
<th>• Cabbage</th>
<th>• Green beans</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>• Cauliflower</td>
<td>• Lettuce</td>
</tr>
<tr>
<td></td>
<td>• Cucumber</td>
<td>• Onion</td>
</tr>
<tr>
<td></td>
<td>• Eggplant</td>
<td>• Summer squash</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Sweet peppers</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dairy substitutes</th>
<th>• Nondairy creamers</th>
<th>• Sorbet or Popsicle</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Rice milk (un-enriched)</td>
<td>• Nondairy whipped topping</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Snacks</th>
<th>• Popcorn (unsalted)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Pretzels (unsalted)</td>
</tr>
</tbody>
</table>

**Disclaimer:** The above list does not include all foods low in potassium. Portion size also plays a role in the amount of potassium you get from the foods you eat.
**Medications that may raise your potassium level:**

ACE inhibitors: These drugs treat high blood pressure, heart disease, diabetes, some chronic kidney diseases, migraines, and scleroderma. People who take ACE inhibitors and also take potassium-sparing diuretics, or salt substitutes may be particularly vulnerable to hyperkalemia (too much potassium). A rise in potassium from ACE inhibitors may also be more likely in people with poor kidney function and diabetes. ACE inhibitors include:

- Benazepril (Lotensin)
- Captopril (Capoten)
- Enlapril (Vasotec)
- Fosinopril (Monopril)
- Lisinopril (Zestril)
- Moexipril (Univasc)
- Peridopril (Aceon)
- Ramipril (Altace)
- Trandolapril (Mavik)

- Heparin (used for blood clots)
- Cyclosporine (used to suppress the immune system)
- Trimethoprim and sulfamethoxazole, called Bactrim or Septra (an antibiotic)

**Medications that may lower your potassium level:**

- Thiazide diuretics
  - Hydrochlorothiazide
  - Chlorothiazide (Diuril)
  - Indapamide (Lozol)
  - Metolzaone (Zaroxolyn)

- Loop diuretics
  - Furosemide (Lasix)
  - Bumetanide (Bumex)
3. **Magnesium**

We monitor your magnesium level on each lab draw. Your physician or transplant coordinator will let you know if you need to change your magnesium supplement dosage.

Like potassium, magnesium is another essential mineral. It plays an important role in muscle contraction and nerves.

- Your immunosuppressant medication will cause you to lose magnesium in your urine.
- If the level of magnesium in your blood falls too low, you may experience neurological side effects.
- Low magnesium levels can cause tremors and may even lead to a seizure.
- The intake of foods high in calcium or calcium supplements decrease magnesium absorption. Therefore you need to take calcium supplements and/or dairy products at different times than your magnesium supplements, especially, if you’re having difficulty maintaining a therapeutic magnesium level.

Magnesium is found in a wide variety of foods but unfortunately these foods are usually high in potassium, therefore, we will prescribe a magnesium supplement for you to take every day.

4. **Calcium**

- Long term use of Prednisone can contribute to osteoporosis or thinning of the bones. Therefore, it is important to include foods rich in calcium in your diet and to have your primary physician or internist monitor you regularly for osteoporosis.

Foods high in calcium include low fat dairy products, low sodium sardines and salmon, shrimp, spinach, collard greens, kale, dried beans, and peas. Additional calcium supplements, such as TUMS, are usually indicated at doses of 1000-1200 mg per day. OsCal is not recommended because of its lead content. It is especially important to take calcium supplements if you are unable to tolerate milk or dairy products or if you are a woman who is post-menopausal.

5. **Sugar and Snacks High In Sugar**

- Long term use of immunosuppressants tends to interfere with glucose metabolism and insulin production, and may result in the development of high blood sugar (diabetes). To reduce this risk, moderation in intake of sweets and sugary food is recommended. Limiting sweets can help to control your weight. Reducing sweets and sugar intake has been shown to be helpful in controlling the "moon face" that some people develop when taking Prednisone.
6. **Fluids**
There is no specific long term need for fluid restriction unless you are advised otherwise by a member of the transplant team.

7. **Total Fat and Cholesterol**

Fat and cholesterol should be consumed in moderation because of the increased risk of developing high blood cholesterol due to the long term use of immunosuppressants. High cholesterol may be controlled by diet, exercise, and if necessary, medication. Limit total fat intake; avoid saturated fats (largely found in animal products); avoid transfatty acids, found in stick margarine and products made with partially hydrogenated oils like shortening. Avoid foods containing fat substitutes such as "Olestra", as it may interfere with the absorption of your immunosuppressants.

8. **Vitamins**

We recommend that you take a daily multivitamin and mineral supplement containing about 100% of the USRDA for the most important vitamins and minerals.

9. **Alcoholic Beverages**

Do not ever consume alcoholic beverages or foods containing alcohol. Use of alcohol can cause your liver to become fatty and may result in abnormal liver function. **If you destroy your transplanted liver by using drugs or alcohol, you will not be eligible to receive another liver transplant.**

10. **Dietary Follow Up**

Any further question or concerns regarding your diet may be addressed with your dietitian, transplant physician or outpatient transplant coordinator.

After you are discharged, your liver transplant dietitian will be available for consults over the phone to address questions and concerns regarding your specific nutritional needs.
GLOSSARY OF TERMS

Antibodies: Proteins produced by your white blood cells that help kill foreign invaders such as bacteria, viruses, fungus, and other harmful organisms. Antibodies trigger other white blood cells to destroy these invaders.

Bacteria: Single celled microorganisms that may cause infection.

Bile: Brown liquid made in the liver that helps the body digest fat.

Bile Ducts: Small pathways (like tunnels) within the liver that carry bile into a big duct or passageway called the common bile duct. The common bile duct is connected to your small intestine and carries bile made in the liver to your small intestine. In the small intestine, your bile helps to digest fats.

Bilirubin: A brown pigment (like a dye) that makes your bile and your stool (bowel movements) brown. Bilirubin comes from old red blood cells that have died. It is changed in the liver into a form that colors bile and makes stool brown. When the liver doesn't work the bilirubin is not changed into this form, so the bile and the stool may be pale. The bilirubin that remains unchanged is reabsorbed into the blood and makes the skin and eyes yellow or jaundiced, and the urine dark.

Cell: The basic unit making up all living things. Your body and your new liver are made up of billions cells with many different functions.

Cilia: Small hairs that line your respiratory passageways and help "sweep" out harmful organisms and particles before they reach your lungs.

CMV: Cytomegalovirus, a normally harmless virus that lives in the environment and enters most of our bodies by the time we become adults. We make antibodies to this virus and are not usually affected by it. However, being immunosuppressed can result in the virus causing infections in the liver (CMV hepatitis) or in other organs of the body. These CMV infections can be prevented or cured by certain anti viral meds.

Diarrhea: Watery (formless) bowel movements. Soft, formed stool is not considered diarrhea. Diarrhea can indicate infection in your intestines, an allergy or intolerance to something you are eating, or a side effect of some of your medications.

Enzymes: Proteins made within cells. Liver enzymes are made inside your liver cells and are known as SGOT (AST), SGPT (ALT) and alkaline phosphatase. They are released into your bloodstream when rejection or hepatitis occurs and are measured by blood tests.
**Fungi:** (singular = fungus) Single celled microorganisms somewhat similar to plant cells. Fungi can occur as yeasts (oval shaped) or molds (which have branching arms called hyphae) that spread and invade tissue. Serious fungal infections usually occur soon after transplantation if at all, and often affect the sickest, most debilitated patients.

**Immune System:** Made up of white blood cells that protect your body form foreign invaders such as bacteria, viruses, and fungi, all of which may cause infections. The immune system also attacks "foreign" cells of your transplanted liver, which can result in rejection.

**Immunosuppressant:** A medication that keeps white blood cells from attacking your liver cells and can prevent or reverse rejection. You will take immunosuppressants for the rest of your life to prevent rejection.

**Infection:** Invasion of any system of your body by organisms that do not belong there, such as certain bacteria, viruses and fungi. Infection by these organisms may result in activation of your immune system and cause symptoms such as fever and fatigue. Many symptoms of infection are specific to the area of your body that is affected.

**Jaundice:** Yellow color of the skin (and eyes) which occurs when the liver is unable to change bilirubin into the form that can be excreted in the bile and stool. This bilirubin is reabsorbed by the bloodstream and carried to small blood vessels under the skin where yellow coloring and itching occur.

**Liver Function Tests:** Bilirubin, SGOT, SGPT, alkaline phosphatase and LDH. These blood tests measure proteins or enzymes that, when elevated, can indicate that liver rejection, liver infection or obstruction (blockage) of the bile ducts may be happening.

**Opportunistic Infections:** Infections caused by organisms that normally live within our bodies and do not cause disease or sickness in non-immunosuppressed healthy people. Persons who take anti-rejection medications have weakened immune systems and may become ill from such organisms. These organisms include CMV (cytomegalovirus) and Pneumocystis jerevici.

**Platelets:** Blood cells that help your blood to clot and prevent you from bleeding.

**Pneumocystis jerevici:** A protozoan (similar to a bacteria) found in the environment that may live in our lungs without usually causing illness. However, individuals who take immunosuppressants can develop pneumonia from this organism.

**Pneumonia:** Infection within the lungs.

**Prophylaxis:** A medication or treatment given to prevent a disease or infection before it happens.
Protozoa: The simplest single celled organism in the animal kingdom. Pneumocystis jerevici, the organism that can cause pneumonia in transplant recipients, is a protozoan.

Rejection: Describes the process of your white blood cells attacking "foreign" cells of your transplanted liver and destroying them. When the liver cells are destroyed, enzymes (proteins) from within the cells enter your bloodstream. They can be measured by blood tests. High enzyme levels in the blood may indicate rejection.

Virus: The smallest known microorganism (smaller than a single cell). Viruses need to invade your cells in order to multiply. They cannot reproduce without help from your body’s cells.

RESOURCES

American Liver Foundation: www.liverfoundation.org
30 East 33rd Street, Cedar Grove, NJ 07009; (800) 223-0179

National Kidney Foundation: www.kidney.org
1425 Pompton Avenue, New York, NY 10016; (800)622-9010

United Network for Organ Sharing: www.unos.org
1100 Boulders Parkway, Richmond, VA 23225-8770; (888)-TXINFO-1

One Legacy Transplant Donor Network: www.onelegacy.org
221 South Figueroa Street, Suite 500, Los Angeles, CA 90012; (213) 229-5600
One Legacy is a transplant donor network serving Southern California.

UCLA’s Transplant Website: http://transplants.ucla.edu
After Class: Complete and turn in!!

Date Completed: ____________________________

Patient’s Name: ____________________________

Who will pay medicine co-pay charges to pharmacy? ____________________________

What language(s) does patient prefer to speak? ____________________________

What language(s) do the caregivers prefer to speak? ____________________________

Address patient will live at after discharge to home? ____________________________

Who will stay with patient at home so they are not alone? ____________________________

Who will give patient their medicines? ____________________________

Who will drive patient to all their appointments? ____________________________

Who should we call to give medical information to? ____________________________

Who else can we call if you are not available? ____________________________

Please list ALL the caregivers’ names and phone numbers:

#1 MAIN Caregiver / Relationship ___________________________________________________

Phone(s): ____________________________ □ Cell □ Home □ Work

#2 Caregiver / Relationship ___________________________________________________

Phone(s): ____________________________ □ Cell □ Home □ Work

#3 Caregiver / Relationship ___________________________________________________

Phone(s): ____________________________ □ Cell □ Home □ Work
LIVER TRANSPLANT CLASSES

Fridays: “Life After Transplant”- Please attend at least once!
(Every Friday at noon – 3pm)

Across from Hemodialysis on the 8th floor
Room 8-8234 RRMC; the Longmire Conference room
With a beautiful view of Westwood Village

- If you did not have a liver transplant yet – you MUST RSVP so we can make sure to have enough room!! Have your nurse page me. We get super crowded.
- If your family member just had a liver transplant, I will find you and invite you!!

- EVERY Friday from noon to 3pm – be sure to eat before class
- Please arrive early! Bring your white binders!
- Dress in layers incase it is hot or cold
- Minimum 1 x Mandatory Attendance for families after patient is transplanted
  - However, you can attend as many Fridays as you want
  - For all family members who will be caring for a transplant patient

- RSVP to Oonagh Sankar RN, MRC, CRC, CCCM
  - Transplant Coordinator I; Pager 95-803

Wednesdays: Liver Transplant Support Group
(Every Wednesday)
- Every Wednesday 12 noon – 1:30 pm – please arrive early!
- 200 Medical Plaza Building Suite 206 at UCLA
  - Peggy Stewart, MSW, CSAC (310) 267-9728
  - Shiraz Gewirz, MSW, LCSW (310) 267-9766

Wednesdays: Liver Cancer Information Class
(Every Wednesday)
- Every Wednesday 11 am – 12 noon – please arrive early!
- UCLA 200 Medical Plaza, Suite 347 from 11am-12pm
  - RSVP to Nallely and Nancy (310) 794-3825 or 3208

Monthly: “What to Expect While You Are Awaiting Transplant”
June 21, July 18, August 16, Sept 20, October 18, November 15, December 20
- FROM 10:00AM to 11:30AM – please arrive early!
- Ronald Reagan UCLA Medical Center; B Level Room B130 Auditorium.
- RSVP to 310-794-3320