

UCLA KIDNEY TRANSPLANT PROGRAM
DISCHARGE HANDBOOK

**TAKING CARE OF
YOUR NEW KIDNEY**

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Med Plaza Laboratory

Monday through Friday, 6 am to 7 pm
Suite 145, Lobby
200 Medical Plaza Building

Renal Transplant Clinic

Monday, Wednesday, Thursday, Friday 8 am
Tuesday 7am
Medical Specialties, Suite 365C
Third Floor
200 Medical Plaza Building
310) 206-7662

Park underground off Westwood Boulevard at the Medical Plaza

Saturday and Sunday 8 am
Clinical Research Center
Room 27-066
Center for Health Sciences (main hospital building)
2nd floor, east end of hall
Park in the Visitors Lot off Le Conte Ave.

INTRODUCTION

The Renal Transplant Team

Background

Surgery

INTRODUCTION

Congratulations on receiving your kidney transplant at UCLA. You are among over 1500 patients who have been transplanted at UCLA since 1964.

As the recipient of a transplant, you are the most important part of the transplant team. The responsibility for reporting problems that may affect your transplanted kidney is yours. There is a lot of information you need to learn to help care for your kidney to help it last as long as possible!

The goal after transplant is to have you return to a “new normal”, free of the constraints of dialysis. Over time you will regain strength and energy you probably have not had for a long time. You may return to work or school and resume most of your favorite activities.

The information in this handbook is important to get you started on life with your new kidney. Before you are discharged, your transplant coordinator will carefully review all of this information with you and your significant others. Read this handbook carefully as soon as possible in order to begin preparation for your discharge. Share it with any family members who may assist in your care at home.

The Renal Transplant Team

The Transplant Nephrologist

The transplant nephrologist makes the decisions about your progress and your care. Any specific issues about your case are addressed at daily rounds with all the members of the team.

The Transplant Surgeon

The transplant surgeon performs the operation and takes care of surgical issues that arise after the procedure.

The Transplant Fellow

The transplant fellow is one of the doctors who carries out the orders after consultation with the head of the team.

The Transplant Coordinator

Teaching and discharge planning are the responsibility of the transplant coordinator. Preparation for life with your new kidney involves educating you about the changes in your lifestyle and familiarizing you with your new medications.

The Transplant Social Worker

We recognize that although you may have waited a long time for your new kidney, any change, desired or not, can be hard. The social worker is available to assist you with many different issues including transportation, housing convenient to the hospital, and emotional changes.

The Renal Dietitian

The renal transplant dietitian will instruct you about diet changes before discharge. Although the focus of your diet will change, diet remains an important part of your health and well-being.

While you are hospitalized, ask your nurse to contact any member of the team if you have questions or concerns.

Background

Kidneys for transplant come from two sources, living or cadaver donors. A living donor may be a blood relative or someone who is not a blood relative such as a spouse or longtime friend. The success rates from living donors, related or unrelated, are high. About 92% of living donor kidneys are still working one year after transplant. The majority of kidneys come from cadaver donors - individuals who have chosen to donate their organs in a special set of circumstances called brain death. These kidneys must be relied upon by patients who have no one to donate a kidney to them. Due to improvements in anti-rejection drugs in the last several years, the success rate for transplants from cadavers is now almost as good as for living donor transplants.

Living donor transplantation has the advantage of being a scheduled procedure. Cadaver donor kidneys may become available at any time and a prolonged wait may be required.

At the time you were admitted for transplant, a chest x-ray, an EKG and lab tests were done in preparation for your surgery. The physicians evaluated your current medical status to make sure you had no problems that would have interfered with transplant surgery. Active infection or significant medical problems would have caused your surgery to be canceled. If your lab results indicated that you needed dialysis, it was done before your surgery was performed. Once those few tests were done and all of the preparations were completed, you were taken to the operating room for your surgery.

An important preparation for surgery was receiving the first dose of immunosuppressive, or anti-rejection, drug. The medication is often given just prior to the transplant to quiet your immune system so that your body will not attempt to actively reject your new kidney.

You may have some curiosity about the cadaver kidney. The kidney was carefully evaluated and found safe for transplantation. The gender, age, or race of your kidney will have little or no effect on the outcome of your transplant. Specific information about the donor, other than age and sex, is not shared with the recipient to protect the privacy of the donor and the donor's family. Remember, this generous gift was given by the donor himself who signed his donor card, or by his family who wanted others to benefit from their loved one's healthy kidneys. You may write an anonymous letter to the donor family if you wish and we will ensure that it reaches them.

Surgery

In the operating room, the kidney you received was taken from the ice and cold solution it was stored in and inspected by the transplant surgeon. The kidney was cleaned and kept on ice until it was ready to be put into your body.

At the same time, the team was preparing you for surgery. You were put to sleep by the anesthesiologist. A tube called a Foley catheter was passed into your bladder to allow your urine output to be followed closely during and after surgery. Your skin was scrubbed with an antiseptic solution. A large IV was inserted into the internal jugular vein in your neck to accommodate the large volumes of fluid given during and after surgery. Blood can also be drawn from this line; it will stay in place until close to the time of your discharge. During surgery your heart was monitored, as well as the oxygen level in your blood.

The surgery itself took about two and a half to four hours. If your original kidneys were still in place before transplant surgery, they were not removed. A six to eight inch incision was made on the right or left side of your lower abdomen. The artery and vein of the new kidney were attached to a major artery and vein in the area of your body where the kidney was placed. The ureter, or tube that drains urine from the new kidney to the bladder, was attached to your bladder. Once the doctors determined that good blood flow to the kidney was established, they settled the kidney into your abdomen and closed the opening in your skin with staples.

AFTER SURGERY

Immediately after surgery you were moved to the recovery room to wake up and have the breathing tube removed. You were then taken to the Intensive Care Unit or to a regular room on the transplant floor. The first 12 to 24 hours after surgery were very busy. The nurses checked your vital signs, lab values, urine output and fluid balance frequently and reported their findings to the doctors. Many of the tubes from surgery were still in place; they will be removed one by one over the next few days. You were given extra oxygen to breathe until you were fully awake. A heart monitor was used for the first day after surgery to watch for any sudden changes in your rhythm due to the rapid fluid and electrolyte loss. The catheter remains in your bladder for three to four days after surgery to allow the connection of the donor's ureter into your bladder to heal.

Do not be surprised if your throat feels scratchy, dry or sore for the first few days after surgery. You may even be a little hoarse. This is from the airway tube that was in place in the operating room and should go away quickly.

Because you have had abdominal surgery, you cannot have anything to eat or drink until you are fully awake and there is indication your bowel function is returning to normal. You should have no nausea and be passing gas. By the day after surgery you should be drinking liquids and your diet will be advanced slowly according to what you can tolerate.

We encourage you to get up and walk around as soon as the first day after surgery. It is a good idea to take pain medication to make moving around more comfortable. Regaining your mobility helps to prevent complications like pneumonia that patients can get from lying in bed. Deep breathing and coughing helps, too. You will want to cough while supporting your incision with a pillow to make you feel more comfortable. Ask your nurse to show you how.

POSSIBLE COMPLICATIONS

Delayed Graft Function

Rejection

Infection

Other Possible Complications

Ureteral Leak

High Blood Pressure

Diabetes

Possible Long-Term Complications

Cardiovascular Disease

Bone Disease

Skin Cancer

POSSIBLE COMPLICATIONS

Delayed Graft Function

The donor kidney is placed in solution and packed in ice until all tests are completed and you are ready for transplant. This “shock” and other factors may cause a delay in function of the new kidney. Delayed graft function can last up to a month or two but typically lasts a few days or weeks until the new kidney “wakes up” or “opens up”. During this time you may continue to need dialysis periodically. If soon after surgery there is an indication that you will have delayed graft function, your medication regimen may be altered during the initial time period after your transplant. This may prolong your hospital stay from five or six days to 10 days or longer.

Rejection

Rejection takes place when your body recognizes that your new kidney is a foreign substance and tries to attack it. If you were not taking medication to suppress your immune system, in a very short time your immune system would attack your new kidney until it no longer functioned. The anti-rejection medications that you have now begun taking interfere with your body’s ability to recognize that the kidney is not exactly like you and therefore should prevent rejection.

Sometimes, in spite of the immunosuppressive medication, your immune system rallies to attack your kidney. This is called a rejection **episode**. If a rejection episode takes place, it usually happens in the first few months after your transplant, but it can happen at any time. This is called an “episode” because most of the time that is just what it is, an episode. Though it is preferable not to have rejection episodes at all, if they do occur they can almost always be recognized and treated.

In order to monitor yourself for signs and symptoms of rejection, follow this schedule at home:

- ◇ **Take your temperature four times a day, before each meal and at bedtime.**
- ◇ **Take your blood pressure four times a day, before each meal and at bedtime.**
- ◇ **Weigh yourself every morning at about the same time with the same amount of clothing.**
- ◇ **Measure all of your urine every time you urinate.**

Record all of this information in the “Daily Log” in the back of this book and bring it to clinic with you every time. You will be instructed by the clinic staff how long to continue monitoring.

Rejection can usually be treated and lasting damage to the kidney prevented if it is recognized and treated early.

If you have any of the following signs and symptoms of rejection, call immediately, day or night 310) 825-6836. During regular business hours, Monday through Friday, 8 am to 5 pm, you will reach the office and speak to one of the coordinators. Nights, holidays and weekends, you will reach the answering service and you will be put in touch with the transplant coordinator or renal fellow on call. **Please do not page after office hours for non-emergencies.** Medication refills, appointments and lab results should be dealt with during business hours only.

Signs and Symptoms of Rejection

- ◇ **Temperature above 101°F or 38°C**
- ◇ **Flu-like symptoms: an achy feeling; sensitivity to light; fatigue; nausea and vomiting**
- ◇ **Weight gain of more than 5 pounds or 2 kilograms in 2 days, swelling of the hands and feet and face, feeling like you need dialysis, shortness of breath, a noticeable decrease in your urine output**
- ◇ **An aching pain or tenderness in your new kidney that does not go away**

When you experience any of these symptoms and notify the transplant team, you will be checked further for evidence of rejection. Tests will be done such as a creatinine level (a rise in your creatinine level along with other signs may indicate rejection) or a biopsy. The doctors may decide to perform a biopsy if they suspect rejection and want a definite diagnosis. Usually the decision to perform a biopsy is made during a clinic visit and the biopsy is completed without delay. If a **fine needle biopsy** technique is performed, it takes place in the clinic and you will be discharged to home, probably to return the next day for the results and further treatment if necessary. A **core biopsy** is done with ultrasound guidance in the ultrasound department of the hospital. After completion, you will remain on bedrest in the outpatient department until early evening, then you will need somebody to drive you home. When the biopsy results are available, further decisions about your course of treatment will be made.

Infection

To prevent rejection, you are given medications to suppress your immune system. Initially the doses of these medications are quite large, so you are somewhat more

susceptible to infection than you were before the transplant. You will remain slightly more likely to get an infection for the lifetime of the transplant but the risk will decrease after the first few months.

During the early period, you should avoid small-enclosed spaces crowded with many people. You will have to avoid church or a movie theater during crowded times and air travel until you are told the initial risk has passed. Although these restrictions are inconvenient at a time when you feel so well and have new independence, it is important to avoid situations that expose you to an infection that may cause serious problems for your kidney. Being exposed to others with an infection or catching an infection may stimulate your body to have a rejection episode. When your body's defense system rallies to fight off any foreign invader, it might not be able to tell the difference between that invader and your new kidney. For this reason, **it is best to notify us when you are not feeling well with symptoms similar to those of rejection, even if everyone around you is sick.**

A mask is not necessary. Wash your hands frequently.

Signs and Symptoms of an Infection

- ◇ **Temperature above 101° F or 38° C**
- ◇ **Shaking chills**
- ◇ **Drainage from your incision line. Straw-colored, clear fluid may be normal and continue for a few weeks after surgery; any pus-colored drainage or redness should be reported**
- ◇ **Burning with urination or a change in color or odor of your urine**
- ◇ **A cough that will not go away, shortness of breath**
- ◇ **A severe headache**

Other Possible Complications

Ureteral Leak

In a very small percentage of patients, the connection between the drainage tube from your new kidney (ureter) and your bladder does not heal properly and urine leaks out and collects around the new kidney. This is an acute problem, usually marked by sudden onset of severe pain which requires an immediate call to the transplant team. This problem usually requires admission and surgical correction. This problem is not always preventable, but voiding every two hours for several weeks after surgery until the ureter/bladder connection heals will avoid stretching the stitch line of the connection.

High Blood Pressure

Normal blood pressures are below 140/90. High blood pressure has many causes but may indicate a change in your kidney function or a side effect of a medication. Please make us aware of elevated blood pressure (systolic > 170 **or** diastolic > 110) so we can determine the cause and treat it accordingly.

Diabetes

The diabetic patient is always at higher risk of complications. It is especially important for diabetic patients to adhere to the team's guidelines concerning weight, temperature, blood sugar levels and skin care after transplant.

Although a transplant will restore kidney function that may have been lost from diabetes, it will not cure your diabetes. Many of the medications you will be taking can change your glucose tolerance, especially in the larger doses given soon after transplant. It is essential that you maintain close supervision of your blood sugars and record them for the team to review so your treatment can be adjusted to your individual needs. A glucometer for home testing of your blood sugars is recommended. A diabetes educator is available in the hospital and clinic for you to learn more about managing your diabetes.

Possible Long-Term Complications

Cardiovascular Disease

Cardiovascular disease, including heart attacks and strokes, are the most common long-term complication after transplantation. It is the most common cause of death in transplant recipients. Risk factors for cardiovascular disease include the following:

- history of vascular or blood vessel disease
- advanced age
- male sex
- diabetes
- cigarette smoking
- hypertension
- high blood cholesterol levels
- family history of heart disease
- obesity
- physical inactivity

Although some risk factors cannot be changed, certain risk factors can be modified with diet, exercise and life-style changes. Weight control and exercise can be effective in lowering blood cholesterol, blood pressure and in helping to control blood sugar in people with diabetes. Medications can also be used in conjunction with diet and exercise to lower blood cholesterol levels. Cigarette smoking is a strong risk factor for heart disease - if you smoke, right now is the ideal time to quit. You can speak with your physician about the best way to accomplish your goal.

By modifying certain risk factors (quitting smoking, keeping your weight in a reasonable range for your height, getting regular exercise, controlling your cholesterol) your risk for cardiovascular disease can be greatly reduced.

Bone Disease

About 15% of patients develop bone disease, affecting the hips and other weight-bearing bones, in the first three years after transplant. The major contributing factor is thought to be steroids. Joint pain, specifically in the hips, knees and shoulders may predate any x-ray changes by several months.

Skin Cancer

In kidney transplant patients, the incidence of skin cancer is 20% higher on sun-exposed areas and 7% higher on non-sun-exposed areas than in non-immunosuppressed people. The incidence seems to increase with the time after transplant. Dermatology follow-up should be part of all transplant patients' long-term

care. Excessive sun exposure should be avoided and protective clothing worn. Sunscreen should always be worn when outdoors.

TAKING CARE OF YOURSELF

Clinic Visits and Lab Tests

Daily Living

Wound Care

Activity

Diet

Returning to Work or School

Drinking Water

Oral Hygiene

Sun Exposure

Pets

Gardening

Travel

TAKING CARE OF YOURSELF

Clinic Visits and Lab Tests

Med Plaza Lab

Monday through Friday, 6 am to 7 pm

Suite 145, Lobby

200 Medical Plaza

Renal Transplant Clinic

Monday, Wednesday, Thursday, Friday 8 am

Tuesday 7am

Medical Specialties, Suite 365C

Third Floor

200 Medical Plaza

(310) 794-1757

Park underground off Westwood Boulevard at the Medical Plaza

Saturday and Sunday 8 am

Clinical Research Center

Room 27-066

Center for Health Sciences (main hospital building)

2nd floor, east end of hall

Park in the Visitors Lot off Le Conte Ave.

When you are discharged from the hospital, you will be required to come for frequent clinic visits to enable the doctors to review your lab studies, adjust your medications, and monitor you for signs and symptoms of rejection and infection. These visits are crucial to the long-term success of your transplant. The schedule for visits varies according to each individual's course, but without complications you can expect to visit clinic three times a week for the first two or three weeks and twice a week for the following two or three weeks. After this initial period if you are stable and have had no major complications, you will be referred back to your nephrologist with a letter from the team reviewing your course. You will still see our team on a periodic basis and of course you can always call us at any time for questions.

In order to help us finish clinic on time each day, **please arrive in the lab between six and six-thirty in the morning for your blood to be drawn.** You may eat breakfast before having your blood drawn unless otherwise instructed but **never take your cyclosporine (Neoral®) or tacrolimus (Prograf®) until after your blood has been drawn.** Labs are ordered by computer so you need only to arrive and give the person at the lab desk your name. Once your blood has been drawn, you may eat breakfast if you have not already done so and **take your pills.** **Arrive in clinic at 8 am** (Tuesdays at 7 am) to sign in. You will be seen by the doctor in the order you had your blood drawn in the lab, as soon as possible after the results are available. Lab results take about two hours; if you arrive late for your blood draw, you will have a longer wait to be seen. Long-term patients, once given permission, may have blood drawn the day before a scheduled appointment to avoid getting up early.

Always bring your medication schedule and your handbook with you to clinic. The clinic staff will check your vital signs and review your list of medicines. Your transplant coordinator will review your at-home records to monitor you for rejection and answer any questions you may have. The nephrologist will perform a physical exam, check you for rejection and adjust your medications if necessary. Please request prescriptions from the coordinator at a clinic visit if you need them. On clinic days, plan to be here for a few hours. Before leaving clinic, stop at the front desk to make an appointment for your next visit.

We know clinic visits can be long and tiring. The system allows the team to examine patients who have problems with their kidney function first, minimizing damage to their transplants, but this may cause a longer wait for you at times.

You will be given different instructions if you need to come to clinic on a weekend or holiday. On these days you are seen in the Clinical Research Center located at the east end of the second floor of the main hospital, Room #27-066. You will arrive in the CRC at 8 am where your blood will be drawn and the doctor will see you.

Long-term patients and Kaiser patients can bring lab results from local sources that have been done as an out-patient.

Your clinic visits are very important to the outcome of your transplant. Please do not fail to continue with the necessary follow-up.

Daily Living

Now that you have had a transplant, your strength and energy should increase. During your recovery phase the following guidelines will help you take advantage of your newfound well-being.

If you anticipate the need for a nurse to visit you at home after discharge, discuss this with the transplant coordinator. She can help you make this decision and arrange for a nurse to come to your house.

Wound Care

You may shower, even with your staples in place. No dressing is needed over your incision, but a light gauze may be applied if your staples are irritated by your clothing. Staples will be removed in clinic about two weeks after surgery. Steri-strips will then be applied which come off eventually on their own. Do not swim or sit in a bath tub or hot tub until your incision is completely healed and the doctor gives you permission to do so.

Activity

Upon leaving the hospital, begin a daily routine of walking for exercise. Any other exercise is too strenuous just after discharge but walking will improve and maintain your health. Walking up and down stairs is permitted.

Avoid lifting heavy objects (over 10-15 lb.) or straining your abdominal muscles for six weeks. This includes not lifting children or grandchildren, grocery bags or laundry baskets, and not mowing the lawn or vacuuming. Lifting and straining may result in the opening of your wound or the formation of a hernia which usually requires surgical repair.

Driving is permitted three weeks after surgery. Until then the team feels it is unsafe for you to be in a situation where you may not be able to react quickly because of pain or medications.

Sexual intercourse is permitted three weeks after surgery or when you feel comfortable. Women should avoid getting pregnant for at least one year and only then after discussion with the doctor. **Birth control is necessary because the ability to become pregnant, which may have been lost on dialysis, will return quickly.**

Try to avoid people who are sick with colds or flu. While we know this is not possible all the time, stay away from situations where you will be in small enclosed spaces with large groups of people. Wash your hands frequently. Do not share utensils, drinking

glasses or toothbrushes. If you are exposed to measles, chicken pox or hepatitis, notify your transplant team. A mask is generally not necessary.

Diet

Diet plays an important role in maintaining your health and in preventing and controlling some of the side effects of your medications. The optimal function of your new kidney is also influenced by what you eat. Although many of the limitations you may have been advised to follow before transplantation no longer apply, **diet is just as important as before you received your transplant - only different.** Individual needs vary, however, the main nutritional goals after transplantation are controlling blood cholesterol levels and avoiding excessive weight gain. A regular exercise program enhances the achievement of these goals. The transplant dietitian will be reviewing all of your new dietary guidelines with you before you are discharged from the hospital at which time you will be receiving additional written materials about your diet. The dietitian will also be available to assist you on an out-patient basis as needed.

Returning to Work or School

You will be given permission to return to work or school when your condition is stable. Generally, a convenient time is when your appointments have lessened in frequency, at about two to three months. Your coordinator or social worker will be glad to help with disability forms or letters to employers or school; you may request these in the hospital or clinic.

Drinking Water

You may drink tap water if it has been treated at a water purification plant and chlorinated. You should not drink well water that has not been treated. Bottled water or a water purification system at home may be used.

Oral Hygiene

Excellent oral hygiene is very important for all kidney transplant recipients in order to prevent infection and to reduce potential medication side effects in your mouth. Good oral hygiene reduces inflammation of the gums and decreases the risk of infection. You should always use a soft-bristled toothbrush. Cleaning aids such as dental floss and interdental cleaners should also be used. Electric toothbrushes are helpful for some individuals. Over-the-counter mouthrinses can be used to aid in your oral hygiene and give you a “fresh” feeling. Be aware that many mouthrinses contain alcohol and may cause oral dryness. Prescription mouthrinses may be indicated for specific problems and can be prescribed by your dentist or periodontist.

Some of your transplant medications can cause or aggravate gum problems. Specifically, some medications can cause overgrowth of the gums which may become painful and/or unsightly. The best known control for these gum enlargement problems is good oral hygiene (both at home and professionally at your dentist). Gum enlargement is a problem because it can lead to pain, difficulty eating, unsightly appearance and more gum/dental problems because it interferes with your ability to perform good oral hygiene. If you develop gum overgrowth problems, it can be treated by your dentist or periodontist.

As soon as the transplant team approves, you should make an appointment to see your dentist for a complete oral exam including x-rays. Your dentist will evaluate your dental health and hygiene, perform a professional cleaning and make recommendations for any necessary treatment to eliminate dental disease. Seeing your dentist every four to six months for an exam and dental cleanings can be very helpful in preventing oral problems or detecting them at an early stage when they are easier to manage. In order to prevent oral bacteria from infecting your transplanted kidney, **antibiotics must be taken before and after each dental visit**. The transplant office or your dentist can provide you with a prescription.

Sun Exposure

Because of the suppression of your immune system by the combination of transplant drugs, you are at a greater risk for certain types of skin cancers. This is especially true for fair-skinned people. You must always wear sunscreen (at least SPF 15) when outside. Protect yourself with long sleeves and long pants. A hat is a good idea. Report any new lesions or changes in your skin immediately.

Pets

Contact with dogs and cats is safe. It is unsafe, however, for you to clean cat litter after transplant. If you must do so, wear heavy gloves and a mask to protect you from the microorganisms in cat feces. Birds and bird droppings should also be avoided. Handling turtles, their water or their tank is also unsafe because of the risk of salmonella infection. Wash your hands after touching your pets.

Gardening

Always wear shoes and socks and gloves when working in the garden or yard. Soil can contain bacteria and fungi that can cause serious infection in transplant patients. Have someone else change the water of indoor cut flowers; wear gloves when working with indoor plants. Wear a mask for heavy, dusty work.

Travel

When traveling, always keep your medications with you. If your luggage is lost, you don't want your medicine to be lost, too! It is very hard to replace medication when you are away from home. You should not be without medication, even for one dose.

Medications

Cyclosporine (Neoralâ)

Mycophenolate Mofetil (CellCeptâ)

Prednisone

Tacrolimus (Prografâ)

**Trimethoprim/Sulfamethoxazole
(Bactrim, Septra, Cotrimoxazole)**

Acyclovir (Zovirax)

**Anti-fungal Agents: Mycostatinâ ,
Nystatin, Mycelexâ , Diflucanâ**

Diltiazem (Cardizem CDâ , Dilacor XRâ)

**Ulcer Prevention: Zantacâ , Pepcidâ ,
Prilosecâ , Tagametâ , Carafateâ**

**Cholesterol Lowering Agents:
Lovastatin, Pravastatin, Pravacholâ ,
Mevacorâ , Lopidâ**

MEDICATIONS

The life of your kidney depends on the medications taken to suppress your immune system. For as long as your kidney lasts, **you will need to take your medications exactly as prescribed**; altering your schedule may allow rejection to creep in and damage your kidney over time. Even if your kidney lasts ten or fifteen years, or longer, your body will not accept the kidney without suppression of your immune system by the medications. Your anti-rejection medications work together, each one targeting a different part of the immune system. If you stop taking your pills, even after years of success with your transplant, your body will reject your kidney. **Never allow yourself to run out of medication.**

Now that you have your new kidney, we want to help you do everything possible to protect it. From now on **do not take any medications other than those drugs prescribed by your transplant team.** Other medications can affect the way your transplant medications are absorbed by your body, interfering with them and causing damage to your kidney. **Check with a member of the transplant team before taking any new drug, including non-prescription cough, cold and allergy remedies, and antacids. Other products to consult with the team before taking are herbal remedies, vitamins and laxatives.** Even some common prescription drugs for blood pressure and other conditions can interfere with the action of your anti-rejection drugs. Any suggested medication adjustments, additions or discontinuations by another doctor should be cleared by the transplant team or your primary physician.

For pain, you should take plain or extra-strength acetaminophen (Tylenol®). Remember not to take this for a fever or pain in your new kidney; these could be signals you are having a rejection episode. **Do not take aspirin or ibuprofen (Advil®, Motrin®, Nuprin®) or non-steroidal anti-inflammatory drugs of any kind (Naprosyn®, Aleve®, naproxen sodium, indomethacin, Feldene®, Butazolidin®, Toradol®, Orudis®) without consulting the transplant team.**

If you experience drug side effects, they will be most noticeable during the first year after your transplant when your drug levels are the highest. As the dosages of your medicines decrease over time, the side effects should fade. Side effects experienced vary from patient to patient and it may be possible to minimize them by dose adjustments. Generally, the sense of well-being associated with a successful organ transplant far outweighs the medication-induced side effects. Be sure to discuss any medication issues with the team in clinic at the time of a visit.

You will be given a schedule of your medications and instructions at the time of discharge from the hospital. At first, it may seem like you are taking many medications - and you are, maybe 12 or 15 different medicines a day. Some of the pills are to

prevent infection or to control your blood pressure or phosphorus levels and probably will only be taken for a short time. **Always bring your schedule with you to be reviewed by the doctor when you come to clinic.** Necessary changes can be made to your schedule in clinic, avoiding dangerous medication errors that can occur from trying to remember dose changes till you get home.

Cyclosporine (Neoral®)

Neoral is one of the most important anti-rejection medications you will be taking. The great success of organ transplantation in the last decade is largely due to its discovery. This drug needs to be maintained at a specific level in your blood; enough to protect your kidney from rejection but not so much that the amount is toxic. In order for us to accurately measure your cyclosporine level, you **must** take your medication at the prescribed times and have your blood drawn at about the same time every clinic visit. **Do not take your Neoral before having your blood drawn on days you come to clinic, but bring your pills with you so you can take them after your blood is drawn.** Often during the first few months after transplant, your cyclosporine (Neoral®) dose will be increased or decreased according to your blood level. Never adjust the dose on your own.

This medication comes in 100 mg and 25 mg gel caps in foil wrappers which may be opened up to a week before the dose is to be taken. Neoral® should be stored at room temperature. Because of the strong odor, you may wish to open the package at least 10 minutes before taking your pills.

Most of the common side effects are noticed when the cyclosporine level is too high. These usually respond to a reduction in dose: headache, tremor, elevated blood pressure, flushing of the face or nausea or vomiting about 15 minutes after the dose. Another side effect is high blood cholesterol. Some people, especially women, notice an increase in hair growth, usually on the face, arms and back.

Mycophenolate Mofetil (CellCept®)

Mycophenolate is used in combination with cyclosporine and prednisone, two commonly used medications that also prevent kidney rejection. Mycophenolate inhibits the multiplication of white blood cells in order to prevent harm to the new kidney. The drug should be taken twice a day on the schedule you have been given, unless you have been directed otherwise by the doctor.

The medication comes in 250 mg pink and blue capsules. The usual dose is 1000 mg (4 pills) twice a day but you will be told exactly what dose to take. Store mycophenolate at room temperature in a closed container. The capsules should not be opened or crushed.

Occasional side effects include gas, bloating, stomach pain, nausea, vomiting, heartburn or diarrhea. Other side effects, as with all immunosuppressive medications, are increased susceptibility to infection, lymphomas, skin cancers. If you experience any of these problems, let the doctor know immediately so the medication can be adjusted.

Prednisone

Prednisone is a corticosteroid which is similar to hormones normally found in the body that maintain blood sugar, blood pressure and the ability to respond to stress. This medication decreases the body's ability to respond once the new kidney is recognized as being foreign. You will probably take this medication to prevent rejection for as long as your kidney lasts.

This medication is available in 5 mg tablets and will be taken once or twice a day with food. Initially after transplant, your dose will be high but you will be given a tapering schedule to decrease your dose over time. **You must follow this schedule exactly.** If you miss a dose, take it as soon as you remember. If you miss more than one dose, call the transplant team for instructions.

Large intravenous doses of steroids may be given to treat rejection episodes. Rejection treatment or a "pulse" of steroids is usually given daily for three to five days as an outpatient and the drug is then tapered back down to pre-pulse doses.

The side effects of prednisone may be the most difficult of all your medications. Commonly, these include elevated blood cholesterol, increased appetite, nausea and vomiting and an exaggeration of your normal moods. Gastrointestinal side effects may range from mild heartburn to ulcers; always taking steroids with food can minimize these problems. Other side effects may be changes in physical appearance such as a rounder appearance of the face, increased fat deposits at the waist and the back of the neck, acne and development of stretch marks. The side effects will improve as your dose of prednisone is tapered. It is important to discuss your concerns with your family as well as the transplant team. Also remember the social worker is available for support in the transplant clinic.

Long term side effects including cataracts, muscle weakness, and osteoporosis or bone weakness may occur after you have been taking prednisone for months or years. In some cases steroids may be discontinued after a long period of stable kidney function but never discontinue them without your doctor's approval.

Tacrolimus (Prograf®)

Tacrolimus is one of the newer transplant immunosuppressive drugs, available in the United States since April of 1995. If you are prescribed this drug, you are taking it instead of cyclosporine (Neoral®). As with other immunosuppressants, you are taking

tacrolimus to quiet your immune system so that your body will not attack your new kidney. You will take tacrolimus for as long as your kidney continues functioning.

Tacrolimus is available in 1 mg and 5 mg capsules. It is taken twice a day, 12 hours apart, exactly as prescribed. The level of Tacrolimus in your blood will be measured at each clinic visit so **it is important not to take your tacrolimus until after your blood is drawn on clinic days, but bring your pills with you so you can take your dose as soon as your blood is drawn.** The blood levels help the transplant physician adjust your dose to the correct amount for you.

Side effects you may encounter with tacrolimus include hand tremors, tingling in the hands or feet, headaches, elevated blood pressure, nausea or vomiting. Other side effects we will be watching for are high blood sugar, high blood pressure and kidney problems. Any side effects usually diminish as the dose of tacrolimus is decreased in the months after your transplant.

Trimethoprim/sulfamethoxazole (Septra , Bactrim , cotrimoxazole)

This antibiotic is used in the initial three month period after transplant when patients are more susceptible to infection. You will take this medicine to prevent pneumonia and certain other infections. Treatment with this medicine may be continued longer or restarted if you are treated for rejection.

This medication is given to you once a day as a single strength (SS) tablet. Take it on an empty stomach for the best blood absorption. Also drink at least two quarts of water daily while on this medicine to maintain good urine flow.

Side effects are uncommon but may include headache, dizziness, nausea, vomiting, diarrhea and skin rash.

Acyclovir (Zovirax)

This antiviral drug is used initially after transplant when patients are more susceptible to viral infections or outbreaks of previously acquired viral infections of the herpes virus family (herpes simplex, CMV, chicken pox and shingles). You will take this medicine for the first three months after transplant. Treatment with this medication may be continued longer or restarted if you are treated for rejection.

Acyclovir is an 800 mg blue pill that can be broken in half if it is too large to swallow. Your dose may change as your kidney function gets better and will eventually be four to five times a day.

Side effects include tiredness, headache or nausea, low white blood cell count, low platelet count and anemia.

Antifungal drugs: Mycostatin, Nystatin, Mycelex, Diflucan

You will take one of these drugs to prevent fungal infections in the first month after transplant. Mycostatin or Nystatin are supplied as a liquid. Mycelex is a lozenge which dissolves in your mouth, Diflucan is a pill. Fungal infections are often evident as white plaque on the tongue or inside of the mouth or as a constant burning sensation in your esophagus.

A measured amount of Mycostatin or Nystatin is drawn up into a syringe and squirted into your mouth after meals and at bedtime. Swish the medication around so all areas of your mouth are covered, then swallow. Mycelex is a lozenge that must be dissolved in your mouth after meals and at bedtime, not chewed or swallowed. Diflucan is a pill taken once a day. You will take one of these medications for the first month to six weeks after transplant but it may be continued longer or restarted if you are treated for rejection.

Side effects are rare but the taste of the liquid is unpleasant to many people.

Diltiazem (Cardizem, Dilacor XR)

Diltiazem is in the family of medications known as calcium channel blockers. It is being given to you after transplant because of its property of slowing the metabolism of cyclosporine by your liver, allowing you to take a slightly lower daily cyclosporine dose. You will take one of these two-tone blue, 180 mg pills once a day. If for any reason this medication is stopped or if the dose is changed, you will need to have your cyclosporine level checked in a few days to make sure you are still absorbing enough cyclosporine to protect your kidney.

Ulcer Prevention: Zantac, Pepcid, Prilosec, Tagamet, Carafate

Because of the many medications you are taking, especially Prednisone, you are at risk of developing stomach irritation or ulcers. You will take one of these drugs until your prednisone dose is much lower and you have experienced no stomach irritation.

Although some of these drugs are available over the counter, several of these drugs may affect your cyclosporine level, so do not take any of them without consulting the transplant team.

Cholesterol Lowering Agents: Lovastatin, Pravastatin, Pravachol, Mevacor, Lipid

Treatment with lipid-altering agents is considered a part of the multiple risk factor intervention for individuals at increased risk of hypercholesterolemia. These individuals include transplant patients on steroids with elevated cholesterol levels.

If you are prescribed one of these medications, you will be started on a small dose at bedtime. This dose may be increased later if you tolerate the drug well. The most common side effect of the drug is muscle pain and weakness. You should notify the transplant team if you experience this side effect.

You may be on other medications for your particular medical condition. All of the medications the team wants you to take currently will be on your medication list at discharge. You were probably taking several medications at home before your transplant. Put all of your old medications aside (you will still have your pills if the team puts you back on an old medicine) and do not take them. If you have any questions about those medications, ask your coordinator.

Some of each of your medications will be dispensed to you before leaving the hospital. If your insurance company restricts where you can obtain your medication, you will be provided with a small supply of medications to last a few days. You will also receive prescriptions to take to your designated pharmacy for larger quantities. Unrestricted insurance coverage will allow us to provide you with a 30-day supply of medications. Refills can be obtained at the UCLA Outpatient Pharmacy but if you prefer, your coordinator can give you prescriptions to take to a pharmacy convenient to your home. A list of mail order pharmacies that can fill prescriptions and deliver them to your home can be provided upon your request.

It is your responsibility as a patient to be informed about your own insurance coverage. If you are eligible for Medicare, your **immunosuppressive medications only** are 100% covered for the first three years after transplant. All other medications are not covered by Medicare and will need to be obtained with a supplementary insurance or by paying cash. During the first three years after your transplant is a good time to explore the options for paying for your immunosuppressive medications when you are no longer covered by Medicare. The transplant social worker and financial counselor can be a great deal of help in providing resources. It is important to consult them early, long before your Medicare expires or you lose medication coverage. You may also want to discuss financial difficulty obtaining drugs with your doctor. Adjustments may be able to be made without endangering your transplant. However uncomfortable it may be to discuss your financial situation with others, remember, you do not want not lose your transplanted kidney.

**CALL THE TRANSPLANT TEAM
(310) 825-6836**

Signs and Symptoms of Rejection

- **Temperature above 101°F or 38°C**
- **Flu-like symptoms: aching in your shoulders or your back; sensitivity to light; fatigue; nausea and vomiting**
- **Weight gain of more than 5 pounds or 2 kilograms in 2 days, swelling of the hands and feet and face, or a feeling like you need dialysis, a noticeable decrease in your urine output**
- **An aching pain or tenderness in your new kidney that does not go away**

Signs and Symptoms of an Infection

- **Temperature above 101° F or 38° C.**
- **Drainage from your incision line. Straw-colored, clear fluid may be normal and continue for a few weeks after surgery; any pus-colored drainage or redness should be reported**
- **Burning with urination or a change in color or odor of your urine**
- **A cough that will not go away**

Blood pressure systolic greater than 170/diastolic greater than 110

Blood sugar greater than 400 if you are diabetic

Any bleeding in your urine, stool, vomiting blood, nosebleeds or gums bleeding

Date ___/___/___

	Morning	Noon	Evening	Bedtime
Weight	lb/kg			
Temperature	°			°
Blood Pressure	/	/	/	/
BS / Insulin	/	/	/	/
Urine Output	cc	cc	cc	cc
cc	cc	cc	cc	24 HR Total
cc	cc	cc	cc	cc

Date ___/___/___

	Morning	Noon	Evening	Bedtime
Weight	lb/kg			
Temperature	°			°
Blood Pressure	/	/	/	/
BS / Insulin	/	/	/	/
Urine Output	cc	cc	cc	cc
cc	cc	cc	cc	24 HR Total
cc	cc	cc	cc	cc

DEFINITION OF TERMS

Antibody	part of the immune system that helps the body fight infection and foreign substances
Antigen	the “marker” that stimulates antibody production, found in every cell on the surface of your new kidney
Bacteria	organisms that can cause infection
Bladder	part of the urinary tract that receives urine and stores it until urination
Cadaveric Donor	an individual who has been declared brain dead of causes that do not affect kidney function
CMV	cytomegalovirus, a normally harmless virus that lives in the environment, immunosuppressed patients can become sick with CMV infection because of the weakened state of the immune system; it is prevented and treated by drugs such as Ganciclovir and Acyclovir
Creatinine	a product of muscle metabolism; creatinine level is a number that serves as a good indicator of kidney function
Crossmatch	a test of compatibility between the potential donor’s and prospective recipient’s blood
Cyclosporine	the active ingredient in Neoral® with unique immunosuppressive characteristics
Delayed Graft Function	reversible kidney damage resulting from the “shock” your new kidney experienced during storage
Dialysis	the process of cleansing and achieving chemical balance in the blood of patients whose kidneys have failed; hemodialysis or peritoneal dialysis

Diarrhea	watery, formless bowel movements; diarrhea can indicate infection in your intestines or a side effect of a medication
	Diastolic measures the force of the heart muscle at rest, when it expands and fills with blood
Endotracheal tube	an airway tube inserted through the mouth into your windpipe to help you breathe during surgery
Fungi	microorganisms which can occur as yeasts or molds that spread and infect tissue
Graft	your new kidney
Hypertension	high blood pressure
Immune system	made up of white blood cells that protect your body from foreign invaders such as bacteria, viruses and fungi; also attacks “foreign cells” of your transplanted kidney
Immunosuppressive medication	a drug that is taken every day to help prevent the recipient’s own immune system from struggling against and rejecting the new kidney
Kidney	one of the two bean-shaped organs located on both sides of the spine, just above the waist which rid the body of waste materials and maintain fluid balance through the production of urine
Nephrectomy	the surgical removal of a kidney
Nephrologist	a physician specializing in the diagnosis and treatment of kidney disease
Noncompliance	failure to take medication as prescribed or making decisions that may shorten the life of the transplant
Opportunistic Infection	infection which may attack a transplant recipient because of a weakened immune system; normal healthy individuals would probably not become sick from contact with these same organisms

Pneumonia	a general term for an infection within the lungs, can be caused by bacteria, virus or fungus
Prednisone	a steroid taken by most transplant recipients to prevent rejection
Prophylaxis	a medication or treatment given to prevent a disease or infection from occurring
Rejection	process where your immune system responds to the “foreign” cells of your new kidney, producing white blood cells which attack and destroy; monitored by serial creatinine levels in clinic and by observing for clinical signs and symptoms: fever, weight gain and fluid retention, flu-like symptoms, tenderness in the transplanted kidney
Renal	having to do with, or referring to, the kidneys
Systolic	the top blood pressure number which measures the force of contraction of the heart muscle as blood is pumped out of the heart’s chambers
Tissue Typing	a blood test done prior to transplant to evaluate the closeness of the tissue match between organ donor and recipient
Ureter	one of two tubes that carry urine from the kidney to the bladder
Urethra	the tube from the bladder through which urine flows out of the body
Urinary tract	the body system made up of the kidneys, ureters, bladder and urethra involving the production, transport, storing and elimination of urine