

# Kidney Transplant

*Post-Transplant Manual*



FHTransplant.com

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# Office Hours and Contact Information

Our office hours are Monday through Thursday from 6:30 am to 4:30 pm, and Friday from 6:30 am until 2:30 pm. We are closed on weekends and holidays.

## Important Contact Information

**Call Nurse Coordinator during normal business hours:**

**After-hours emergency number:**

(407) 303-2474

**FAX number:**

(407) 303-0679

**Florida Hospital Community Pharmacy:**

(407) 303-2513 or (407) 303-2559

**Pharmacy technicians:**

(407) 303-2731

**Florida Urology Associates**

(407) 992-4361



# Transforming Lives for More Than 40 Years

The Florida Hospital Transplant Institute, a not-for-profit organization, has transformed lives for more than 40 years through personalized care of those awaiting the gift of life. Established in 1973, our program offers transplantation services, patient and professional education and dedication to those in need of lifesaving organ transplants.

## Your Transplant Team

### Medical Director of Transplant Services

As well as overseeing all aspects of patient care, the medical director of transplant services also manages research and medical-related issues within the program.

### Transplant Physician/ Nephrologist

The transplant physician or nephrologist specializes in the treatment of kidney disease and transplantation. This individual provides pre- and post-transplant care at the hospital and transplant clinic. The nephrologist will request testing, oversee treatment and adjust medications as necessary.

### Transplant Surgeon

The transplant surgeon performs the operation. You will work together to identify any possible complications that may affect your recovery. The surgeon is involved in the evaluation process as well as post-transplant care.

### Transplant Nurse Practitioner/ Physician Assistant

The nurse practitioner/physician assistant aid the surgeon with your care throughout the transplant process.



## Living Donor Coordinator

The Living Donor Coordinator will guide the donor through the process of living donation. The coordinator will set up all appointments and will be with the donor through the entire process.

## Social Worker

The social worker refers you to community agencies that can address the changes and difficulties you and your family may experience. Connecting you with others who have experienced transplantation firsthand is another aspect of this role. One resource is the New Life Transplant Group, which meets monthly.

## Financial Coordinator

Your coordinator can provide specific information regarding the costs of transplantation. You will meet with the financial coordinator to assess financial needs, identify options and create a plan that works best for you and your family. It's essential that you communicate any changes in insurance to your financial coordinator.

## Nurse Transplant Coordinator

While in the hospital, the floor nurse will be your main caregiver. He or she will see you daily to ensure your progress continues and needs are

met. Once you are discharged from the hospital, a dedicated staff of transplant coordinators and nurses will care for you in our outpatient transplant clinic.

## Dietitian

It is very important that you get adequate nutrition and that your diet related lab results are in the acceptable range to promote healing and avoid complications. A Registered Dietitian will evaluate your nutritional status after your surgery and work with the transplant team to make recommendations to help insure that you will be able to tolerate advance to solid food and address any nutritional concerns if necessary.

## Pharmacist

Your post-surgery care will require a daily program of immunosuppressive drug therapy. The pharmacist is an authority on these medications and can answer questions about your doctor's instructions for taking them.

## Pharmacy Technician

The pharmacy technician will coordinate refills and authorizations for your medications. The pharmacy team works with the finance team to assist with financial grants for medications, if needed.



## Transplant Surgery

### Preparation

In preparation for your surgery, you will be asked not to eat or drink fluids. Once you have been admitted to the hospital, several lab and diagnostic tests will be performed to get you prepared for your surgery. Once you arrive in the operating room and sleep is induced, an airway tube will be utilized to help you breathe.

Typically, the tube is removed once the operation has concluded or you begin breathing well without assistance. It will cause a sore throat, and this discomfort may last for a few days. Once you are asleep, a urinary catheter will be placed to monitor urine output very carefully, as well as a ureteral stent that will need to be removed four to six weeks after transplant.

### Surgery

A kidney transplant usually takes three to four hours to complete. An incision is made to most of the lower abdominal pelvic region, and staples are used to close the incision. Family members are directed to wait in the surgical waiting room, and the transplant surgeon will inform them when the transplant is complete.

### Post-operative Care

Post-transplant care first begins with a team of health care professionals dedicated to making you feel as comfortable as possible. You will remain in the recovery room shortly before transferring to the Intensive Care Unit (ICU), where you may stay one to two days, depending on your progress.

The intravenous lines remain to track fluid volume. You are watched very closely during this time.

Normally, patients notice a change right away, as their energy, appetite and concentration increase. Discomfort from the incision should improve within a few weeks.

Patients in stable condition are soon moved to the transplant floor, where they will receive ongoing care. You will be asked to cough and deep breathe frequently to avoid surgical complications, such as pneumonia.

Vital signs, fluid volume and weight are measured regularly to determine if the kidney is working well. Daily blood tests will also take place. Other exams may become part of the treatment, if necessary.

It is highly recommended that you limit the amount of visitors to reduce the risk of infection.

Before you are released from the hospital, the transplant team will provide information on follow-up appointments. On average, patients are seen two to three times a week for the first few weeks following discharge.

Post-transplant tests and procedures are common, as they assist the transplant team with monitoring kidney function and overall health, as well as detecting side effects to medications. For information about these tests, speak with your transplant coordinator.

A nurse transplant coordinator will visit you in the hospital prior to discharge. The transplant coordinator will provide post transplant education, and provide you with a booklet.

# Transplant Clinic



Patients who have had a kidney and/or pancreas transplant will be seen in the same clinic where they had pre-transplant appointments, located at 2415 North Orange Avenue, Suite 700, Orlando, Florida 32804.

Although some patients will require an individual plan based on health status and lab results, most will follow the same basic schedule: two to three clinic visits per week for the first month, twice per week for the second month, then once per week in the third month. This schedule may be adjusted if complications arise.

After the third month, those who are stable will be referred back to their primary nephrologist. Clinic visits will continue at six months, 12 months then annually after that. Remember—we want the best outcome for you and your kidney.

## Day of Clinic

### *What to Bring*

- For the first visit, bring all your medication bottles. For all other visits, bring just your medications that you will be taking that morning.
- Bring blood pressure machine to the first clinic visit.
- Bring your medication book to every clinic visit, which includes your daily recording of weight, temperature and blood pressure.
- Write down any questions you may have and bring with you.
- Have your support person come with you.
- Bring anything to make you comfortable and keep you entertained.

## On the Morning of Clinic

On the mornings of your clinic visit, do not take any of your medications, with the exception of pain medication, nausea medication, and/or medication instructed by your physician to take prior to labs (do not take your tacrolimus and/or sirolimus (rapamune) prior to having labs drawn).

Bring your medications with you for the entire day. There are two exceptions to eating something prior to your blood draw:

- You are diabetic and your blood sugar is low (if you eat something, let us know)
- You need to take pain medication (you may eat crackers to avoid nausea)

You may, however, drink water and are encouraged to drink water.

## Checking In

### *Time*

It is important that you come to clinic between 6:30 and 7:30 am to have your blood drawn, times may vary based on appointment given.

### *Why is it important to be here at this time?*

It is important to have your blood drawn at this specific time to obtain a “trough” level of your tacrolimus and/or sirolimus (rapamune). A trough level is the measurement of the drug level in the blood at the time when it is lowest, which occurs just before your next dose is due. Taking your medication at the correct time every day and coming in for bloodwork at the same time will help us accurately adjust your medication.

### *Where do I go?*

When you first arrive on the seventh floor, check in with our secretary to start the clinic process. Laboratory staff will then be notified that you are here. Your name will be called for the blood draw in the order that you checked in. Give the laboratory staff your lab order sheet that was provided by the transplant team.

### *Then what?*

Once your blood has been drawn, a transplant coordinator will check you in. After we receive your lab results (usually between 9:30 and 10:00 am), you will meet with your transplant coordinator to:

- Review your medical care
- Discuss any questions or concerns
- Be aware of and understand any changes in your care or medication
- Meet with the physician to review your blood test results and medications
- Schedule or report for any procedure or tests (biopsy, X-ray, etc.) that may be necessary

## Tips for Taking Medication

- Be sure you know what to take and how to take it.
- Keep a daily record.
- Report side effects.
- Consult your physician before taking any other drugs or herbal supplements.
- Food can affect your medication absorption. Be consistent in taking your medications with or without food.

# Importance of Medications

Unfortunately, the third major cause of transplant failure occurs when patients don't follow their drug-therapy program. You will use a combination of medications to give you the best possible defense against organ rejection. These medications prevent rejection by suppressing your immune system. This class of medications is called immunosuppressants. Careful monitoring and adjusting of the dosage of these medications will be needed to develop a regimen that is best for you.

- Be sure to follow your drug-therapy program exactly as instructed. Never skip a dose or change the amount of medication you take unless told to do so by your transplant physician or coordinator. Ask your transplant coordinator how to handle missed doses.
- Do not change your medications or take anything other than what was prescribed or approved by your transplant team. It is important to note that many over-the-counter medications, herbal supplements and vitamins can interact with your immunosuppressive drug therapy. This can be dangerous. Before you take any of these products, discuss them with your transplant team.
- Remember that as long as you have the transplanted organ, you will have to take your immunosuppressant medications.

## What You Need to Know About Side Effects

Immunosuppressant medications have many side effects. The number and type of side effects are unique to each person. It is important to know the possible side effects so that you can report them to your transplant coordinator or physician.

The following is a list of medications from which your physician will choose to help achieve a successful transplant. This is only an overview, as your transplant team may prescribe other medications not listed.

## List of Medications and Side Effects

### *Tacrolimus (Prograf)*

Tacrolimus is an immunosuppressant medication given to help prevent your body from rejecting the transplanted organ. Tacrolimus comes in 0.5mg, 1mg and 5mg capsules. It is important to take this medication at the same time every day. We will monitor how much of this medication is in your blood. This medication must be monitored for as long as you take it.

#### SIDE EFFECTS

- Higher risk for infection
- Headaches
- Numbness or tingling in hands, feet or lips
- Nausea and vomiting
- High blood sugars
- Tremors

### *Mycophenolate Mofetil (Cellcept) OR Mycophenolic Acid (Myfortic)*

Mycophenolate mofetil/mycophenolic acid are immunosuppressant medications that are given to help prevent your body from rejecting the organ transplant. Mycophenolate mofetil comes in 250mg and 500mg capsules. Mycophenolic acid comes in 180mg and 360mg tablets.

#### SIDE EFFECTS

- Higher risk of infection
- Diarrhea
- Leukopenia (decrease in white blood cells)
- Nausea and vomiting

### *Prednisone*

Prednisone is a steroid that is given to help prevent your body from rejecting the organ transplant. It is given with other medications to prevent rejection. Not all transplant recipients will have to take this medication long-term. Prednisone comes in 1mg, 2.5mg, 5mg, 10mg and 20mg tablets.

## SIDE EFFECTS

- Higher risk of infection
- Swelling of the face, hands or ankles due to fluid retention
- Cataracts and vision changes
- Skin changes (acne, bruising and sensitivity to the sun)
- Muscle weakness
- Mood swings
- Stomach ulcers
- Steroid-induced diabetes
- Bone and joint changes

### **Sirolimus (Rapamune)**

Sirolimus is an immunosuppressant medication that is given to prevent rejection of the transplanted organ. It comes in 0.5mg, 1mg and 2mg tablets.

## SIDE EFFECTS

- Higher risk for infection
- Joint pain
- Decrease in red blood cells
- Diarrhea
- Rash or acne
- High blood pressure
- High cholesterol
- Delayed wound healing

### **Antibiotics**

Due to risk of infection from the immunosuppressant medications, your physician will also prescribe some medications to prevent different types of infections.

### **Trimethoprim/Sulfamethoxazole (Septra or Bactrim)**

This medication is used to prevent a type of pneumonia called pneumocystis carinii pneumonia (PCP). The dose of this medication is single strength.

## SIDE EFFECTS

- Nausea and vomiting
- Rash
- Itching
- Decrease in white blood cells

### **Clotrimazole Troche (Mycelex)**

This medication is used to prevent thrush, which is a fungal infection you can get inside your mouth. This medication comes in a 10mg lozenge/troche. You will dissolve and swallow this lozenge three times a day for the first three months after the transplant.

## SIDE EFFECTS

- Nausea and vomiting

### **Valganciclovir (Valcyte)**

Valganciclovir is an anti-viral medication used to prevent a virus called cytomegalovirus (CMV). This medication comes in a 450mg tablet.

## SIDE EFFECTS

- Fever
- Headache
- Diarrhea
- Decreased white blood cell count
- Decreased platelet count

## Other Medications

There are other medications that you will take after the transplant. These could include the following:

- Stomach medications to prevent ulcers, nausea, heartburn, etc.
- Enteric-coated baby aspirin to thin the blood
- Stool softeners to prevent constipation
- Pain medication for surgical pain
- Diabetes medications if blood sugars are high
- Blood pressure medications if blood pressure is high

## Precautions

- Be familiar with your medications. Know their names, doses and frequencies.
- Follow your doctor's instructions for taking them.
- Know all the possible side effects, reporting those you may experience to your transplant coordinator.



## Post-transplant Care

### Incision and Wound Care

- You may clean your incision by showering daily. To prevent infection, do not take a tub bath until staples have been removed and the incision is fully healed. The incision may be cleaned by allowing soap and water to run over it, rinsing and then patting dry with a clean towel.
- Do not use spas or hot tubs; swim in swimming pools, lakes or ponds; or take a bath until the incision is completely healed, and your transplant team gives the okay.
- There may be a small amount of drainage from the incision. Do not panic; this is not unusual. Use clean, absorbent material such as towels, feminine pads, gauze or baby diapers to absorb the fluid. Note what color the fluid looks like, and if there is any odor. If there is an odor/foul smell, **contact transplant coordinator on call.**

- If there is redness, swelling, a large amount of drainage or odor with drainage, contact the on-call transplant coordinator. Small openings can occur; if this happens, keep area clean and dry, and **notify the clinic or transplant coordinator on call.**

### Signs of Infection

Being on immunosuppressive medications puts you at higher risk for infection. Signs and symptoms of infection of which you should be aware are:

- Redness, swelling or drainage from incisions
- Fever (100.5 F or greater)
- Pain, burning, discoloration, odor when urinating
- Frequent and watery diarrhea
- Productive cough

**If you develop any of these symptoms, call the clinic or transplant coordinator on call.**

## Signs of Rejection

Rejection means your body's immune system is trying to harm the transplanted organ. The immune system's job is to destroy foreign objects that invade your body, such as bacteria and viruses. Without daily use of special drugs to alter your immune system, your body will attack the new kidney.

Despite the drugs you take to suppress your immune system, it is not uncommon for transplant patients to have a rejection episode. Many times, you may feel well, but your blood tests could indicate a potential rejection episode. It is important to be prepared for the possibility of hospital admission any time you come and are seen in clinic.

Do not panic if you do have to be admitted to diagnose and/or treat a potential rejection episode. There are medications that can effectively treat rejection. The sooner we catch a rejection episode, the faster it can be treated with better results. This is why it is important you come to your clinic appointments on time and get labs drawn as requested.

## Constipation

Constipation is common after the transplant operation. If you do not have a bowel movement within three to five days of your operation, a tap water or Fleets enema may be used for relief while in the hospital. All transplant patients are sent home on a stool softener called Senekot.

While at home, over-the-counter remedies such as magnesium citrate or docusate may also be used. If you do not have a bowel movement for two or more days after leaving the hospital, **call the clinic or transplant coordinator on call.**

## Signs of Organ Rejection

- **Tenderness:** Pain or swelling in the area of your new kidney should be reported to your transplant team.
- **Fever:** A temperature above 100.5° F should be immediately reported. Fever is most often a sign that the body's immune system is in battle. Your transplant team must be kept informed in order to build a strong defense.
- **Swelling:** Sudden weight gain indicates fluid retention. Keep a daily record of your weight. Look for swollen hands, feet or eyelids, and report these signs immediately.
- **Flu-like symptoms:** Symptoms may include muscle aches, joint discomfort and chills. While these could be from the flu, they could also be signs that rejection is occurring. Always report these symptoms to your transplant team.
- **Decreased urine output**

**If you have any of these symptoms, call the clinic or coordinator on call.**



## Stent Removal

### ***What is a ureteral stent?***

A stent is any tube or catheter that is inserted into a body cavity to prevent the constriction of flow. The ureter is a muscular tube that carries urine from your kidney to the bladder. During the transplant operation, the end of the transplant ureter is connected to your own bladder so that urine can exit your body through the normal route. Most of the time, a small ureteral stent is placed inside the ureter during the operation to help this connection heal without too much narrowing.

### ***When should the stent be removed?***

The stent should be removed four to six weeks after transplant surgery. Once you have an appointment scheduled, let the transplant

coordinator know when you come to clinic. The transplant coordinator will give you an antibiotic prescription to take prior to stent removal to prevent a urinary tract infection.

### ***How is the stent removed?***

The stent is removed in an outpatient setting at Florida Urology Associates. A cystoscopy is done in which a fiberoptic scope is inserted through the urethra (where the urine leaves the body) and used to locate and remove the stent. Prior to the procedure, sterile lubrication that contains a local anesthetic is instilled into the urethra. There is no general anesthesia involved, and you can eat right after the procedure.

## Dialysis Access

### Post-transplantation Management

A **fistula** placed for hemodialysis is typically constructed by sewing an artery to a vein. It is usually placed in either the lower or upper part of the arm. After your kidney transplant, your fistula may be used if you need hemodialysis. You will need to care for your fistula the same way you were taught prior to your transplant. Since your fistula is your own vein and artery, it cannot be removed post-transplantation. It may continue to work even though it is not being used, and you will still be able to feel a thrill (the vibration or buzzing) or hear a bruit (the rushing sound). A vascular surgeon may tie off a fistula if it is placing too much demand on your heart or if you develop a pseudo-aneurysm that may cause further complications.



FISTULA



AV FISTULA PSEUDO-ANEURYSM



AV GRAFT



PERITONEAL DIALYSIS (PD) CATHETER

A **graft** is a plastic tube placed under your skin for hemodialysis if your own veins are unsuitable. You will care for your graft the same way you did pre-transplantation. Since a graft is a plastic tube, it is more likely to stop working at some point, unlike the fistula that uses your own veins and arteries. If you notice any redness, swelling, discharge or pain over your graft, notify your transplant team as soon as possible, as this may be an infection and the graft may need to be removed by a vascular surgeon.

If you have a **catheter** in your chest/neck used for hemodialysis, it will usually be removed one to two weeks after your transplant. Depending on the type of catheter, it may be removed in the post-transplant clinic or by a vascular surgeon. You should continue to watch your catheter site for signs and symptoms of infection and notify your transplant team as soon as possible. Signs and symptoms of infection include redness, warmth, tenderness or swelling.

A **peritoneal dialysis (PD) catheter** is usually placed in the abdomen, and it may or may not be removed during your transplant surgery. This decision will be left to the transplant surgeon's discretion. If your PD catheter is not removed at the time of your surgery, it will be removed a few weeks after your transplant. An appointment will be scheduled, and it will be removed in the hospital setting under general anesthesia. Your PD catheter may be used post-transplantation if your kidney takes a while to start working. If your PD catheter does not need to be used post-transplantation, it usually does not need to be flushed. It is also important that you notify your transplant team immediately if your PD catheter becomes open to air, such as when the PD catheter's cap becomes loose or comes off completely, because you may need to be treated for prevention of infection. **Inform your transplant team if you notice any redness, swelling, pain or discharge from your PD catheter exit site as soon as possible.**

## Medication Adjustments

### Following Lab Results

After your lab work has been completed and results are back, the transplant team will review your labs and adjust your medication based on these results. Medication dosage adjustments are frequently made within the first month after your transplant. If you need to leave clinic before results are reported, make sure you provide valid contact information to the clinic coordinator.

## What to Monitor at Home

From the moment you are transplanted with your kidney or kidney/pancreas, you assume responsibility for your health and your new kidney's health. It is very important to track specific health information daily.

### What to Record in Your Transplant Book

- Weigh yourself daily every morning after urinating. Wear similar clothes, and use the same scale. Try to weigh yourself around the same time.
- Check your blood pressure twice a day: once in the morning before you take your blood pressure medications, and once in the evening before you take them again. Follow provided parameters about when to hold pressure medication if blood pressure is low. If blood pressure is higher or lower than usual, notify clinic or coordinator on call.
- If you feel like you have a temperature, always check it. If your temperature is greater than 100.5° F, notify clinic or coordinator on call.

It is important to record this information, as it can show how your body is responding to the transplant and the medication you are taking. Remember to bring this information in your transplant book every clinic visit.

### Additional Items to Monitor

- Wash your hands frequently.
- Due to immune-system suppression, avoid people with colds, the flu or any other contagious illnesses.



- If you have any of the following, notify clinic or your coordinator:
  - Fever more than 100.5° F
  - Frequent and watery diarrhea
  - Vomiting: If you have just taken your medication and vomit, and you can see every medication you have taken, you make re-take. If you are not sure what stayed down or came up, do not re-take medications and just continue with medication regimen.
  - Persistent productive cough
  - Pain, burning, discoloration when urinating; urinating less than normal
  - Blood in urine or stool
  - Redness, swelling or drainage from incision
  - Any new rash and/or itching

## The First Period of Recovery

### Protein

It is important that you get adequate protein after your surgery which will be needed to promote healing. Remember that high-protein choices include eggs, milk, cheese, meat, poultry, seafood or vegetable sources of protein, like lentils. Include some high-protein sources at each meal.

### Phosphorus

After kidney transplant, most people will no longer be on a phosphorus restriction because your kidney will now be able to regulate this. Many people after kidney transplant actually have a low phosphorus level. It is important for you to keep the minerals in your body at the acceptable range.

We therefore encourage most of you to increase your milk products or other high-phosphorus foods. Instead of avoiding milk, cheese, yogurt, black beans, lentils or nuts, you are advised to include two to three servings a day. This will also help you get the necessary protein and replace the minerals that will help strengthen your bones.

### Potassium

Dietary potassium recommendations are based on the individual needs right after surgery. Some people are asked to continue to limit their potassium intake to 2000 mg each day but others won't have to restrict dietary potassium intake. This can be different due to things like response to higher doses of immunosuppressant, delay in kidney function and post surgical stress. This typically resolves to normal levels as the medication dose is lowered.

### Fluids

After the transplant, you are more easily prone to dehydration, making fluid intake very important to maintain good kidney function. Most people can accomplish this by taking in at least two liters of fluid a day. This is the same as 67 ounces a day, or about eight cups a day. Keep in mind that alcoholic and/or caffeinated beverages may actually cause you to lose fluids, so do not include them as part of your eight cups per day.

### Calories

Healthy, balanced meals are important for acquiring the necessary vitamins and minerals that promote healing and prevent the breakdown of muscle mass. Some patients may experience discomfort during the early period of recovery, a loss of appetite, a feeling of fullness, constipation, diarrhea and/or nausea. This is common and will resolve over time as you recover and activity increases.

We suggest you try to eat small, frequent meals of easy-to-tolerate foods if these symptoms occur. If you are having persistent problems that affect your nutrition, we will have a transplant dietitian see you in clinic.

### Avoid

- Pomegranate, grapefruit, star fruit, ginger (concentrated ginger drinks or large amounts of ginger spice/fresh ginger) due to it can increase your tacrolimus level.
- Salad bars, buffets due to you do not know how long the food has been left out, or who has touched it. Do not eat any raw food such as sushi, or rare meat.

### Clean your food

Use a separate cutting board (do not use a wood cutting board) or wash very well between cleaning/cutting meats, vegetables, and fruits. Wash fruits, and vegetables prior to eating/preparing food.



## Life After Transplantation

### When to Resume Activities After Transplant

Following transplant, you are encouraged to resume normal activities as tolerated, with the following exceptions:

- Before taking medication that has not been prescribed by your transplant team, call clinic or bring the medication to your clinic appointment.
- Call or bring to clinic appointment any herbal supplements you are considering so the doctor/dietitian can determine its safety.
- Check with the doctor about when you can resume driving. Usually it is three weeks after transplant, once the staples are removed and you are no longer taking pain medication.
- No lifting, pulling or pushing anything heavier than 10 pounds (about a jug of milk) for at least two months after surgery, or per doctor's discretion.
- No running, jumping or sexual intercourse for at least two months after surgery.
- We recommend you see a dermatologist yearly for skin assessment, as immunosuppressive medications place you at high risk for skin cancer.
- Wear sunscreen when outside at all times. Sunscreen should be SPF 30 or greater. Do not go to a tanning salon.
- When gardening, wear a mask, gloves, and wash your hands when finished.
- When fishing, wear mesh gloves when hooking and unhooking fish.
- Your nephrologist will determine when it is safe for you to return to work.
- If you are exposed to chicken pox, immediately call the clinic or coordinator on call. It is important to avoid anyone who has developed a rash after having the chicken or small pox vaccine.

- Wearing a mask is not required but recommended if you are walking or working in a particularly dusty area. Do wear a mask while at a doctor's office, or in large crowds within the first 3 months post transplant.
- You should not keep outdoor cats, reptiles or birds as pets, since their excrement can cause particularly harmful infections. If you do have a cat, have someone else clean litter box. If that's not an option, wear a mask and gloves when cleaning litter box, and wash hands afterwards.

## Physical Exercise

It is very important for your health and recovery to incorporate physical exercise into your life. We recommend that you start a daily walking regimen. Physical therapy may be ordered for those who need help with strengthening and retraining muscles and joints.

During the first six to eight weeks after surgery, it is important to avoid any activities that can cause strain, stress or pull the skin around your incision. Examples of strenuous activities to avoid are sit-ups, strength training, contact sports, push-ups, bowling and golf.

To maintain good health, the government recommends at least 150 minutes of moderate exercise per week. Take a brisk 30-minute walk five times a week, but always check with your doctor before starting an exercise routine.

When you are ready for a more vigorous exercise plan, discuss with your transplant doctor.

## Your Local Doctor

After approximately three months, you will be referred back to your local nephrologist if your transplant issues have been stabilized. We allow the local nephrologist to take over your care and management of medications. We will still see you back in clinic in three months, and then on an annual basis. We are always available to you if an urgent issue arises and you need assistance.

## Your Local Lab

Once you have been referred back to your nephrologist, we ask that you have bloodwork every month for the first two years, and then every two months thereafter. Know your lab results, particularly your tacrolimus level and creatinine. Tacro levels should be between 8 to 10 for the first six months, then 5 to 8. Ask your local nephrologist to FAX us a copy of your labs for review (FAX # 407-303-0679). If at any time your creatinine rises above baseline, let us know immediately.

## Dental Care

Many infections can start in the mouth, and as a transplant patient, your immune system is suppressed. It is important that you:

- Maintain good dental hygiene
- See your dentist every six months or as directed
- Brush your teeth with a soft-bristle toothbrush several times a day, and floss regularly
- Report to the transplant team and/or nephrologist if you are having any dental work (they will prescribe an antibiotic beforehand to prevent infection)

## Social Work

The transplant social worker will meet with you to identify any emotional, financial and/or physical stressors that may impact you and your family before, during and after transplant. In addition, the transplant social worker can provide emotional support and education, community resource referrals and practical ideas for coping with transplant. The transplant social worker will provide direction on planning for your life after transplant, including returning to work and other activities, and will encourage you to become more independent. The transplant social worker facilitates the New Life Transplant Group, which will be a resource offered to you for additional support and education.

The New Life Transplant Group is a psycho-educational group for Florida Hospital patients undergoing evaluation for transplant, awaiting

transplant and those who are post-transplant. It also serves as an informational and emotional resource for patients both before and after transplant. Patients can listen to guest speakers, share experiences, voice concerns and volunteer to help others during these regularly scheduled meetings.

## Pregnancy After Transplant

Even though successful pregnancies have occurred after transplantation, there are higher rates of fetal complications when compared to non-transplant patients. There are many uncertainties about pregnancy after transplant, including the risks to your new organ, your health and the health of your fetus. Pregnancy is associated with a higher risk of rejection during pregnancy and following delivery. Because of this, all pregnancies in transplant are considered high risk and must be planned and managed together by a high-risk obstetrician and transplant physician.

Certain medications can cause fetal harm, such as CellCept or Myfortic. These medications have been associated with fetal malformations and miscarriages. It is important you do not discontinue

these medications without speaking with transplant physician. Stopping these medications on your own can cause rejection of your kidney. Discuss with your transplant physician if you are pregnant or plan on becoming pregnant.

Speak with your transplant physician about what contraception can be used that won't interact with your transplant medication.

## Immunizations and Vaccines

Immunizations and vaccines can either be live or dead. If the vaccine is dead, it is safe for transplant patients to be around those who have had these dead vaccines/immunizations and to have the vaccination themselves.

Because your immune system is suppressed, you cannot fight live vaccination/disease and can become sicker. You can only receive a dead, inactivated vaccine post-transplant.

During the first three months post-transplant, we do not recommend you receive any vaccination. We recommend that you receive the flu vaccine every fall, and the pneumovax every five years.



Always contact your coordinator or transplant physician before immunization.

**Safe vaccines include:**

- Diphtheria (DPT)
- Hepatitis A
- Hepatitis B
- Flu (injectable)
- Pneumococcal
- Tetanus
- Polio

**Vaccines to avoid include:**

- Flu mist
- Small pox
- Shingles
- Chicken pox
- Small pox
- Measles, mumps and rubella (MMR)

If possible avoid direct contact with anyone who has received a live-virus vaccination for about six to eight weeks. If unable to do so, please contact post clinic staff for further instructions. You should also avoid changing diapers, the exchange of bodily fluids and/or sharing food/utensils with anyone who has had live-virus vaccination.

## Compliance is Crucial

The key to your success is compliance. It is important to follow up with your transplant team, come to your appointments, get bloodwork done and take your medications as instructed. Remember, your kidney transplant is a gift, and it is important to honor the organ donor and his/her family by taking good care of your transplant and yourself.

## Long-term Possible Complications of Transplantation

### **Diabetes Mellitus**

A common complication after transplant is post-transplant diabetes mellitus. Refer to nutritional considerations.

### **Skin Cancer**

Immunosuppressive medications place you at a higher risk for skin cancer. It is important to see a dermatologist yearly to observe for any lesions, sunspots or foreign moles. Wear SPF of 30 or greater, re-apply and avoid long-term sun exposure.

### **Recurrence of Disease**

Transplantation is not a cure for your underlying disease process that caused your kidney damage. The underlying disease can recur in your transplanted kidney.

### **Rejection**

Rejection is something that can happen at any time after transplant. Treatment for rejection is individualized based on clinical data/course.

### **Impact of Transplant on Disability Status and Health Insurance**

If you have Medicare as your primary insurance, are not older than 65 or do not have another disability besides end-stage renal disease, you can lose your Medicare coverage one to three years post-transplant. Having a kidney and/or pancreas transplant does not qualify you for disability status.

The purpose of transplantation is to restore good health and get you back out into the community. If you have any questions about this, it is important to speak with the financial coordinator and social worker.



## Nutritional Considerations

There are two adjustment periods after transplant: the first six weeks and thereafter. During the first adjustment period, your body will be healing and your immunosuppressive or post-transplant medications will be adjusted down to a lower maintenance dose. We are also watching to ensure the transplanted kidney is functioning at its fullest capacity. Thereafter, you will simply be trying to maintain good health to protect your kidney function. If you are maintaining a healthy diet and a healthy weight and getting regular exercise, your kidney will be more likely to function longer for a better quality of life.

To stay healthy and avoid kidney damage, it is very important to eat a healthy diet and maintain an acceptable weight. **There are many models of a healthy diet, and general healthy guidelines can be found at <http://www.CNPP.USDA.gov/DietaryGuidelines.htm>**

After the early post-transplant period with a functioning kidney graft, you will no longer need to restrict phosphorus, potassium, fiber or fluid, as you were likely previously advised. However, you will be advised to continue to limit your sodium to a suggested 2000 milligrams per day. Sodium is the mineral in salt. Many studies have shown the effectiveness of sodium restriction to lower blood pressure, also known as hypertension. Fifty to eighty percent of kidney transplant recipients experience high blood pressure, which is associated with kidney damage and heart disease. (pg 79-81)

Another nutrition concern after transplant is the higher risk of developing an elevation in your lipids (fats), like cholesterol and triglycerides. The studies indicate this occurs in 60 percent of kidney transplant recipients. (pg 63) Having these elevated fats are often already present at the time of transplant but can worsen due to the effects of

the antirejection medications. When these fats are elevated, the risk of heart disease increases. The diet should therefore be limited in fat to 30 percent of your caloric needs. The saturated fats that typically come from animals should be avoided and or limited. Studies have shown that kidney transplant patients following the American Heart Association (AHA) Step One Diet (pg 71) were able to achieve healthy reductions in their weight and cholesterol levels.

New-onset diabetes after transplant (NODAT) is a disorder that can cause high sugar levels in the blood and lead to serious health risks, including damage to your new kidney. This is often a side effect of some of the post-transplant medications and is also associated with obesity. It is estimated that about 10 to 40 percent of those who did not have diabetes will become diabetic within the first year of transplant. (pg 50-52) It is not uncommon to gain 10 to 35 percent of weight within the first year. (pg 111-113) This is related to feeling better post-transplant, which can lead to the consumption of an excessive amount of calories. A sedentary lifestyle can also contribute to undesired weight gain.

Those of you who were already diagnosed with diabetes before your transplant will need to continue to follow a diabetic diet and will likely need more medication to control your sugars.

The diabetic diet is a healthy, balanced diet that is limited in calories and controlled in the amount and type of carbohydrates you eat. Carbohydrates are types of food that turn in to sugar. They are needed but should be controlled to achieve the proper sugar or glycemic level in your blood. Your transplant registered dietitian can provide you with more specific guidelines to meet your needs. It is also very important to achieve a healthy weight range and maintain it. This will also help you avoid diabetes, high blood pressure and heart disease.

Unfortunately, the immunosuppressive medications necessary to prevent kidney rejection may place you at a slightly higher risk for experiencing foodborne illness. The limited information available about foodborne illness in the transplant population indicates that the incidence is low, but the illness is lengthier, more severe and more likely to lead to death. It is therefore prudent for you to practice safe food handling and avoid eating foods that are more likely to lead to infection. Riskier foods include raw fish or sushi, undercooked meat or poultry, unpasteurized dairy or juices, raw sprouts and buffets or salad bars.

**More information on food safety can be found by visiting the USDA website at [www.FSIS.usda.gov/pdf/Food\\_Safety\\_For\\_Transplant\\_Recipients.pdf](http://www.FSIS.usda.gov/pdf/Food_Safety_For_Transplant_Recipients.pdf)**

## In Summary

- A low-fat, low-sodium, high-fiber diet that is rich in fruits and vegetables and moderate in protein is recommended. A high-protein diet is not suggested for the long term. This diet is simply a healthy eating pattern that all people are advised to follow.
- Maintain a healthy weight range with control of your calories, and include regular exercise when your doctor has given you the clearance to do so.
- Ask to speak to one the transplant dietitians for any further concerns or clarifications.

# Glossary

**ACUTE** - Describing an experience that comes on rapidly, is sharp and lasts a short time, as in acute pain. Differs from chronic, which describes a long-lasting or frequently recurring experience.

**ADVERSE REACTION** - Side effect. Any unintended, abnormal reaction to medicine taken at normal doses.

**ANTIBIOTIC** - Medication that kills or limits the growth and multiplication of bacteria and other microorganisms. Most non-prescription antibiotics are applied topically.

**ANTIBODY** - A protein made by the body's immune system to fight infection and foreign substances. Your body produces antibodies in response to something foreign. Transplant recipients take immunosuppressive medication to prevent antibodies from attacking a new kidney.

**BIOPSY** - Removal of cells from a newly transplanted kidney to be closely examined for signs of rejection. A biopsy may be necessary if your kidney doesn't work right after transplant. Biopsies are the best way to find out if there is rejection and to allow your doctor to treat the problem. The procedure is usually done by your physician and may take place in a hospital room or in the X-ray department.

**CAPSULE** - Medicine-containing shell or gelatin or other material that can dissolve in the stomach, releasing the capsule's contents.

**CMV** - Cytomegalovirus, member of human herpes virus-causing disease.

**DECEASED DONOR** - An individual who died of reasons not related to kidney failure or kidney problems, and whose wish was to donate organs to help others awaiting the gift of life.

**DELAYED GRAFT FUNCTION** - Sometimes the transplanted kidney may not clean the blood or make urine immediately after transplant. This condition is called delayed graft function, or acute tubular necrosis (ATN). Delayed graft function is a common complication following kidney transplant, particularly in deceased donor transplantation, and is usually reversible.

**DIASTOLIC** - The bottom of two blood pressure numbers that measures the force of the heart muscle at rest, when it expands and fills with blood.

**DOSAGE** - Information contained on product packaging or label that tells how much medicine to take, when to take it and any special instructions.

**ENDOTRACHEAL TUBE** - An airway tube inserted through the mouth to help you breathe during surgery.

**EXPIRATION DATE** - The date prior to which the product can be expected to retain its full strength as stated on the label, according to the manufacturers. Products should be disposed of properly once they reach their expiration date.

**GLUCOSE** - A type of sugar found in the blood.

**IMMUNOSUPPRESSANT** - An agent capable of suppressing immune responses, commonly referred to as anti-rejection medication.

**INFECTION** - The condition in which the body is invaded by a pathogenic agent that multiplies and produces effects.

**INTRAVENOUS (IV)** - Literally into or within a vein. Also refers to fluids and medications that are injected into a vein through a needle or catheter.

**LAXATIVE** - Agent that promotes bowel movement by softening or increasing the bulk of the stool, lubricating the intestinal tract or stimulating muscle contraction of the intestine.

**LYMPHOCELE** - Sometimes fluid may collect around the new kidney. This fluid collection is called a lymphocele and occurs in about 10 percent of patients who have a kidney transplant. The lymphocele will usually go away on its own, but sometimes this fluid collection needs to be repaired through surgery.

**REJECTION** - When the body tries to get rid of a transplanted kidney by making antibodies to go on attack. Transplant recipients take immunosuppressive medication to prevent rejection from happening.

**RENAL ARTERY STENOSIS** - The renal artery, the main blood vessel that enters the kidney, may become stenosed (scarred) as it heals. If the artery becomes scarred, this blood vessel becomes very narrow and constricted. If the artery is narrowed, blood flow to the kidney decreases. The renal artery carries blood that contains oxygen, so this blood is very important to maintain good kidney function. A decreased amount of blood from the renal artery may affect kidney function and cause high blood pressure.

**SIDE EFFECT** - Unintended, but sometimes not unexpected, effect on the body apart from the principal and intended action of the medication.

**SYSTOLIC** - The top of the pressure number that measures the force of contraction of the heart muscle as blood is pumped out of the heart chambers.

**URETERAL STENOSIS** - The ureter is the tube that drains urine from the kidney to the bladder. During kidney transplant surgery, the ureter is attached to the recipient's bladder. If this occurs, an area of narrowing develops that can cause the flow of urine to be blocked.

**URETERAL STENT** - Occasionally the ureter/bladder connection develops a leak that may require surgical repair. To avoid this complication, a ureteral stent is put in place. It is a long, spaghetti-sized plastic tube that supports the ureter as it heals and helps drain urine from the kidney to the bladder. The stent is removed four to six weeks after transplant.

**VASCULAR THROMBOSIS** - Is a rare but very serious complication after transplant. This occurs when blood clots form in the small blood vessels of the kidney, causing a blockage of blood flow to or from the kidney. People who have a history of blood clots or certain types of autoimmune diseases are at a higher risk of developing blood clots in the kidney.