

PATIENT EDUCATION

Kidney Transplant Education Guide



OSF[®]
HEALTHCARE

OSF HEALTHCARE SAINT FRANCIS MEDICAL CENTER

Kidney Transplant Education Guide

IMPORTANT PHONE NUMBERS

Office phone number: **309-655-4101**

Office hours: 8 am – 4 pm

A transplant nurse coordinator is always available “on call” if you are ill after normal business hours, on weekends, or holidays.

To call the on-call coordinator:

on call phone number: **309-655-2000**

Ask for the kidney transplant coordinator on call

POST-TRANSPLANT INTRODUCTION

Congratulations, you have successfully completed surgery and now life with your new organ begins!

We have created this education guide to assist you and your care partners in understanding the post-transplant process. It can help guide you and give you the information you need to know about taking care of yourself.

Although patients want to return to a “normal lifestyle” right away, this will take time. It may be several months before you start to regain your strength. It may take time to have a good understanding of how to manage your treatment. However, when you leave the hospital, you will leave with the knowledge of your medications, your diet, and your basic care.

Depending on the amount of time you and your family had to prepare for your transplant, you may be feeling somewhat overwhelmed. Remember that you need to heal emotionally and mentally, as well as physically.

This will take time and patience

After your transplant, there are support groups available which may be helpful for you and your family. During these support groups, you can speak with another post-transplant patient and his/her family. It may also be helpful to talk about any concerns you may have with a transplant team member. You may be surprised to hear how normal your feelings are at this stage. This is a big change; it may take time to get comfortable.

A transplant nurse will review this education guide with you prior to going home, please keep this guide within reach and refer to it when you have questions. Use this as a resource for questions that come up after transplant. Do not be afraid to ask questions about anything. No question is silly. Our goal is to help you go home with the confidence and knowledge that you need to manage your life as a transplant patient!

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For more health education resources, visit
Health & Wellness at osfhealthcare.org



CHAPTER 1 – Office Information and Resources

Important Phone Numbers and Office Information

OSF HealthCare Saint Francis Medical Center
Kidney/Pancreas Transplant Program
420 NE Glen Oak Ave
Hillcrest Building
4th Floor Suite 401
Peoria, IL 61603-3112

Telephone: (309) 655-4101

Office Hours:

Our office is open Monday through Friday from 8 a.m. to 4 p.m.

The office is closed on weekends and holidays.

After Hours Information:

A Transplant Nurse Coordinator and doctor is always available “on call” if you are ill after normal business hours, on weekends or holidays. Patients who are ill (such as fevers greater than 100.5°, vomiting, pain, or tenderness over the transplant site, etc.) should contact the on-call coordinator.

To do so, call the direct paging service at (309) 655-2000 and ask for the kidney transplant coordinator on call.

All non-emergency calls, such as prescription refills, lab results, or appointment changes, need to be made during regular office hours.

If at any time you have a life-threatening emergency, call 911.

Web Resources

OSF HealthCare Transplant Services

osfhealthcare.org/transplant/

National Kidney Foundation

kidney.org/

Gift of Hope Organ and Tissue Donor Network

giftofhope.org/

Renal Support Network (RSN) empowers people who have kidney disease to become knowledgeable about their illness, proactive in their care, hopeful about their future and make friendships that last a lifetime.

rsnhope.org/

UNOS Transplant Living

transplantliving.org

Transplant Friends community mission is to provide a unique and personal point of view for those pre- and post- transplant patients/families who are traveling down the road to transplant

transplantfriends.com

American Transplant Foundation mission is to save lives by reducing the growing list of women, men, and children who are waiting for a transplant. They do this by maximizing living organ donation, which is the most effective way to fulfill their mission. They provide a three-tiered approach with educational, emotional, and financial support for living donors, transplant patients, and their families across the country.

americantransplantfoundation.org

Financial Resources

Help Hope Live is a national 501(c)(3) nonprofit. Our mission is to support community-based fundraising for people with unmet medical and related expenses due to cell and organ transplants or catastrophic injuries and illnesses.

helphopelive.org

The Children's Organ Transplant Association (COTA) helps children and young adults who need a life-saving transplant by providing fundraising assistance and family support.

cota.org

GoodRx is a website you can compare prescription drug prices and find coupons at more than 60,000 US pharmacies.

goodrx.com

NeedyMeds is a website to help find patient assistance programs to help with medication costs.

needymeds.org

The Official U.S. Government site for Medicare

medicare.gov/basics/end-stage-renal-disease

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CHAPTER 2 - Financial Information

FINANCIAL PLANNING: MEDICARE for ESRD

Financial planning for a kidney transplant includes signing up for Medicare A&B.

- Medicare B has a monthly premium (based on income)
- ESRD (End Stage Renal Disease) Medicare eligibility continues 36 months after a successful kidney transplant.
- Medicare enrollment is done at your local Social Security office – with a copy of your 2728 (from dialysis or transplant center if transplant before dialysis, or on dialysis less than 3 months)

Why enroll in ESRD Medicare* at the time of a kidney transplant?

- **Coverage for your living donor!** Medicare requires that for a donor to have payment for costs of potential complications related to the donor nephrectomy, both Medicare A&B will need to be active at the time of your kidney transplant.
- **Better coverage for you!** Have Medicare A & B active when your current medical insurance becomes secondary to Medicare. For you, Medicare will be primary as of _____. Both Medicare A&B need to be active on this date.
- At that time, private insurance should cover 20% of costs and Medicare should cover 80% of costs.
- Medicare B will pay 80% of your immunosuppressant (anti-rejection) medication when primary and when you become eligible once again at the age of 65.

If you choose not to sign up for Medicare A&B at the time of a live donor kidney transplant the following are in jeopardy:

1. Your insurance and/or employer group could pay only 20% of my medical bills when Medicare would be primary [calculated by ESRD Medicare Coordination of Benefits (COB)].
2. Costs associated with live donor nephrectomy complications are at risk of not being covered (denied) by recipient's commercial/group medical insurance – If not covered **you could be financially responsible for such donor medical costs.**
3. Medicare B will **not** pay 80% of your anti-rejection medication when you are 65 if you did not sign up for Medicare when you became eligible at the time of transplant.

* While ESRD Medicare based on ESRD will end 36 months after a successful kidney transplant, Medicare could continue longer if you are also eligible for Medicare based on disability or age.

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CHAPTER 3 – Caring for yourself

From the moment you receive your new organ transplant, you assume responsibility to care for that organ. To ensure continued success of your transplant, you will need to track your progress by monitoring and recording specific health information daily. You have just had major surgery. Tracking your health information is crucial to the early detection of issues – such as infection, rejection, or complications.

In this chapter we will discuss:

- Monitoring yourself at home
- Incision care
- Hydration/drinking fluids
- Restrictions and activity
- Driving restrictions
- Returning to work
- Exercise
- Precautions to take after transplant
- Steps to monitor your health after transplant
- Skin cancer risks post-transplant (handout)

DAILY HOME ROUTINE

Monitoring Yourself at Home

Record the following information on your record sheets located in the back of your education guide. Your recorded entries show how your body has responded to the transplant and medication. This information is valuable to the transplant team in identifying and resolving any issues before they become severe. Be diligent in tracking your progress. Bring your completed record sheets to ALL of your clinic visits.

Weight

- Measure and record your weight every morning on the same scale prior to eating and drinking. Notify the transplant nurse if you have sudden weight gain (e.g., two to three pounds overnight or five pounds in a week) during normal business hours.

Temperature

- Measure and record your temperature twice every day, in the morning before you eat or drink and again in the evening. Notify the transplant nurse if your temperature is greater than 100.5° for two consecutive readings.

Blood Pressure

- Measure and record your blood pressure twice a day, after sitting quietly for five minutes prior to taking any medication. If your blood pressure is higher/lower than it usually is, notify the transplant nurse.

Blood Sugar

- If you have diabetes, measure, and record your blood sugar before each meal and before bed.

Intake and Output

- Measure and record your daily oral intake and urine output for the first week or until the physician instructs you to stop. You should drink approximately 64-96 ounces of fluid each day. If you notice a significant decrease in urine output, please notify the transplant nurse.

Foley

Some patients are discharged with an indwelling foley catheter to help drain the bladder. It is important that you still measure and record your urine output from the foley catheter until directed to stop. Your foley catheter will be removed approximately 1-3 weeks, or per your surgeon's orders.

Ureteral Stent

Some patients have a ureteral stent placed at the time of transplant. This helps to protect the connection of the kidney to the bladder. The stent should be removed 3-6 weeks after transplant surgery.

How is the stent removed?

- The stent will be removed by a urologist. It is removed in an outpatient setting through a procedure called a cystoscopy. A referral will be placed for OSF HealthCare Urology in Peoria for you to have your stent removed. The procedure involves placement of a small flexible tube through the urethra (the opening where the urine exits the body). The procedure usually only takes a few minutes and causes little discomfort. Immediately before the procedure, a sterile lubrication containing a local anesthetic (lidocaine) is instilled in the urethra. You can eat normally before and after the procedure.

You will be scheduled for this procedure by the urologist's office. If you have questions about this appointment, please call the transplant nurse coordinator.

Dialysis Catheter

If you were previously on peritoneal dialysis and have a peritoneal catheter, it might be removed during the transplant operation, prior to discharge. Otherwise, arrangements will be made to have it removed in several weeks.

Constipation

Constipation is often a concern in the first few weeks after transplant. Call your transplant nurse to discuss if you are having trouble with constipation.

Hydration and Fluid Intake

After the transplant you are easily prone to dehydration, so you need to drink plenty of fluids each day with a goal of at least 64 ounces of non-caffeinated beverages. More fluid intake may be necessary in the first few months after your transplant.

Keep in mind that drinking more fluids will cause you to urinate more. It is very important that you do not allow large volumes of urine to collect in your bladder. To avoid this, we recommend you empty your bladder frequently, at least every two hours, even if you do not feel the urge to do so.

Adequate fluid prevents dehydration, which may be harmful to your kidney. Water and other non-calorie beverages are the best options. Dehydration can cause acute kidney injury, causing an increase in BUN and creatinine levels.

It is important for you to know the signs and symptoms of dehydration:

- Low blood pressure, especially when standing up
- Dizziness when standing up
- Rapid pulse rate
- Weight loss
- Fatigue, loss of strength, and confusion
- Dry mouth
- Certain lab values may increase, such as your BUN, creatinine, and hemoglobin
- Low urine output



Eight - 8 ounce glasses

Incision and Wound Care

Clean your incision by showering daily.

No baths, hot tubs, or swimming pools until the incision is completely healed, at least 1 month.

Drainage from the incision may be a small or large amount. This is not unusual. If you have drainage, use a clean, absorbent material such as gauze, feminine pads, or a baby diaper to absorb the fluid. Note what the fluid looks like and if it has an odor. Call the office or the on-call nurse for further directions.

If there is any redness, swelling, or large amounts of drainage from your incision, notify the transplant nurse coordinator.

Restrictions

Activity and Lifting Restrictions

You may have low energy and a lower level of strength after transplant for a couple months. After you are out of the hospital, it is important that you are still able to take care of yourself, such as dressing, bathing, eating, and walking every day.

Walking as much as you can helps to rebuild your energy levels, control weight, prevent constipation, prevent joint and muscle weakness, and can help contribute to your overall sense of physical well-being. It is okay to climb stairs at your own pace. Plan to rest frequently and listen to your body's cues.

Do not do strenuous activity such as heavy lifting (includes pushing/pulling heavy items) for at least 8 weeks after transplant. Do not lift anything greater than 20 pounds for approximately 8 weeks, or as directed by your doctor. After 8 weeks, you may return to non-contact sports such as golfing, swimming, and bowling. We recommend that you check with the transplant office before you participate in any contact sports. Avoid jarring activities such as speed boating, snowmobiling or horseback riding for at least 3 months.

Driving

Driving is allowed approximately 2 weeks after surgery or when cleared by your surgeon.

Returning to Work

If your job requires you to lift heavy objects, you will need to be cleared by the transplant team. If you feel well and the job does not require heavy lifting, you may return at 4 to 6 weeks after surgery. If you need a medical release for your employer, please tell your transplant team during business hours or talk to your nurse coordinator during your office appointment.

Disability Status

Your disability status may change after you have had a transplant. The purpose of a transplant is to restore you to a healthier life. Transplant does not qualify as a disability status. Each patient must be evaluated individually to determine their disability status.

Sexual Activity

You may resume sexual activity 6 weeks after your transplant surgery. If you are sexually active and do not have a steady sexual partner, it is recommended you use condoms to reduce the risk of sexually transmitted diseases such as AIDS, HIV, syphilis, herpes, hepatitis, or gonorrhea.

Females will need to take precautions against becoming pregnant. You should use some type of birth control if sexually active. Should you want to become pregnant, it is very important to discuss this with your transplant doctors. Exposure to some immunosuppressive medication may cause harm to an unborn child. See the Mycophenolate REMS information form located in the Transplant Medications chapter.

Exercise

Once recovered from surgery and cleared by your transplant team, exercise can be great for your physical and psychological health. The rule of thumb is to take it slow and work up to exercising four to six times a week for at least 30 minutes. Be consistent and stop if you experience chest pain, shortness of breath, nausea, rapid heart rate or faintness.

Physical Benefits of Exercise

- Lowers your risk of heart disease
- Tones and strengthens muscles
- Helps to build bone mass, while slowing bone loss
- Improves sleep patterns
- Improves alertness/memory/retention
- Provides energy
- Controls weight
- Lowers your risk of diabetes

Psychological Benefits of Exercise

- Increases your sense of health and well-being
- Lowers anxiety level
- Increases coping abilities for stress
- Improves self-esteem

Precautions to Take

Sun

Some of the medication you take may make you sensitive to the sun; you can burn and/or tan easier, faster, and to a greater degree than before your transplant. If you have a fair complexion, you have an even greater chance of getting severe sunburn.

Transplant patients have a greater chance of developing skin and lip cancers. Skin and lip cancers occur more frequently in people who have increased sun exposure. This is especially common in people who work in the sun, those with lighter skin pigment (fair complexion), and those in areas that have more sunny days.

Ultraviolet rays from the sun may induce skin cancer. These rays are present even on cloudy days and in shady areas. We advise you to always protect your skin from exposure. We suggest that you wear broad brimmed hats and apply sunscreen lotion on any exposed skin. Try to avoid the midday sun, as ultraviolet rays are strongest then.

If you must be outside, plan to be outside in the early morning or late afternoon. Window glass in cars and tractor cabs stop most harmful ultraviolet rays. Swimming should be done in the late afternoon rather than midday, and lotion applied a minimum of 15 minutes before swimming and reapplied frequently. If your occupation requires a great deal of exposure to the sun, wear protective clothes and apply sunscreen (SPF 30 or higher) often.

Please see additional information regarding skin cancer located in the handout at the end of this chapter.

Smoking

If you smoke- we highly recommend you quit. Smoking can cause damage to the lungs, making it much easier for you to have lung infections, including bronchitis, emphysema, and pneumonia. It increases the risk of heart attack and cancer and decreases life expectancy. All of these are worse in someone who is immunocompromised.

Drinking Alcoholic Beverages

You may drink alcoholic beverages in moderation. However, drinking large amounts of alcohol on a daily basis has a possibility of causing damage and failure of the liver. Drinking alcohol may also interfere with the liver's ability to handle certain medications. Drinking alcohol heavily may alter your decision making, which could lead to missing important medications.

Dental Care

Dental follow up is very important after transplant. It is recommended that you should have a dental checkup at least once a year, and if necessary, every six months. However, because of the risk of infection, we recommend you wait until six months after transplant before routine dental care. Traditionally, an antibiotic was given to transplant patients before dental visits to prevent infection. More recent guidelines no longer recommend this as routine practice. Speak with your dentist or transplant physician if you have concerns.

Travel

After your transplant, long trips should be postponed for the first 2 months. After your transplant, be sure to notify your transplant team that you will be leaving the area for extended periods of time. This allows for arrangements to be made for any necessary lab tests. If you should become ill, you should seek medical care immediately.

If you are planning to travel to a foreign country, please check with your transplant team before you receive any vaccines. Plan ahead so you will have enough medication for your trip. Always carry your medicine with you and not in your luggage which could be separated from you.

Steps to monitor your health following transplant:

- Because your immune system is suppressed, you should avoid people with colds, the flu, or other contagious illnesses.
- Wash your hands frequently
- Urinate frequently after transplant, even if you do not feel the urge to do so

Please call the nurse coordinator with any questions, concerns, or problems you may have.

YOUR COMPLIANCE IS CRUCIAL!

One of the most important aspects of success with your transplant is your willingness and ability to follow the healthcare advice of your transplant team. Your transplant organ was a gift. Following the medical advice of the transplant team allows you to care for that gift and honor the organ donor. Take good care of your new organ by taking your medication as directed, get labs drawn when instructed and go to your clinic appointments.

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CHAPTER 4 - LABS AND FOLLOW UP

After discharge, patients typically need blood tests (labs) two times a week and will need to see the transplant surgeon or transplant nephrologist 1-2 times a week in the office. Initially, all labs will be done at OSF HealthCare Saint Francis Medical Center in Peoria, but as your progress allows, you may get labs at a local facility closer to home.

It is very important to get your labs drawn and come to all of your appointments as scheduled by your physician. If you need to cancel an appointment for any reason, please be prepared to reschedule immediately while on the phone with the transplant team. Failing to reschedule your appointment and get your lab work as recommended may increase your risk for kidney transplant rejection.

After transplant, the transplant surgeon and transplant nephrologist will manage your care for the first six months. After six months, we will partner with your pre-transplant nephrologist for care. You can expect alternating visits between your nephrologist and the transplant office during this time. After 3 years, if you are stable after transplant, your care will fully return to your pre-transplant nephrologist. In some instances, the transplant office will always manage your immunosuppression medications.

In this chapter we will discuss:

- Transplant clinic visits
- What to expect on the day of your clinic visit
- Blood draw check in process
- Blood work on days you do not have appointments
- Routine lab schedule for the first 6 months
- Communication
- Common labs / tests we monitor
- Transfer of care / follow up

Transplant clinic visits

New transplant patients should expect to have labs drawn at the OSF HealthCare Saint Francis Medical Center lab, located in Zone 9 by admitting on the day of your appointment. This needs to be done prior to coming to the office for your clinic visit.

On the Day of Your Appointment:

On the morning of your follow up appointment, and on days you are required to get blood drawn, take all of your regular medications **except** Tacrolimus (Prograf).

You may eat and drink prior to labs unless instructed otherwise.

Your first several clinic visits can take several hours. You may see multiple team members, including a nephrologist, transplant surgeon, nurse, pharmacist, and medical assistant. Social workers are also available for support and resources when requested. Be prepared for a long morning and bring what you will need to be comfortable.

What to Bring to Your follow up appointments:

- Your patient education guide
- Your daily dose of tacrolimus (After your blood draw, you can take your transplant medicines)
- Your most current medication list and all of your medication bottles*
- Daily record, including weights, temperatures, blood pressures, pulse, and blood sugars if applicable.
- Note of any medications for which you will need new prescriptions or refills
- A snack and pain medication if you feel you will need them
- A list of questions you may have
- Any paperwork given to you at discharge
- Your support person

*Always bring a list of your current medications to every visit. Your medications are an important and essential part of your care. We recommend that you write down any medication changes or new instructions given to you anytime a medication is changed. You will receive a new and updated medication list every time you come to the transplant office for an appointment. **Always follow directions on your medication list provided. Never rely only on medication bottle labels, these may not reflect changes made.**

Blood Draw Process, Common Labs, and Diagnostic Tests

Blood Draw Check-in Process:

When you arrive at the hospital for a follow up appointment, you will go directly to the lab at OSF HealthCare Saint Francis Medical Center in Zone 9 by admitting. The laboratory orders (requisitions) will be ordered in the computer system for you. Always use the lab orders provided by the transplant team. These orders may be placed under any of the transplant physicians.

It can also be helpful to make a laboratory appointment on the days your labs are due. Please ask your transplant coordinator for further instructions on how to make appointments if you need assistance.

OSF HealthCare Saint Francis Medical Center – Main Campus Entrance

Parking Deck A/ Circle Drive
1300 N. Berkeley Ave
Peoria, IL 61637

Lab hours:

Monday - Friday 5 a.m. - 6:30 p.m.
Weekends and Holidays - 6 a.m. - 2:30 p.m.

Parking Deck A is the best to use when visiting the main campus lab.

Blood Draw Timing:

A trough level is required for one of your anti-rejection medications called tacrolimus (Prograf). A trough level is the measurement of a certain drug level in the blood at the time when it is the lowest and occurs just before your next dose of the drug is due. This level should be done 12 hours after your evening dose of tacrolimus (Prograf).

For example: If you take your medication at 8:00 PM, the level should be drawn as close to 8:00 AM as possible the next day, prior to taking your morning dose of the medication.

The best time to get your labs completed is 12 hours after the last dose of tacrolimus. We understand that your wait in the lab may delay being able to get your labs completed exactly 12 hours after your evening dose, therefore, an acceptable time would be 11-13 hours after your last dose of tacrolimus.

Occasionally, you may need to give a urine sample. Therefore, we recommend you do not stop at the restroom on your way into the medical center until you know that the lab does not need a sample.

After labs have been collected, proceed to the Transplant Services office on the 4th floor of the Hillcrest building. Once you arrive, check in at the transplant desk with the front office staff.

OSF HealthCare Transplant Services

420 NE Glen Oak Ave
Peoria, IL 61603

Parking Deck C is best to use when visiting the Hillcrest Medical building.

Blood work on days when you do not have an appointment:

You will need to have blood tests between office visits.

Your routine lab schedule for the first six months after transplant is defined below. With a new transplant, you will need blood tests frequently to evaluate how your new transplant is functioning. Frequent blood work also helps with managing the dosing of your anti-rejection medication and may help to indicate any other health problems or electrolyte imbalances that may need to be corrected.

You may eat and drink fluids prior to your labs unless you have been directed not to do so.

Initially after transplant, your labs will need to be collected at OSF HealthCare Saint Francis Medical Center in Peoria in order to receive prompt results. Once your medications are well regulated and your labs are stable, your blood tests can be done at an outpatient facility near your home. The frequency of your labs will gradually change over time, and eventually you will only need labs once a month.

If you will be transitioning to a lab near your home, you may go to an OSF HealthCare location or another outpatient lab near you. If you need assistance to find an OSF HealthCare facility closer to home, please ask your transplant coordinator. If you choose an OSF HealthCare facility, the lab orders will be in the OSF HealthCare computer system for you. If you choose a non OSF HealthCare facility, the transplant team will provide you with a standing order form for labs.

Example routine lab schedule after transplant (this can vary from patient to patient)

Post op status	Frequency of labs and location
0-3 weeks	Twice weekly at SFMC in Peoria
4-8 weeks	Twice weekly at local hospital if applicable
9-12 weeks	Weekly
3-6 months	Every other week
>6 months	Monthly

All transplant recipients must continue routine blood tests as long as they have a functioning transplant.

Common Labs We Monitor

The following tests will be collected every time labs are done:

- Renal function panel (creatinine, electrolytes, glucose)
- Complete blood count (WBC, RBC, hemoglobin/ hematocrit)
- Magnesium
- Tacrolimus level

Creatinine: This is a waste product that comes from your muscles and is cleared out by the kidneys. A low creatinine means the kidney is doing a good job cleaning the blood. A higher creatinine is a sign the kidney may not be doing well.

Electrolytes: Potassium (K), sodium (Na), magnesium (Mg), phosphorous (PO₄), calcium (Ca). These are basic elements important to your body's normal functioning. The levels can be affected by your diet, kidney function, and medication.

Blood sugar/glucose level: Measures the amount of "sugar" in your blood.

White blood cell count (WBC): These are infection-fighting cells. A high count can be a sign of infection. A low count may be due to transplant medications.

Hemoglobin (Hgb): A low blood count is called anemia. Hemoglobin carries needed oxygen to all parts of the body. Many patients with kidney disease have anemia. After a kidney transplant, anemia usually improves.

Some additional tests we may get with labs include:

Virus PCR (BK virus): Polyoma BK Virus is a common virus that can affect the kidney transplant. See more information regarding BK virus in the infection section of this education guide.

Cytomegalovirus (CMV): This is a virus that cause a flu-like infection after transplant that can be serious. Anytime a patient takes immunosuppressant medication, they are at risk for this virus to "attack" the body. You may need to take antiviral medicine for several months after transplant to avoid becoming ill from this. See more information regarding CMV in the infection section of this education guide.

Urine Protein: Creatinine Ratio: Protein in the urine can be a sign of kidney problems.

Other Diagnostic Tests

Transplant Ultrasound: This is done in the radiology department to look at the kidney transplant. A handheld wand will be put on your skin near the transplant incision and pictures of the kidney transplant are taken. An ultrasound shows blood flow and appearance of the kidney transplant. Ultrasounds can be repeated as often as needed without any danger to you or your kidney.

Communication

Medication Adjustments Following Lab Results

After review of your lab results by the transplant team, medication dosages are frequently adjusted. It is very important that we are able to communicate with you. Please make sure to set up voicemail and keep your voice mailbox clear so that you can accept messages. If we are unable to get a hold of you and are required to leave a voicemail, we request you call our office back to confirm that you have received the message. We also suggest you provide an alternate number where we can contact you if needed, and if you move or change your phone number, please notify our office as soon as possible.

Patient Portal

Another option for communication is via OSF MyChart. We strongly recommend that you sign up for OSF MyChart to communicate with your transplant team. This is also a wonderful way to keep track of your health and monitor your own labs. It is important to read messages in a timely manner and send back a reply if needed.

You can access OSF MyChart by visiting osfmychart.org and follow instructions to sign up.

Transfer of Care Follow Up Post-Transplant

Primary Care Doctor and Local Nephrologist

Primary Care Doctor

It is necessary to have a primary care physician to see you for routine medical issues other than your kidney and/or pancreas transplant; this is recommended after your 6-month post-op visit. The transplant team cannot provide routine healthcare for you, such as for colds, flu, pain management and routine health maintenance services, therefore it is important to continue your routine health maintenance through your primary care physician.

We do not prescribe antibiotics for symptom management over the telephone. In the event you do not establish a relationship with your primary care physician, and you become ill, you will be sent to your local urgent care or emergency room. Always contact our office with any health status changes and to review any medication prescribed by non-transplant doctors before taking the first dose.

Be sure to inform your primary care physician of all the medications you are taking as some drugs cannot be taken with immunosuppressive medications.

If you need assistance with finding a primary care doctor, please reach out to the transplant office.

Local Nephrologist (Kidney Doctor)

We will partner with your local nephrologist in managing your care after transplant. We require that you have a local nephrologist who will collaborate with us in taking care of you. Our office will help you make an appointment to reestablish care with your local nephrologist.

At your 6-month post-transplant visit, if you are stable, you will start to transition back to your primary local nephrologist. At that time, they will start to manage certain medication such as blood pressure medication, and any electrolyte supplements you may be on (phosphorous, magnesium, bicarb).

The transplant office will continue to manage your immunosuppression medication and tacrolimus levels until you are 3 years post-transplant. The transplant team will see you for your 1 year, 1.5-year, 2-year, 2.5 year, and 3-year visit. We will partner with your local nephrologist to make sure they are also seeing you in between your visits with the transplant team. Ultimately, you should be seeing a provider every 3 months, whether that is the transplant nephrologist or your local nephrologist. After 3 years your care will be fully assumed by your local nephrologist. In some cases, we will continue to see you once a year or more frequently as needed.

Endocrinologist

If you are diabetic and had an endocrinologist prior to transplant, we will also begin to transition you back to your endocrinologist approximately 6 months post-transplant.

Kidney Transplant Patient Education Guide

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CHAPTER 5 - Infection

Immunosuppressive medications limit the action of your white blood cells (WBC) and weaken your immune system. This prevents the immune system from attacking your new organ but makes it harder for you to fight off infection. It is important that you try to prevent infection and watch for signs and symptoms of infection.

The types of infections that can occur include:

- Bacterial (infection from bacteria)
- Viral (infection from a virus)
- Fungal (infection from fungus)

You will be on certain medications to try and prevent these infections.

In this chapter, we will review some infections that can occur post-transplant.

Signs and Symptoms of Infection

While you are on immunosuppressive medication you will need to watch for the following signs and symptoms of infection:

- Fever of 100.5
- Joint pain
- Fatigue
- Sores or rashes in mouth or on skin
- Redness, swelling, or drainage from incisions
- Pain or burning with urination and frequent urination of small quantities
- Blood in your urine or stool
- Persistent headaches
- Sore throat
- Decrease appetite
- Nausea / Vomiting / Diarrhea
- Productive cough
- Any feelings of being “sick” that you cannot explain

If you develop any of these signs or symptoms, contact your transplant nurse coordinator.

Prevent Infection by Protecting Yourself

Early in transplant you are more at risk for infection. There are ways to try and prevent infection by protecting yourself.

- Wash your hands frequently. This is the best way to stop the spread of germs and to prevent infection.
- Always keep a bottle of hand sanitizer with you
- Keep your hands away from your face and mouth. Wash your hands after coughing or sneezing, and throw tissues in the trash immediately
- Shower daily. Take good care of your skin. If you have a cut or scrape, no matter how small, clean with soap and water.
- Practice good dental hygiene
- Eat a healthy, well-balanced diet and follow safe food preparation guidelines. Do not eat unpasteurized foods (farm-fresh eggs/milk/cheeses).
- You may keep your pets, but you should not handle cat litter. The feces of some animals contain parasites and can cause infections. If you cannot avoid pet waste, use gloves, and use excellent hand washing afterwards.
- No birds should be in the house that a transplant recipient is living in. Birds kept inside the home put you at high risk for a life-threatening infection called histoplasmosis.
- Wear gloves and wash hands after gardening
- Wear a mask in situations where you may inhale dirt, soil, dust, or mold

For the first 6 weeks, try to avoid large groups and limit the number of visitors. You should avoid being around friends or relatives that you know are sick. If someone who lives with you gets sick with a cold or the flu, precautions should be taken such as using separate drinking glasses and covering their mouth when they cough. Once someone in your family is sick, the exposure to you has already occurred. If you get sick, notify the transplant office.

COMMON INFECTIONS

Bacterial Infections

Bacterial infections can happen at any place in the body, including:

- Lungs
- Bloodstream
- Urinary tract
- Incision area

If being treated with medicine to fight the infection, called antibiotics, it is very important to finish all of the medicine. Even if you feel better before taking all of your medicine, you must finish it as ordered. Do not start antibiotics until speaking with the transplant team.

Pneumocystis jirovecii Pneumonia

This is caused by a fungus. This fungus is common in the environment and rarely causes illness in healthy people, however, it can cause a lung infection in people with a weakened immune system.

Symptoms include:

- Cough
- Fever
- Shortness of breath

You will be placed on a medication called sulfamethoxazole / trimethoprim (Bactrim, Cotrimoxazole) to prevent this infection. If you are allergic to sulfa, you may be given a different medication.

Urinary Tract Infection (UTI)

Urinary Tract Infection symptoms include:

- Increased pressure and/or urgency to urinate
- Increased frequency of urination
- Burning with urination
- Low back or abdominal pain
- Blood in urine
- Fever

Preventing a urinary tract Infection

- Do not use bubble bath
- Women should clean from front to back after voiding and bowel movements
- Urinate before and after sexual intercourse

Viral Infections

Community Acquired

- Influenza (flu)
- Common Cold
- COVID-19

Viral Infections from your body

Some of the viral infections that are of particular concern are CMV, BK Virus, Herpes simplex virus (HSV), and varicella virus (chicken pox).

A history of infection with CMV or HSV is common. You may have been exposed to some of these viruses earlier in life. This is checked in the pre-transplant workup.

These infections can stay dormant in your body for a lifetime, and you may not even know. After transplant, because of your immunosuppressive medication, these viruses can reactivate and cause serious illness.

Cytomegalovirus (CMV)

CMV is a common infection following kidney transplant. You can get it from the donor if you have never had it, or it may be a virus you have already had in your body. CMV usually causes a mild illness, with flu-like symptoms in the general population. Reactivation of the dormant CMV or new CMV infection can cause serious illness after transplant.

You may be placed on a medication called valganciclovir (Valcyte) for the first three to six months in order to prevent serious illness from this virus.

Signs of CMV infection:

- Extreme tiredness (fatigue)
- Fever
- Nausea / vomiting / diarrhea
- Night sweats
- Aching joints
- Headaches
- Shortness of breath
- An overall feeling of “just not feeling good”

Call your transplant team if you have any of these symptoms.

Polyoma BK Virus

BK virus is a virus that most people get earlier in life. Once you get BK virus, the virus stays in your system forever. This is called latent, or “asleep” in your body, and it generally doesn’t cause a problem in most people. Sometimes, when your immune system is not working well, the virus “wakes up.”

BK virus can become active in the transplant patient as a result of the anti-rejection medicines and can affect the transplanted kidney.

BK virus can harm the kidney and slow the kidney function. In order to detect the virus before any changes in kidney function are seen, the transplant team screens your blood for BK virus. If you have BK Virus, your doses of anti-rejection medicines may be lowered.

Herpes Zoster (Shingles)–(VZV)

Shingles is also called herpes zoster. It is a skin rash caused by the varicella zoster virus. This is the same virus that causes chickenpox. After a person has chickenpox, the virus remains inactive. Years later, the virus can become active again and travel to the skin. It appears as a rash or small water blisters, and most commonly appears on the chest, back, or face, but may occur in other areas. This rash may or may not be painful. Call your transplant coordinator immediately if you have this kind of rash. A vaccine is available to reduce the risk of this.

Herpes Simplex Virus (HSV)

These viruses most often infect the mucous membranes.

HSV type I causes cold sores and blisters around the mouth and can cause genital lesions. HSV type II causes genital sores. HSV is transmitted by direct contact of secretions from an infected person to one who is not infected. Most infections are mild, but sometimes they can be severe.

Symptoms of herpes include:

- Tingling sensation before an outbreak
- Painful, fluid-filled sores in your mouth or genital area.
- Fever

If you have sores or lesions, contact your transplant team right away

Medication can shorten an outbreak but must be started within 2-3 days.

Fungal Infections

Candida (Yeast)

Yeast infections occur when yeast grows in moist areas of the body such as the mouth, groin, armpits, or genital areas. When it is growing in the mouth, it is called **thrush** and appears as white, patchy fuzzy areas on the roof of the mouth, sides of mouth, throat, or esophagus. It can cause pain and tenderness and make swallowing difficult.

It is prevented with nystatin “swish and swallow liquid.” You will start this medicine after your transplant and continue until you have been home for approximately 1 week. If thrush occurs after completion of nystatin, there are several additional drugs your physician can choose from to treat it.

Rare infection (Birds, dust, mold, soils)

Aspergillosis

Aspergillus is a common mold/fungus. Aspergillosis enters the body by breathing infected air found in damp or dusty places such as old barns, construction sites, basements, attics, etc.

Histoplasmosis

Histoplasmosis is a disease that travels through the air. It is found in bird and bat droppings. You can also come in contact with it when contaminated soil is disrupted by construction or renovation activities. It typically causes a lung infection (pneumonia).

Because these fungal (mold) infections enter the lungs, we recommend you always wear a mask when working in situations where soil, dust, or mold may be disturbed.

Other Types of Infection

Toxoplasmosis

Toxoplasmosis is an infection caused by a parasite that is often found in cat feces. It can cause a brain abscess (infection). Because it can cause severe symptoms in someone with a weakened immune system, you should not change litter boxes.

Tuberculosis (TB)

Tuberculosis is an infection contracted by breathing infected airborne droplets. TB is mainly an infection of the lungs. Tell the transplant team right away if you have contact with a person suspected of having or has been diagnosed with TB.

Symptoms include:

- Cough
- Coughing up blood
- Night sweats
- Shortness of breath
- Weight loss
- Chills

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CHAPTER 6 - Biopsy and Rejection

Organ rejection happens when your body's immune system recognizes something that does not belong in your body and tries to protect you by attacking it. It is important to get blood tests as directed by your transplant team. These blood tests can help the doctors and nurses understand how well your kidney and immune system are working.

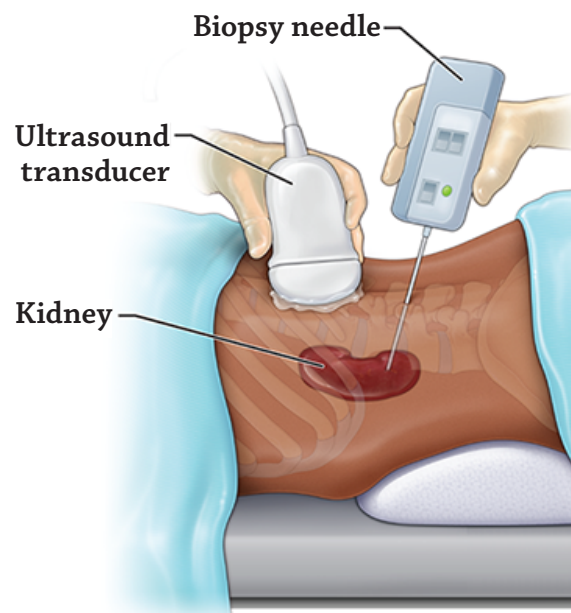
A biopsy is the best way to detect early problems with your kidney transplant. Treatment plans can then be developed for identified issues. Biopsies can be performed at any time if there is any question of how your kidney is functioning.

Biopsy

Sometimes, blood and urine tests are not enough to determine how the kidney is functioning. In order to accurately diagnose rejection, a biopsy is performed. This is an outpatient procedure. A biopsy is done to obtain a tiny piece of kidney tissue for examination under a microscope. It is usually performed using ultrasound and a special needle. This can also be performed by CT guidance, or in the operating room.

The physician will numb the biopsy site. A needle will then be inserted into the transplant organ under the guidance of an ultrasound or CT scan. 2-3 tissue samples will be taken for analysis. The procedure itself takes 30 -45 minutes and is performed at the bedside in your hospital room. You will be asked to remain in bed for a period of time to prevent complications. A blood count will be performed 4 hours after the biopsy to check for bleeding. If the blood count is stable and your condition is stable, you may be discharged home. Risks include bleeding and injury to the kidney.

The tissue sample will be tested and studied under a microscope. The pathologist will assess the tissue for signs of rejection, recurrent disease, toxicity, or viruses. Based on the results, a course of treatment will be determined. You will be notified of the results 24-48 hours after the biopsy.



Rejection

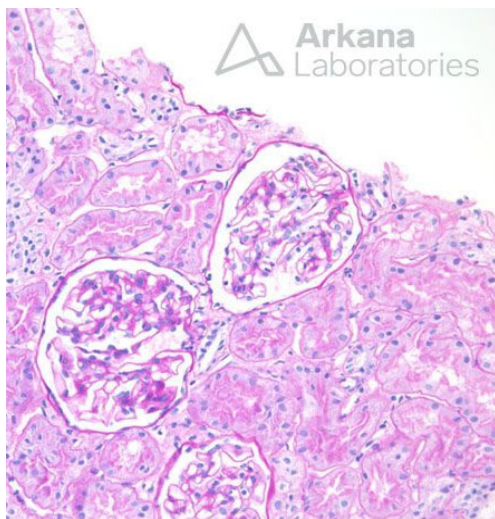
Rejection is a natural response by the immune system when the body sees something it considers foreign, for example, your new transplanted organ. Rejection can be thought of as inflammation (an immune response) against the kidney. Episodes of rejection can happen at any time following transplant. While rejection is most likely to occur within the first few months after surgery, it can also happen years later. Rejection is classified by how long it has been going on and how severe it is:

How long has the rejection been happening?

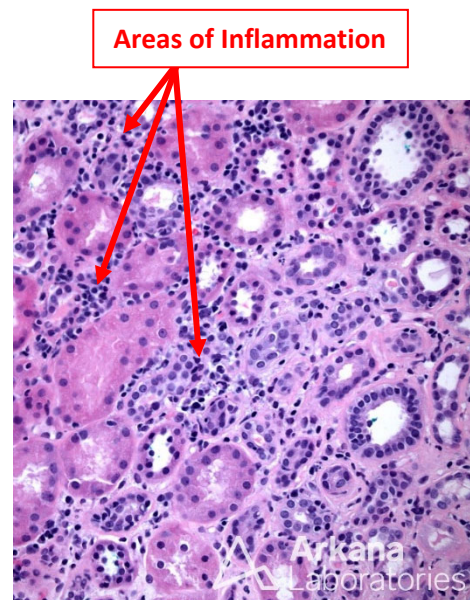
- Acute rejection: recent, quick-moving attack (days or weeks)
- Chronic rejection: slow, gradual long-lasting attack (months or years)

How severe is the rejection?

- Mild rejection: only a small amount of inflammation in the kidney
- Moderate rejection: a medium amount of inflammation in the kidney
- Severe rejection: a very large amount of inflammation in the kidney



Normal



Moderate Rejection

The following slides were obtained from Arkana Labs.

<https://www.arkanalabs.com/>

Kidney transplant biopsies obtained at OSF HealthCare HealthCare Saint Francis Medical Center are sent out to Arkana Labs for testing.

Typically, an episode of rejection will cause no symptoms. The only sign that something is wrong may be changes in your blood or urine tests. **This is why you will need to get regular lab tests for the life of the kidney.**

Sometimes, if the rejection is unusually severe, there can be symptoms. These could include:

- Fever
- Pain or tenderness over the organ
- Swelling in the legs
- Decreased urine output.

A kidney biopsy is the only reliable method to find out if rejection is developing. Rejection is usually treatable with anti-rejection medicines.

What treatment is needed, and how successful we will be at recovering the kidney, depends on what type of rejection it is. Generally, a rejection episode that is mild and/or acute is more likely to be treatable than one that is severe or chronic.

This is why it is so critical to get regular lab tests as scheduled. If we can catch a rejection in the very early/mild stage, we have a very high likelihood of fixing it. If the rejection continues for weeks or months without treatment or is allowed to become so severe that there are symptoms – there is a high chance that we will not be able to save the organ.

Rejection treatment

The treatment for a rejection episode depends upon the type of rejection found.

- Oral or IV steroids
- IV antirejection medication – this will require inpatient admission.
 - These are very potent immunosuppressive drugs, which target the cells that are causing the rejection.
- Plasmapheresis – a treatment to remove antibodies from the blood

A follow-up biopsy of the organ is sometimes done to make sure treatment is working.

If the rejection cannot be reversed, your anti-rejection medication will be adjusted, and your transplanted organ may need to be removed. At this time, you would return to dialysis, and may be referred for another transplant when fully recovered.

The best way to prevent rejection is to take medicines as ordered by your doctor. Each rejection episode can hurt your transplanted kidney. You may have less chance of damage to your kidney, the sooner the treatment is started. Do not miss lab appointments or checkups. Medicine levels will be checked by blood sample, and this will help make sure you are on the right dose of your medicines to help prevent organ rejection.

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CHAPTER 7 - Transplant Medications

One of the most important keys to success after transplant is to make sure you take your medicine as ordered by your physicians. You are responsible for taking your medicine as directed. Your transplant coordinator and pharmacist will help you learn about your new medicines. **Never stop or start a medication or change a dose without approval from the transplant team.** Some of the medication you were on prior to transplant may be stopped after your transplant. This will be reviewed prior to your discharge.

A transplant patient must take medicine to prevent the immune system from rejecting the new organ. Anti-rejection medicine must be taken exactly as prescribed by your transplant team. These drugs decrease the body's immune response to help protect your organ, causing your immune system to have a reduced ability to fight infection. This is called immunosuppression.

Your physicians, transplant coordinator, or transplant pharmacist are all available to answer any questions or discuss any concerns you may have. It is important that you NEVER run out of medicine. Please plan ahead of time to avoid any problems or delays in receiving your medicine.

Before leaving the hospital, you should know:

- The names of all your medication
- What each pill looks like
- The purpose of each medication
- The dose of each medication
- When to take each medication
- Possible side effects and important information

Multiple new medications will be started after receiving an organ transplant.

Anti-Rejection Medications:

Anti-rejection medications help to prevent your immune system from attacking your new kidney as a foreign object.

Initially, you will be given multiple intravenous drugs to prevent acute rejection. These medications will protect you and your new kidney until oral medications are started and are at acceptable levels to prevent rejection. The most commonly used induction medication is basiliximab (Simulect) and methylprednisolone (Solu-Medrol), which is a steroid. Sometimes, antithymocyte globulin (Thymoglobulin) is given.

Most patients take a combination of three oral medications to prevent rejection

- tacrolimus (Prograf)
- mycophenolate (Myfortic or Cellcept)
- prednisone

Medication to Prevent Infection

Anti-infection medication is a group of medications that helps prevent infections in your body. These will be given because your body's immune system will not be able to fight infection, due to your anti-rejection medication.

You will take three medications to prevent infection

- One to prevent bacterial infections
- One to prevent viral infections
- One to prevent fungal or yeast infections

The following pages will explain each medication in detail along with possible side effects.

Anti-Rejection Medications

Tacrolimus (Prograf, “Fk” or “Fk-506”)

Tacrolimus is used to prevent or treat rejection. It lowers the body’s immune response to the transplanted kidney.

Instructions

Tacrolimus should be taken every 12 hours and at the same time every day.

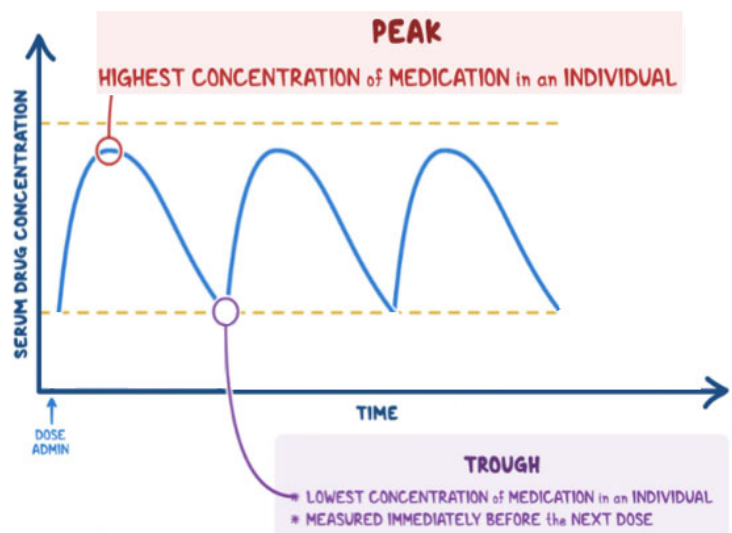
Example: If you take your morning dose at 8 a.m., your evening dose is at 8 p.m.

Dose Changes and Lab Monitoring:

- Tacrolimus doses will be changed based on a blood level drawn by the lab, called a tacrolimus level
- Do not take your tacrolimus dose before your blood is drawn. The transplant team wants to see the “trough” level, which occurs approximately 30 minutes before you take your next dose. Take the prescribed dose after your blood is drawn. The transplant doctor will evaluate the result of the tacrolimus level and make changes if needed.
- The transplant team will occasionally make changes to your dose based on additional lab tests or any of the following side effects. The transplant coordinator will call you if you should change your dose.

Possible Side Effects of Tacrolimus

- Tremors
- Headaches
- Hair loss
- Trouble sleeping/ vivid dreams
- Difficulty with concentration
- High blood pressure
- High blood sugar
- Increase in cholesterol levels
- Decrease in magnesium levels
- Increase in potassium levels
- Abnormal kidney function



Important information / special considerations

Do not drink grapefruit juice or pomegranate juice because it can interfere with your tacrolimus level. Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Mycophenolate Sodium (Myfortic, Mycophenolic acid) or Mycophenolate Mofetil (Cellcept)

Mycophenolate is used to prevent or treat rejection. It lowers the body's immune response to the transplanted kidney.

Instructions

Mycophenolate should be taken every 12 hours and at the same time every day. For example, if you take your morning dose at 8 a.m., your evening dose is at 8 p.m.

Dose Changes

Your mycophenolate dose will generally not change unless you are having intolerable side effects, or if your white blood cells are too low.

Possible Side Effects of Mycophenolate

- Stomach discomfort
- Diarrhea
- Nausea/vomiting
- Decrease in platelets
- Decrease in white blood cells
- Increase risk of infection

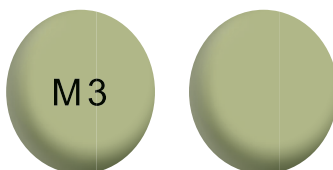
Important Information / Special Considerations

Mycophenolate usually comes in tablets or capsules; these should not be opened or crushed. Wash with soap and water if contents of capsules come into contact with skin.

Women of childbearing age should use two forms of birth control while taking mycophenolate and for six weeks after stopping the medication. Mycophenolate has been associated with birth defects or fetal death in pregnancy. Always check with the transplant team before planning a pregnancy.

Please see REMS education located at the end of this chapter for more information.

Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Prednisone

Prednisone is a corticosteroid and is used to prevent or treat rejection. It lowers the body's immune response to the transplanted kidney.

Instructions:

Prednisone is usually taken once a day and should be taken with food.

Dose Changes

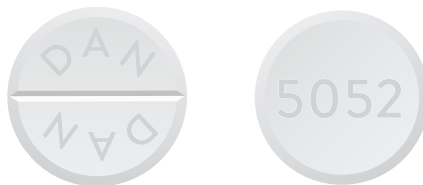
Initially after transplant, your prednisone dose will be gradually tapered down to a maintenance dose. Your prednisone dose may be changed in the future based on how your organ is doing.

Possible Side Effects of Prednisone

- High blood sugar
- Increase in appetite and weight gain
- Round face or “chubby cheeks”
- Mood changes or anxiety
- Trouble sleeping
- Night sweats
- Pimples
- Purple or red bruising
- Vision changes
- Osteoporosis
- Increased risk of infection
- Increase in cholesterol levels
- Stomach irritation/ulcers
- Diabetes

Important information / special considerations

Do not stop taking prednisone all at once. Doses should be reduced with a doctor's instruction. Be alert for infections and report any black tarry stools or abdominal pain. Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Belatacept (Nulojix)

Belatacept is used to prevent rejection. It lowers the body's immune response to the transplanted kidney. This medication may be used to replace tacrolimus. Belatacept usually has fewer side effects than the other medications. You may be changed to this medication if your transplant physician thinks it is appropriate.

Instructions

Belatacept is given as an infusion for approximately 30 minutes every 28 days. Belatacept may be given more frequently during the first few months when starting therapy.

Dose Changes

Doses of Belatacept are based on your weight. The dose usually remains the same.

Risks of Belatacept

- Decreased white blood cell count
- Increased risk of infection
- Increased risk of malignancy
- Abnormal kidney function

Side effects are uncommon, but could include:

- Headaches
- Nausea/vomiting/diarrhea
- Constipation
- Edema
- Fever
- Cough

Important information / special considerations

Because Belatacept is administered through your vein, if you have difficulty with intravenous access, you may not be a candidate to receive Belatacept.

Belatacept is used in place of tacrolimus. You may be instructed to slowly decrease your dose of tacrolimus when starting Belatacept. Your doctor will give you specific instructions. You must continue to take your other anti-rejection medication as instructed by your doctor. Belatacept is typically given as part of a regimen in combination with mycophenolate and prednisone.

Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements

Azathioprine (Imuran)

Azathioprine is used to prevent or treat rejection. It lowers the body's immune response to the transplant kidney.

Instructions

Azathioprine is usually taken once a day.

Dose Changes

The transplant team will determine your dose of azathioprine based on your weight, white blood cell count, and renal function. Your dose may also change based on other factors, such as lab tests or possible side effects.

Possible Side Effects of Azathioprine

- Nausea or vomiting
- Increased risk of infection
- Decrease in white blood cell count
- Decrease in platelets
- Bone marrow suppression
- Elevated liver enzymes
- Increased risk of skin cancer

Important information / special considerations

Report any unusual bleeding or bruising, report any rash or yellowing of skin or whites of eyes, do not take allopurinol (a medication for gout) when you are taking azathioprine, it can suppress your bone marrow.

Check with the transplant team for any possible drug interactions before taking any new medications, including herbal supplements.



Medications to Prevent Infection

Sulfamethoxazole/Trimethoprim SS (Bactrim, Septra, “Smz-Tmp,” Cotrimoxazole)

Bactrim is used to prevent pneumocystis carinii (jirovecii) pneumonia (PCP), and some UTI’s. This is a “sulfa” medicine. The transplant team will prescribe a different medication for you if you are allergic to sulfa medication.

Instructions

Bactrim 400/80 mg daily for at least one year. This is often continued indefinitely. Please do not start or stop medication unless directed by your physician.

Possible Side Effects of Bactrim

- Nausea
- Rash/itching
- Increase in sensitivity to sunlight
- Do not take Bactrim if you are allergic to sulfa medication
- Wear sunscreen to protect your skin from sunburn

Important information / special considerations

Report any rash or skin blistering to your doctor. Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Valganciclovir (Valcyte)

Valganciclovir (Valcyte) is used to prevent viral infections, including a virus called cytomegalovirus (CMV). Transplant patients are more susceptible to developing this infection if they have not had cytomegalovirus in the past, but the donor has. This will be checked in your pre-transplant evaluation.

Instructions

Valganciclovir is usually taken once or twice daily for 3-6 months. The dose or schedule may be adjusted based on your kidney function. Please follow the directions given to you by your transplant team regarding how long you will need to take valganciclovir.

Possible Side Effects of Valganciclovir

- Nausea
- Headache
- Diarrhea
- Dizziness
- Numbness or tingling in hands or feet
- Decrease in white blood cell count
- Decrease in red blood cell count
- Decrease in platelets
- Increase risk for infection

Important information / special considerations

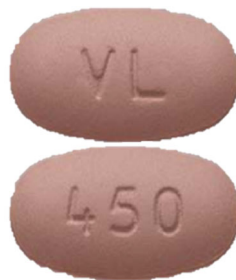
Your transplant team will monitor your white blood cell counts while you take this medication.

Report any unusual bleeding or bruising

Do not crush, chew, or cut tablets before swallowing. Avoid direct contact of broken or crushed tablets with the skin or mucous membranes

Valganciclovir may cause birth defects and impaired fertility; men and women of childbearing age should use birth control during treatment with valganciclovir.

Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Valacyclovir (Valtrex)

Valacyclovir (Valtrex) is used to prevent / treat viral infections, including herpes simplex viruses, shingles, and chickenpox.

Instructions

Valacyclovir is usually taken once or twice per day for 3 months. However, the dose or schedule may be adjusted based on your kidney function.

Possible Side Effects of Valacyclovir

- Nausea
 - Headache
 - Diarrhea
 - Vomiting
 - Rash
 - Dizziness
 - Decrease in white blood cell count
 - Decrease in red blood cell count
 - Decrease in platelets
- Special Notes**
- Your transplant team will monitor your blood cell counts while you take this medication
 - Report any unusual bleeding or bruising

Important information / special considerations

Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Nystatin Liquid

Nystatin liquid is used to prevent and/or treat oral thrush, which is white, patchy areas in the mouth or on the tongue due to a yeast infection. Sometimes this yeast can also irritate the esophagus.

Instructions

Nystatin liquid should be used four times a day after eating and at bedtime. You should not eat or drink for at least 30 minutes after using nystatin. Patients should swish the medicine in their mouth and then swallow it, allowing it to coat the surfaces of the mouth. You will take 1 week after discharge home.

Dose Changes

Your nystatin dose will not change during the course of therapy. Remember that the dose of 5 mL (measured in a dose cup or syringe) is equal to one teaspoon.

Possible Side Effects of Nystatin Liquid

- Unpleasant taste
- Nausea/vomiting
- Diarrhea

Important information / special considerations

Check with the transplant team for any possible drug interactions before taking any new medication, including herbal supplements.



Other Routine Medications

High Blood Pressure Medication

The medication that you take to prevent rejection can cause high blood pressure. The transplant team will determine if you need medicine for high blood pressure and which one is right for you.

High Blood Sugar Medication

The medication that you take to prevent rejection can also cause high blood sugar levels. This may increase your risk of developing diabetes after transplant. Even if you had diabetes that was controlled before transplant, you may need adjustments in your oral medications or insulin after transplant.

Refer to the post-transplant diabetes handout at the end of this chapter to learn more.

Antacids/Anti-ulcer Medication

Some of the medications you are taking can cause stomach irritation. You will usually be prescribed one of the following medications to protect your stomach: omeprazole (Prilosec) or pantoprazole (Protonix).

Vitamins

Vitamins are used to supplement the diet, so you receive the recommended daily nutrition requirement. Please avoid multi-vitamins with “extra” ingredients such as weight loss, energy boosters, etc. These “extras” can interfere with the absorption of your transplant medication. You may be asked to take a daily multivitamin. After transplant, you will no longer need the “dialysis vitamin.”

Aspirin

Some transplant patients may need to take an aspirin each day to reduce the risk of heart problems. You will be taking this medication to decrease your chance of blood clots after your transplant. The specific action of this medication is to keep platelets from sticking together, which helps prevent blood clots from forming.

Special Notes

Transplant patients should never take extra aspirin for pain or fever. Any excessive bruising, blood-tinged urine or blood-streaked sputum should be reported.

Pregnancy and Transplant Medication

Some medication used after transplant can pose a risk to an unborn baby developing in the mother’s womb. Always check with your transplant doctor before planning a pregnancy; contact your transplant doctor immediately if you think you are pregnant.

Refer to REMS education at the end of this chapter for more information.

Over-the-counter Medication

Headache, Muscle Aches, or Pains

You may take Tylenol (acetaminophen) or a pain medication that is prescribed by the transplant team. Do not take more than 3,200 mg of Tylenol per 24 hours, which is no more than six double-strength (500 mg) tablets or ten regular-strength (325 mg) tablets.

Do not take:

- Ibuprofen (Motrin, Advil) or Naproxen (Aleve)
- Any other non-steroidal anti-inflammatory (NSAID) medication

These medications can harm your kidneys.

Constipation

You may take Fiber-Con, Miralax or Senakot for constipation. Taking docusate (Colace) regularly can also be used to prevent constipation. Exercising, drinking plenty of water and increasing fiber in your diet are other ways to help relieve constipation. Contact the transplant team if constipation persists.

Diarrhea

Always drink enough fluids to prevent dehydration. Call the transplant team if you have more than five loose stools in a 24-hour period.

Do not take an antidiarrheal medication such as Lomotil, Immodium, etc., until you talk to the transplant team. The transplant team may order stool tests to determine the cause of the diarrhea. The stool culture should be done before taking medication to stop diarrhea.

Allergy/Cold Symptoms

Allergies – You may take diphenhydramine (Benadryl), loratadine (Claritin), cetirizine (Zyrtec), fexofenadine (Allegra), triamcinolone acetonide nasal spray (Nasacort, Flonase)

AVOID Claritin D, Zyrtec D, or Allegra D (the D is for decongestants, which should be avoided)

Sneezing/runny nose – chlorpheniramine and acetaminophen (Coricidin HBP Cold and Flu)

Congestion – You may take guaifenesin (Mucinex, Robitussin (plain). Combination products with dextromethorphan are also allowed (Robitussin DM, Coricidin HBP Chest Congestion and Cough, Tab Tussin DM, Equate Tussin DM)

AVOID decongestant like pseudoephedrine (Sudafed) or phenylephrine (Sudafed PE)

Cough – Dextromethorphan (Robitussin cough gels, Robitussin DM, Coricidin HBP, Tab Tussin DM, Equate Tussin DM)

Indigestion and Heartburn

You may take omeprazole (Prilosec), lansoprazole (Prevacid), famotidine (Pepcid or Pepcid AC), or calcium carbonate (Tums) for heartburn or indigestion. **AVOID** cimetidine (Tagamet) and alka seltzer (it contains aspirin).

Please contact the transplant team before choosing an over-the-counter medication that has not been discussed in this section.

Herbal Medication/Supplements

Do not use any herbal products or supplements. There may be an interaction between your transplant medication and these products, which may be harmful to you and your new kidney.

Important Information / Medication Considerations

- Never stop, start, or change your dose of your medication without approval from the transplant team, always take your medication as directed. If you are uncertain about your medication or its dose, contact the transplant team.
- Maintain an up-to-date list of your medication and bring the current list with you to each doctor's appointment. Anytime a medication change is made, be sure to update your list and your pillbox. If you are prescribed a new medication from a doctor other than your transplant physician, check with your transplant team before taking it.
- Contact your transplant team for further instructions if you miss a dose of your medication, do not double the next dose.
- Store all medication away from extreme temperatures, direct light, and moisture. Make sure that they are always kept away from children and pets.
- When traveling, always keep your medications with you in your carry-on bag and keep an updated medication list with you at all times.
- If you are feeling too ill to take your medications due to nausea, vomiting, or diarrhea, contact your transplant team.
- Do not take any over-the-counter medicine or herbal supplements without the approval of the transplant team. Some of these products interact with your transplant medication or cause side effects, which may be harmful to you and your new kidney.
- Always check with the transplant team before planning a pregnancy. Adjustments in your medications may need to be made.

Never let yourself run out of your medications.

Contact your pharmacy approximately 1 week prior to needing a refill in case the medication needs to be ordered. If you are having financial trouble and are unable to get your medications, notify the transplant team during business hours as soon as you realize there is a problem. Our transplant coordinators, social worker, and financial coordinator will work with you to find out if there are other options for obtaining your medications. Please do not wait until Friday afternoon to notify us that you have a problem, do not wait until you are out of your medication to notify us that you have a problem. It can take time to resolve issues with insurance and/or the pharmacy.

Kidney Transplant Patient Education Guide

For more health education resources, visit
Health & Wellness at osfhealthcare.org



CHAPTER 8 - Psychological and Social Considerations

Transplant is a life-changing event, a day you and your loved ones will not soon forget. One of the predictors of successful transplant and long-term survival is the presence of a stable support system for the patient. This support may come from a spouse, parent, close friend, or other family member. This person is expected to help the patient during the evaluation and in the critical time after transplant when the patient is unable to fully care for him or herself and requires help to do well after leaving the hospital – this includes transportation to and from the transplant office and outpatient lab while the patient is unable to drive. Please be aware that caregiver burden does exist; should you need help, support, or need to talk about this, please reach out to our transplant team.

Both before and after transplant, it is important to be aware of psychological and social issues that may affect your recovery. It is imperative to have a daily routine that will help you adjust to your new organ, stay healthy, and get back to the activities you enjoy.

Dear Transplant Recipient,

CONGRATULATIONS!

You have worked hard to get to this point
and there is still more to do!

Your emotions might be all over the place...

EXCITED

SAD

ANXIOUS

FEARFUL

HAPPY

SHOCKED

OVERWHELMED

All of this is completely normal as you start life with your new kidney!

You and your care partner have a whole team available to you and the
Transplant Social Worker is part of that team!

If you are having a hard time coping with your “new normal”, don’t hesitate to
reach out or ask to see the Transplant Social Worker when you are in clinic.

In the following pages, there is some information that we hope you find helpful
as you start this new journey.

However, these pages do not replace your Transplant Social Worker...
if you need help with resources in your community, information,
support, encouragement, WHATEVER...
Please reach out!

CONGRATULATIONS AGAIN!

*Please contact your Transplant Social Worker with any questions or concerns.
Contact information can be found in Chapter 1 on the “Transplant Team” page.*

IT IS OK TO GET HELP.

The Roller Coaster of Awaiting a Transplant

By: Lisa Hutchison, MSW, LSW
OSF HealthCare Transplant Services

How many of us like the thrill of a roller coaster ride? Even those that may love it can find the ups and downs a bit exhausting. That is how waiting for a kidney and/or pancreas transplant can be for the patient, the care partner(s), and their family and friends.

There was the diagnosis that a transplant would be needed. There was a referral to class to learn about transplant and other treatment options. There was an evaluation with each member of the transplant team. There were tests. There were more medical appointments and procedures. All along the way, new information and more questions.

Then, the listing... the highest point on the roller coaster, for now, you did it! You checked everything off your list. You passed!

Now what? Limbo, stuck at the top of the ride waiting for the next move. Now, the wait begins. Their job is to wait. Your job is to wait. Anxiety and depression are often emotions that come along with this part of the process mainly due to the unknown and uncertainty about the future.

It is best to deal with the anxiety and depression that can come from waiting with solid ground. Jump off the roller coaster for a time and gather up the information you need to keep yourself healthy and ready for a transplant. Communicate with the transplant team when any chances arise. Be a voice for yourself. Share your story. There is still much to do and working towards the goal of a transplant will help ease the emotions that might stop you in the tracks.

The call comes! That roller coaster is back in motion to the top of the ride. Sometimes, patients and their loved ones may have to go through “false alarms.” For one reason or another, things may not work out. Those calls can be frustrating and discouraging. Your job is to keep your spirits up; focus on the positive. Take care of their health. This is a long ride and there can be many ups and downs along the way.

Eventually though, the surgery is a go! All of the waiting, preparing, and planning is about to pay off. Now a different kind of work starts. You will be going through many changes physically and emotionally. Medications can play a part in this. Education will begin with the Post-Transplant RN Coordinators while you are in the hospital. You will need to have your care partner involved in these education sessions as you may not feel well enough to absorb all of the education that will be shared. In order to make for a successful outcome, a team approach to education works best. You need to rely on your care partner as a part of your team.

In the hospital, you will be meeting with a dietitian, as the diet needs, and restriction change once transplant. A pharmacist and the transplant social worker will also be following in the hospital to offer education and assist you in planning a successful discharge home.

The anxiety and depression that may have been present during the wait for the transplant may continue after the transplant. Transplant is another treatment option. It comes with its own

set of new challenges and opportunities. It's easy to become overwhelmed. It is important to keep reaching out to the transplant team. Call the social worker, contact information is located at the bottom of this article. Feelings of grief that were persistent prior to transplant can take on different forms, including anger, depression, anxiety. This should be a happy time, but it can be emotionally exhausting for everyone involved. A "new normal" can be hard to find. The roller coaster still goes up and down.

Getting a transplant is usually an exciting event, but because it is also a major life change, it is normal to have all kinds of emotions afterward. If you are experiencing feelings of anxiety, depression, or guilt, please know that you are not alone; many transplant patients experience these feelings at first, for many reasons.

- *Mood changes may be a side effect of the immunosuppressive medicines you are taking*
- *You may feel stressed or anxious about your new lifestyle*
- *You may feel guilty about getting a kidney from a living or deceased donor*
- *If you have been on dialysis for a long time, you may feel guilty about leaving other dialysis patients "behind" once you get your transplant*
- *Your family members may also have emotional changes as they adjust to your new lifestyle*

You do not have to deal with these feelings alone. Getting a kidney transplant is a major life change, and it is normal to feel stressed and anxious about big life changes.

(American Kidney Fund, Life After Transplant)

Your team is here to help every step of the way. Reach out to us.

Lisa Hutchison, MSW, LSW

Coping Emotionally After an Organ Transplant

When most people think about getting an organ transplant, they focus on the obvious physical aspects: the illness, the operation, and the healing. They are less likely to think about the emotional impact. But that can be life-changing too, both for you and the people around you.

Nearly all people who receive a transplant feel elated and experience a sense of relief and hope after a surgery that goes well. But with time, that initial excitement may be joined with other feelings. You may start to worry about the “what if’s.” You may be afraid of rejecting your new organ. Or you may be having a hard time dealing with a new routine and the unexpected.

It is perfectly natural to have these feelings. But if these worries take over your life, you need to do something about it.

Coping with Feelings after an Organ Transplant

When patients receive their kidney transplant, it is often at the end of a long and, for many, challenging time. Many have been dealing with years of poor health, treating their kidney disease with dialysis, which is a lot for anyone to manage. Even under the best possible circumstances, the journey of getting a new kidney can be difficult and stressful. In addition, transplant recipients may have had to wait a long time for a kidney that was a match.

Organ transplants are a very successful treatment option, and most people who get them live normal lives. But there still may be bumps in the road to recovery. For some people, those bumps can be hard to handle.

For one thing, you need to keep your expectations from getting too high. It will take time to get back to “normal.” Not being prepared for that reality can cause disappointment and contribute to depression.

The recovery time can be especially difficult if your transplant is a preemptive transplant (before dialysis). Most people who get a transplant have been very sick and feel much better as soon as the transplant is done. But it is the opposite if you get a preemptive transplant. You may have been on the verge of organ failure. But you may not have had any symptoms before the operation. As a result, you will feel worse during recovery than you did before you had surgery, and that can make coping difficult.

Organ Transplant and Family Issues

Problems with family present another emotional hurdle for many people after a transplant. In most cases, transplants happen rather suddenly, so it’s not something you can plan for. As a result, your home life may be turned upside down. Also, you will not be able to predict how you will feel afterwards.

In addition, the steroids you will likely be taking can have the effect of a mood amplifier. In the first few weeks, especially when the doses are highest, the medicine will wind you up and make it hard to sleep. The sudden changes in the family—and in your behavior—can be extreme. Just keep in mind that recovery is a process that needs adjustment and time.

Guilt after an Organ Transplant

Guilt is a common reaction people have after a transplant. Patients often report thinking a lot about the donor and feeling guilty about benefiting from the donor's death. This feeling can be especially strong for people who became very ill while waiting and prayed or hoped for an organ to become available. After the procedure, some get the feeling that they had been wishing for someone else to die.

One way people come to terms with these feelings is by focusing on the fact that, for both the donor family and the recipient, the transplant is one way to get a sense of meaning from a death. That understanding, the experts say, can be a source of comfort.

Writing to your Donor Family

For many people, getting in touch with the donor family can help. The decision to write to your donor family is one that you and your family should carefully consider. Communication is not required, though we encourage you to consider sending the donor family a thank you note. To respect privacy, organ donation organizations will not allow you to get in direct contact without the donor family's agreement. Your transplant social worker and coordinator will help facilitate your note reaching the donor family with the Gift of Hope Organ Procurement Organization.

See the provided handout on writing to the donor family for more information.

A New Life

The period immediately following a kidney transplant can be stressful as patients adjust to a new routine. Patients are at higher risk for depression (which can be common among post-surgical patients) during this time. Some medications can cause an increase in anxiety and other changes in mood. In addition, people who have struggled with addiction in the past may find this is a particularly vulnerable time and need extra support. Some patients find that talking to a counselor or checking out OSF's Silver Cloud, <https://www.osfhealthcare.org/mental-health/resources/silvercloud/>, can be helpful resources.

Patients may also experience anxiety as they may worry about possible complications and potential failure of their new organ. It is important that the patient actively participate in their mental health at this time to help avoid complications with their new kidney.

This includes:

- Taking prescribed medications as ordered
- Attending scheduled appointments and getting labs drawn as ordered
- Eating a healthy diet
- Exercising
- Finding ways to manage stress
- Reengaging in meaningful activities
- Talk to your team if something does not feel right
- Reach out to your support system

These things can help a person begin to feel a sense of control, rather than anxiety and worry.

As you adjust to an organ transplant, some of these feelings may bother you less. Part of living with a transplant is accepting uncertainty.

Experts say it is important to stay optimistic while at the same time accepting that it is impossible to know exactly what is going to happen. We tell our patients to **FOCUS ON THE THINGS YOU CAN CONTROL.**

But while living with some uncertainty is necessary, you should never accept depression or constant anxiety as something you have to live with. If you feel that you are becoming depressed or chronically anxious, talk to your transplant team. **Get help.**

Many people also find that support groups can make a big difference. In everyday life, you do not run into many people who have had a transplant. By joining a support group, you get to talk to people who are going through the same things that you are. Just meeting people in your position can make a big difference. There are several on-line options for support as well.

Adapted from original article found at Coping Emotionally After Your Transplant (webmd.com)

Your Social Worker is here to help!

Support Groups

After receiving a new kidney, patients report feeling happiness, relief, and excitement about the future. However, some patients who received a kidney transplant from a deceased donor may experience survivor guilt as they acknowledge their new chance at life resulted, in part, from the death of another person. This can put an understandable damper on the positive, hopeful feelings they are experiencing. Talking to other kidney transplant recipients may help them understand that they are not alone in having the same mixed emotions after transplant surgery.

Transplant patients and their families can gain support from many different types of groups, including group gatherings, educational programs, one-on-one support, social activities, newsletters, written materials, Internet groups, and talking on the phone. As a patient's transplant experience continues, they often gain confidence and reach out to others, in turn making lifelong friends, enjoying social activities, and finding opportunities to promote the need for organ and tissue donation.

Our support group meets four times a year. We have a mix of pre- and post-transplant patients and their families. In addition to time for sharing and support, we offer educational topics each time as well.

Online support groups

These groups can provide you with a broad range of experiences from all over the world. In addition, Internet support groups allow you to ask personal questions in the comfort of your own home. You can find many Facebook and other social media sites that specialize in organ types or diseases.

Professional organizations

Professional organizations provide educational seminars, materials, and activities. They also may conduct fundraising to support research and help shape healthcare policy.

Source: Adapted from UNOS Transplant Living at transplantliving.org.

Listed below are some good resources for online communities / professional organizations.

National Kidney Foundation (NKF) Online Community

The National Kidney Foundation provides a safe and supportive space where you can share your experiences, ask questions, and get answers that are accurate and up to date. NKF is a lifeline for all people affected by kidney disease. They enhance lives through action, education and accelerating change.

To sign up for this online community go to: <https://healthunlocked.com/nkf-kidneytransplant/about>

Renal Support Networks (RSN) Online Kidney Disease Support Groups

Renal Support Networks (RSN) series of topical zoom meetings are informative and fun. Topics include kidney disease support groups, exercise, hobbies and more. This is a great way to connect with others living with kidney disease, make new friends, and learn new things.

To sign up for this online community go to:

<https://www.rsnhope.org/rsn-events/rsn-zoom-room-meetings/>

If you have any questions or need assistance – please reach out to your Transplant Social Worker.

Going Back to Work after Transplant

Maybe you've been working this whole time and returning to work is not a concern for you...

Maybe you are retired and returning to work is not a concern for you...

Maybe you are disabled for another reason, other than kidney failure and you don't plan to return to work...

OR MAYBE?

You might be looking to return to the work force after being disabled or not working due to your kidney failure and you are not quite sure how to start.

The Ticket to Work Program through Social Security has excellent information on return to work and these handouts are included in the patient that follow.

REMEMBER: If you are receiving disability benefits due to your kidney disease, these will likely STOP after a successful kidney transplant, unless you have another disability that would qualify. The rule of thumb is one year post-transplant, however, once you are doing well and cleared to work, its best to being with the Ticket to Work Program.

For more information regarding the Ticket to Work Program – contact the Transplant Social Worker.

If you have any questions or concerns, please reach out to our Transplant Social Worker!

Kidney Transplant Patient Education Guide

For more health education resources, visit
Health & Wellness at osfhealthcare.org



CHAPTER 9 - Food and Nutrition

Healthy eating is an important part of your recovery. Our Transplant Dietitian can help you develop a healthy diet that will assist in your recovery.

After your transplant, your body may require extra protein. Meeting your increased nutritional needs will help your body heal and fight infection. Even if your appetite is not strong after surgery, it is **important to eat**. Think of food as another medicine to help you get well. Try eating several smaller meals a day rather than two or three large meals.

A low fat, low sugar diet can help you control your weight and blood sugar. Eating right will help keep you at a healthy weight and in the best shape. Certain medication that you take can cause your blood pressure, blood sugar, cholesterol, and weight to increase. To help regulate these factors, it is important for you to limit your daily intake of fried foods, baked goods, salt, and sugar. Your use of salt may be restricted to help limit the amount of fluid your body holds and to control your blood pressure. Consult your dietitian about using salt, sugar, and fat in your diet. Along with a good healthy diet, it is equally important to drink plenty of fluids to stay well hydrated.

Your diet should include a variety of foods, such as:

- Five fruits and vegetables per day
- Whole grain cereals and breads
- Low fat or non-fat milk and dairy products or other sources of calcium
- Lean meats, poultry, and fish are good sources of protein
- Sugar free beverages

You should avoid:

- Fried foods
- Sweets
- Processed or convenience foods
- In place of salt, consider using a salt free seasoning, such as lemon pepper, garlic, onion powder, vinegar, and herb mix.
- Grapefruit, pomegranate, starfruit, and Seville oranges (rinds often used to make marmalade jam) due to drug – nutrient interaction.

Please contact your Transplant Dietitian with any questions or concerns.

Contact information can be found in the beginning of this guide on the “Transplant Team” page.

Nutrition Following Kidney Transplant

Your diet may change after transplant. Nutrition following a kidney transplant is important to keep your new kidney healthy. Nutrition should be based on your needs and may require some changes throughout your post-transplant period.

If your new kidney is slow to start functioning, you may need to remain on your dialysis diet of low sodium, low potassium, low phosphorous, and limited fluids. However, as kidney function improves, you will be able to enjoy much more variety.

Your medicines may affect the levels of certain electrolytes in your body, especially potassium, phosphorous, and magnesium. You may need to decrease or increase the foods you eat that are high in these electrolytes.

It is best to talk to a registered dietitian with all of your nutrition-related questions. A registered dietitian has specific training and can provide you with the best information regarding the foods you eat and any diet restrictions you may need.

Acute Post- Transplantation Period (up to 8 weeks post-transplant)

- Eating foods **high in magnesium** can help prevent low blood magnesium levels.
- Eating foods **high in phosphorous** can help prevent low blood phosphorous levels.
- **Limit sodium** to prevent high blood pressure or body holding on to fluid/ swelling
- It is important to **limit sugar** and follow a carbohydrate-controlled diet to prevent high blood sugars or new-onset diabetes after transplant.
- Increased Protein and Calorie needs
 - Protein and calories are important for surgical healing
- Food Safety
 - Immunosuppressant medications make you more likely to develop infections. Preparing and cooking foods will be discussed further in this chapter to help prevent foodborne illness.

Long Term Post-Transplant Period (9 weeks post-transplant and after)

- Achieve a healthy body weight
- Maintain goal blood sugar levels
- Maintain normal blood lipid levels
- Control blood pressure
- Get adequate vitamin D and calcium for bone health

AVOID Grapefruit and grapefruit juice, this can cause changes in the way certain medications are absorbed. This is also found in Squirt and Fresca. Pomegranates, star fruit, and Seville (sour) oranges used to make marmalade jam also have similar drug interactions.

Safe Food Handling

Because of your medications, you have a lower-than-normal immune system. It is important to avoid food-borne illnesses. Safe food handling is a must!

- Wash hands frequently in warm soapy water for at least 20 seconds at a time; always wash after using the bathroom and before handling your food
- Wash ALL fruits and vegetables under running water
 - Rinse surface dirt off raw fruits and vegetables
- Separate raw produce from uncooked meats; use separate cutting boards if possible; clean cutting utensils/boards between use on fresh produce and animal products
- Sanitize sinks and chopping boards with ½ teaspoon bleach in two cups water
- At the store, buy produce that is not bruised or damaged. If buying fresh already cut produce, be sure it is refrigerated or surrounded by ice
- After purchase, put produce that needs refrigeration away promptly. Fresh produce should be refrigerated within 2 hours of peeling or cutting. Leftover cut produce should be discarded if left at room temperature for more than 2 hours.
- Raw sprouts should be cooked thoroughly before eating to reduce risk of illness
 - When eating away from home, ask that raw sprouts not be added to your food
 - Homegrown sprouts also present a health risk, if eaten raw or lightly cooked, and should be avoided
- Do not eat eggs that are raw or have cracked shells
- No dented cans – clean lids before opening
- Throw away/ discard leftovers after 2-3 days – even if they look or smell okay.
- Heat deli /lunch meat /hot dogs thoroughly before eating
- Avoid soft cheeses made from unpasteurized (raw) milk
 - Includes feta, brie, camembert, blue-veined, queso fresco
- Avoid flour, raw dough including cookie, cake mix, batter, or any other raw dough that is supposed to be cooked or baked.

Cooking Foods to Proper Temperature

- Use a fast check thermometer to check the temperature of meats

Hamburgers, hot dogs, and sausage	160° F
Chicken/Poultry	165° F
Beef, veal, pork, lamb	145° F
Ground poultry	165° F
Casseroles, egg dishes	160° F
Leftovers	165° F
Scallops	Cook until flesh is milky white or firm
Clams, oysters, muscles	Cook until shells open during cooking
Shrimp, lobster, and crab	Cook until they turn red, and flesh is pearly and opaque
Deli-style meats	Until steaming hot or 165
Eggs	Yolks and whites are firm and not runny, unless using pasteurized eggs

Foodborne illness often presents itself with these symptoms:

- Nausea, diarrhea, vomiting, fever, and abdominal cramps

Contact your transplant team immediately if you develop symptoms or think you may be at risk of food poisoning.

Websites for food recalls:

<https://www.fsis.usda.gov/recalls>

<https://stopfoodborneillness.org/>

Dietary Needs

You can increase the variety of foods in your diet by enjoying foods from all major food groups.

In the **first 2 months**, you continue to need the same amount of protein that you needed during dialysis. After your incision has healed, your **protein** needs may go down. The best sources of protein are:

- Meats, fish, poultry
- Dairy products
- Eggs
- Nuts
- Dried beans, lentils, and peas
- Soybeans, soy milk, tofu

You may need to increase the **phosphorus** foods in your diet. The best sources of phosphorus are:

- Dairy products – low fat milk, cottage cheese, cheese, yogurt
- Nuts and nut butters
- Dried beans, lentils, and peas
- Seeds

You may need to increase the **magnesium** foods in your diet. The best sources of magnesium are:

- Wheat bran/wheat germ
- Almonds/peanuts/cashews
- Spinach
- Raisin bran cereal

You may be able to have normal amounts of **potassium** foods. The best sources of potassium are:

- Dark green leafy vegetables
- Tomatoes
- Oranges
- Milk
- Bananas
- Dried beans, lentils, and peas
- Potatoes
- Nuts and nut butters

It is important to take in adequate calcium to protect your bones. The best food sources of calcium are:

- Dairy products (low fat milk, yogurt, cheese, puddings)
- Dark green vegetables

Adequate calcium and vitamin D intake is crucial to keep bones healthy. The transplant team may recommend vitamin D and/or calcium supplement.

Please see the following pages for more information on foods high in phosphorous, foods high in magnesium, and foods high and low in potassium

Foods High and Low in Potassium

Potassium often will go up and down after surgery. In the beginning, transplant medications are at slightly higher levels and may cause elevation in potassium. It will be important to limit potassium if needed in your diet until you are sure your new kidney is filtering out the excess potassium and you are on a stable dose of transplant medications.

A food that is considered “high potassium” generally has 200 mg or more potassium per serving. While food that meets this criterion is considered “high potassium,” some will have more potassium than others, therefore it is important to monitor the serving sizes. A large amount of low potassium foods can turn into a high potassium food.

Approximate serving of fruit and vegetables ½ cup (unless specified)

High Potassium Foods (>200 mg/serving)

Apricots	Chicken (3 ounces)	Mango	Prunes and prune juice
Artichoke	Chinese cabbage	Milk (1 cup)	Pumpkin
Avocado (1/4 of a whole)	Chocolate (2 ounces)	Nectarine	Raisins
Bananas	Dates	Nuts and seeds (1 ounce)	Salmon (3 ounces)
Beans (baked, black, dried, refried)	Acorn squash	Oranges	Seaweed
Beef (3 ounces)	Dried figs	Orange juice	Spinach (cooked)
Beets	Dried fruits	Papaya	Tomatoes and tomato products
Bran and bran products	Granola	Parsnips	Vegetable juices
Broccoli (cooked)	Greens (except kale)	Peanut butter (2 tablespoons)	White mushrooms (cooked)
Brussel sprouts	Honeydew melon	Peas, dried	Yogurt
Butternut squash	Kiwi	Potatoes (white and sweet)	
Carrots, raw	Kohlrabi		
	Legumes		
	Lentils		

Low Potassium Foods (<200 mg/serving)

Alfalfa sprouts	Celery	Mandarin oranges	Raspberries
Apple	Cherries	Mixed vegetables	Rhubarb
Apple juice	Coffee (limit to 8 ounces)	Noodles	Rice
Applesauce	Corn	Onions	Strawberries
Asparagus	Cranberries	Parsley	Tangerine
Beans	Cucumber	Pasta	Tea (limit to 16 ounces)
Blueberries	Eggplant	Peaches	Water chestnuts (canned)
Bread and bread products	Fruit cocktail	Pears	Watermelon
Broccoli	Grape juice	Peppers	Yellow squash
Cabbage	Grapes	Pineapple	Zucchini squash
Cake (yellow or angel)	Kale	Pineapple juice	
Cauliflower	Lettuce	Plum	
		Radish	

Foods High and Low in Phosphorus

Phosphorus is a mineral found in your bones. Along with calcium, phosphorus is needed to build strong healthy bones and keep other parts of your body healthy. If your kidney is working well, the physicians may decide you need more calcium, phosphorus, or vitamin D than your diet provides. You may be started on a supplement. Some transplant medicines can make your phosphorus levels low, so eating 2 to 3 high-phosphorus foods each day, such as beans, nuts, and dairy, can help you stay at a healthy level.

High phosphorus foods

- Dairy products such as milk, cheese, custard, cottage cheese, yogurt, ice cream, pudding, cream soup
- Nuts, seeds, peanut butter, chocolate candy, brewer's yeast
- Dried beans and peas such as baked beans, black beans, chickpeas, garbanzo beans, kidney beans, lentils, limas, northern beans, pork and beans, split peas, and soybeans
- Bran cereals, whole grain products, oat bran muffin
- Beverages such as cocoa, chocolate drinks, and dark cola drinks

Low Phosphorus foods

- Fresh fruits such as apples, apricots, blackberries, grapes, tangerines, pears, peaches, pineapple, plums, and strawberries
- Fresh vegetables such as cauliflower, carrots, cucumber, celery, green beans, and broccoli
- Popcorn, crackers
- Rice cereal
- Sherbet, sorbet
- Coffee or tea without milk, light colored sodas, fruit juices

Foods High in Magnesium

Eating a wide variety of beans, peas, whole grains, and vegetables (especially dark-green, leafy vegetables) will help you meet your daily need for magnesium.

High magnesium foods

- Mixed nuts, Pumpkin seeds, almonds, cashews, peanuts, dark chocolate, peanut butter, cocoa powder
- Spinach, broccoli, avocado, carrots, potatoes
- Bananas, apples, raisins
- Cereal, oatmeal, fortified breakfast cereal, bran flakes
- Soy milk (plain or vanilla), milk, chocolate milk, chocolate pudding, yogurt
- Black beans, edamame, kidney beans, pinto beans, lentils, black eyed peas
- Whole wheat bread, brown rice, white rice
- Atlantic salmon, halibut, chicken breast, ground beef

Reading Label Tips

Follow these general guidelines when reading food labels:

- Check for expiration dates
- Look at the serving size and compare it with the portion you usually eat
- Generally, choose foods that have less than 250 milligrams (mg) sodium per serving
- Read the label for the fat, saturated fat, and trans fat content
- If you have diabetes, read the label for total carbohydrates content. Each carbohydrate choice should contain 15 grams (g) carbohydrates
- “Light” or “lite” does not always mean a food is low in calories, fat, sugar, or salt. It may be “light” in color, taste, or texture

1. Check the **Serving size** first. All the numbers on this label are for a 2/3-cup serving.
2. **This package has 8 servings.** If you eat the whole thing, you are eating 8 times the number of calories, carbs, fat, etc., shown on the label.
3. **Total Carbohydrate** shows you types of carbs in the food, including sugar and fiber.
4. Choose foods with **more fiber, vitamins, and minerals.**
5. Choose foods with **lower calories, saturated fat, sodium, and added sugars.**
Avoid *trans* fat.

Nutrition Facts	
8 servings per container	← 2
Serving Size 2/3 cup (55 g)	
Amount per serving	
Calories 230	
% Daily Value*	
Total Fat 8g	10%
Saturated Fat 1g	5%
Trans Fat 0g	
Cholesterol 0mg	0%
Sodium 160mg	7%
Total Carbohydrate 37g	13%
Dietary Fiber 4g	14%
Total Sugars 12g	
Includes 10g Added Sugars	20%
Protein 3g	
Vitamin D 2mcg	10%
Calcium 260mg	20%
Iron 8mg	45%
Potassium 235mg	6%

*The % Daily Value (DV) tells you how much a nutrient in a serving of food contributes to a daily diet. 2,000 calories a day is used for general nutrition advice.

Maintaining Weight

A common problem with transplant patients is **weight gain**. It is common for someone to gain up to 10-15% of their weight. There are several reasons for this:

- You can eat your favorite foods again
- You have a much-improved appetite
- You feel better, so eating is once again a pleasure
- Foods may taste better with good renal function

Achieving and maintaining a desirable weight is a major goal of your post-transplant nutrition care plan. Obesity affects your self-image, contributes to high blood pressure and diabetes, and may lead to heart attacks and strokes.

Weight management is achievable through exercise and diet. Exercise should be a planned program that is done on a regular basis, 4-5 times per week. Walking is an excellent way to exercise, is inexpensive and easy to do!

Additional Nutrition Tips

- Limit sodium to less than 2,000 mg per day
 - Too much sodium will cause your body to hold fluid
 - 1 teaspoon of table salt = 2,300 mg of sodium
 - Use herbs and seasonings like Mrs. Dash instead of table salt
 - Do not use salt at the table or when cooking and limit canned and processed foods
 - Ask your dietitian for more tips on how to cut back on sodium
- Limit sugar and simple carbohydrates
 - Some medication can cause your blood sugar levels to be higher than normal
 - It is critical to keep your blood sugar near a normal level. High blood sugar can prevent the body from healing.
 - Avoid sugary drinks like soda and juice, and white bread, rice, and pasta
- Choose healthier fats and limit cholesterol
 - Limit saturated fats, which are fats that come from animal sources like red meat and cheese. Eat more skinless chicken, turkey, and fish.
 - Eat more unsaturated fats, which are fats that come from plant sources like olive and vegetable oils. Nuts are made of this good fat, too. The healthiest unsaturated fats (called omega-3s) are found in fatty fish like salmon and tuna.
 - Do not eat trans-fat. Any food item that has “partially hydrogenated” in the ingredients list contains trans-fat, even if it is not listed on the nutrition label. Some baked goods, snack foods, and fast foods have trans-fat.
 - Choose low-fat or non-fat dairy products like milk, yogurt, and sour cream
 - If you eat eggs, eat three or less whole eggs per week and use egg whites or egg substitutes instead.
 - Eat 25-35 grams of fiber per day to keep cholesterol low. Fiber foods include whole grain breads, brown rice, beans, oatmeal, fruits, and vegetables.
- Try to have 5-6 servings of fruit and vegetables every day.

Diet and Transplantation

<https://www.kidney.org/atoz/content/nutritrans#:~:text=What%20about%20potassium%3F,other%20medicines%20may%20decrease%20it.>

Safe food handling

<https://www.fda.gov/food/buy-store-serve-safe-food/safe-food-handling>
Food Safety For Older Adults and People With Cancer, Diabetes, HIV/AIDS, Organ Transplants, and Auto-Immune Diseases (fda.gov)

Potassium in your CKD diet

<https://www.kidney.org/atoz/content/potassium-ckd-diet>

Phosphorous in your diet

<https://www.kidney.org/atoz/content/phosphorus>
https://www.kidney.org/sites/default/files/02-10-0411_ABB_Phosphorus.pdf

Understanding Food Labels

www.cdc.gov/diabetes/managing/eat-well/food-labels.html

What to eat after Kidney transplant, part 1

<https://blogs.davita.com/kidney-diet-tips/what-to-eat-after-kidney-transplant-part-1>

Magnesium rich foods

<https://my.clevelandclinic.org/health/articles/15650-magnesium-rich-food>

Kidney Transplant Patient Education Guide

For more health education resources, visit
Health & Wellness at osfhealthcare.org



CHAPTER 10 - Immunizations and Vaccines

Immunizations and vaccines consist of viruses or bacteria – either “live” or “inactivated.” Most vaccines are made from viruses or bacteria that are inactivated or “dead” and are safe for patients to take themselves or to be around people that were recently immunized.

Immunizations that are inactivated and may be given post-transplant are as follows:

Disease	Vaccine	Who gets it?
Tetanus (T) Diphtheria (D/d) Pertussis (aP/ap)	DTaP: Daptacel®, Infanrix® Tdap: Adacel®, Boostrix® Td: TDVax®, Tenivac®	DTaP: Routine childhood immunizations Tdap: One time pediatric or adult dose followed by booster every 10 years with Tdap or Td
Human Papilloma Virus (HPV)	Gardasil 9®	Children 11-12 years of age, adults 19-26 years of age, and certain adults up to the age of 45 years
Meningitis	MenACWY: Menactra®, Menveo®, MenQuadfi® MenB: Bexsero®, Trumenba®	MenACWY: Children 11-12 years of age with booster at age 16, as well as certain immunocompromised adults MenB: Adolescents and young adults aged 16-23. Older adults can also receive the vaccine if they are at increased risk
Haemophilus influenza type b (HIB)	PedvaxHIB®, ActHIB®, Hiberix®	Routine childhood immunizations or for high-risk adults
Hepatitis	HepA: Havrix®, Vaqta® HepB: Engerix-B®, Heplisav-B®, Recombivax HB® HepA+B: Pediarix®, Twinrix®	HepA: Routine childhood immunizations, travelers, and high-risk adults HepB: Routine childhood immunizations or for high-risk adults
Polio (IPV)	IPOL®	Routine childhood immunizations or for unvaccinated adults at high risk Inactive form (injectable) must be used
Pneumonia	Prevnar 20®, Prevnar 13®, Vaxneuvance®, Pneumovax 23®	Routine childhood immunizations, older adults, and high-risk adults Product choice depends on age/vaccine history
Influenza (Flu)	Multiple	Given yearly during influenza season Nasal vaccine is LIVE, only use inactivated, injectable form
Herpes Zoster (Shingles)	Shingrix®	Adults 50 years or older and adults 19-50 with high-risk conditions
Covid-19	mRNA Vaccine: Comirnaty®, Spikevax® Adenovirus Vector Vaccine: Janssen Subunit Vaccine: Novavax	All patients 6 months or older (age cutoffs vary between manufacturers)

All transplant recipients are encouraged to receive a flu vaccine every fall.

Live Vaccinations

Some vaccines are made from a weakened “live” virus. The vaccine from a “live” virus rarely causes the actual disease in the immunized person. Patients who are immunosuppressed are less able to fight the weakened version of the virus and can become sicker.

Patients who have had a transplant should not have vaccines from a “live” virus and should avoid direct contact with persons who have received any “live” virus vaccines for a period of 4 weeks - especially with live smallpox and oral polio vaccines.

If close contacts/household family members must receive the following live vaccines, the vaccine recipients should:

- Live Influenza Vaccine = Vaccine recipients should wash their hands frequently for 2 weeks following vaccination
- Measles-Mumps-Rubella = Vaccine recipients should wash their hands frequently for 2 weeks following vaccination
- Varicella or Measles-Mumps-Rubella-Varicella = If the vaccine recipient develops a rash, the vaccinated household member should avoid contact with the transplant recipient for the duration of the rash. The transplanted patient should monitor closely for a development of any rash and to call their healthcare provider if they develop one
- Rotavirus = Post-transplant recipients should avoid handling the diapers of infants who received the rotavirus vaccine for 4 weeks following vaccination. All household members should also practice good handwashing to help prevent spread

Immunizations that are live vaccinations and are NOT to be given to transplant patients post-transplant are as follows:

Disease	Vaccine
Measles, Mumps, and Rubella (MMR)	MMR: M-M-R® II, Priorix® MMRV (includes Varicella): ProQuad®
Varicella (Chickenpox)	Varivax®
Live Attenuated Influenza Vaccine (LAIV)	Flumist® Quadrivalent
Polio (oral)	Used in countries outside of the US
Typhoid (oral)	Vivotif®
Cholera	Vaxchora®
Yellow Fever	YF-VAX®

Kidney Transplant Patient Education Guide

For more health education resources, visit
Health & Wellness at osfhealthcare.org



Quick Reference Guide

QUICK REFERENCE GUIDE

This Guide can be used as a reference to make sure you know the most important topics from the education guide, prior to discharge.

Daily Routine

- Measure and record blood pressure and pulse every morning and evening before taking your blood pressure medication
- Measure and record your temperature every morning and evening
- Measure and record your weight every morning when you get up around the same time each day
- Measure intake and output and record until directed to stop. This is usually stopped a few days after you go home.
- If diabetic: Monitor your blood sugar 4 times daily and record
- Monitoring this in your daily log will help your physician determine how you are doing and if medication adjustments are needed.

Incision care:

- Check your incision once daily and keep it clean and dry
- Showers are OK – no tub baths, hot tubs, or pools until your incision is well healed.
- Clean the incision with mild soap and water and pat dry

Activity after Transplant:

- Plan to be off work for up to 6 weeks.
- No driving until released by your surgeon
- No foreign travel for at least 6 months – discuss with your transplant team prior to planning any trips

Precautions to take after transplant:

- Keep visitors to a minimum with short visits
- Live plants are OK but if touching dirt, wear gloves
- Cats and dogs are OK; avoid cleaning out litter boxes
- Avoid all birds and bird droppings
- No dental procedures for 6 months – call your transplant team prior to dental procedures to see if antibiotics are needed
- Get your flu shot yearly
- Keep up to date on all vaccinations recommended by your physician. No vaccines for approximately 2 months after transplant.
- If you smoke – we highly encourage you to stop

For more information regarding daily routine, incision care, activity after transplant, and precautions after transplant, refer to chapter 3 that discusses “Caring for yourself”

Follow-up expectations and transplant clinic follow-up:

- Clinic visit with the physician will initially be 1 to 2 times a week. This is individualized and you will be directed at each appointment on when you will need to return for labs and follow up.
- You will initially get labs twice weekly at OSF HealthCare Saint Francis Medical Center in Peoria. If things remain stable you may get labs closer to home under the direction of your physician.

***For more information regarding labs and follow up,
refer to chapter 4 that discusses “Labs and Follow up”***

Medications

- Never skip any of your anti-rejection medications
- Never let yourself run out of medication. Call your pharmacy for a refill when you have approximately 1 week left of your medication.
- On lab days, **DO NOT** take your tacrolimus (Prograf) until after your blood is drawn.

Over the Counter medication information:

- For pain, only take acetaminophen (Tylenol)
- No Ibuprofen (Advil, Motrin), Naproxen (Aleve), Excedrin or additional Non-Steroidal Inflammatory medication
- Check with transplant office before starting any herbal medicines or supplements

***For more information regarding medication,
refer to chapter 7 that discusses “Transplant Medication”***

Nutrition/Diet:

- Follow a balanced diet
- Monitor your salt intake – this can affect your blood pressure and increase swelling
- Drink a good amount of fluids unless otherwise instructed
- **DO NOT** eat grapefruits, pomegranates or drink grapefruit or pomegranate juice – it interferes with your anti-rejection medication

***For more information regarding diet and nutrition,
refer to chapter 9 that discusses “food and nutrition”***

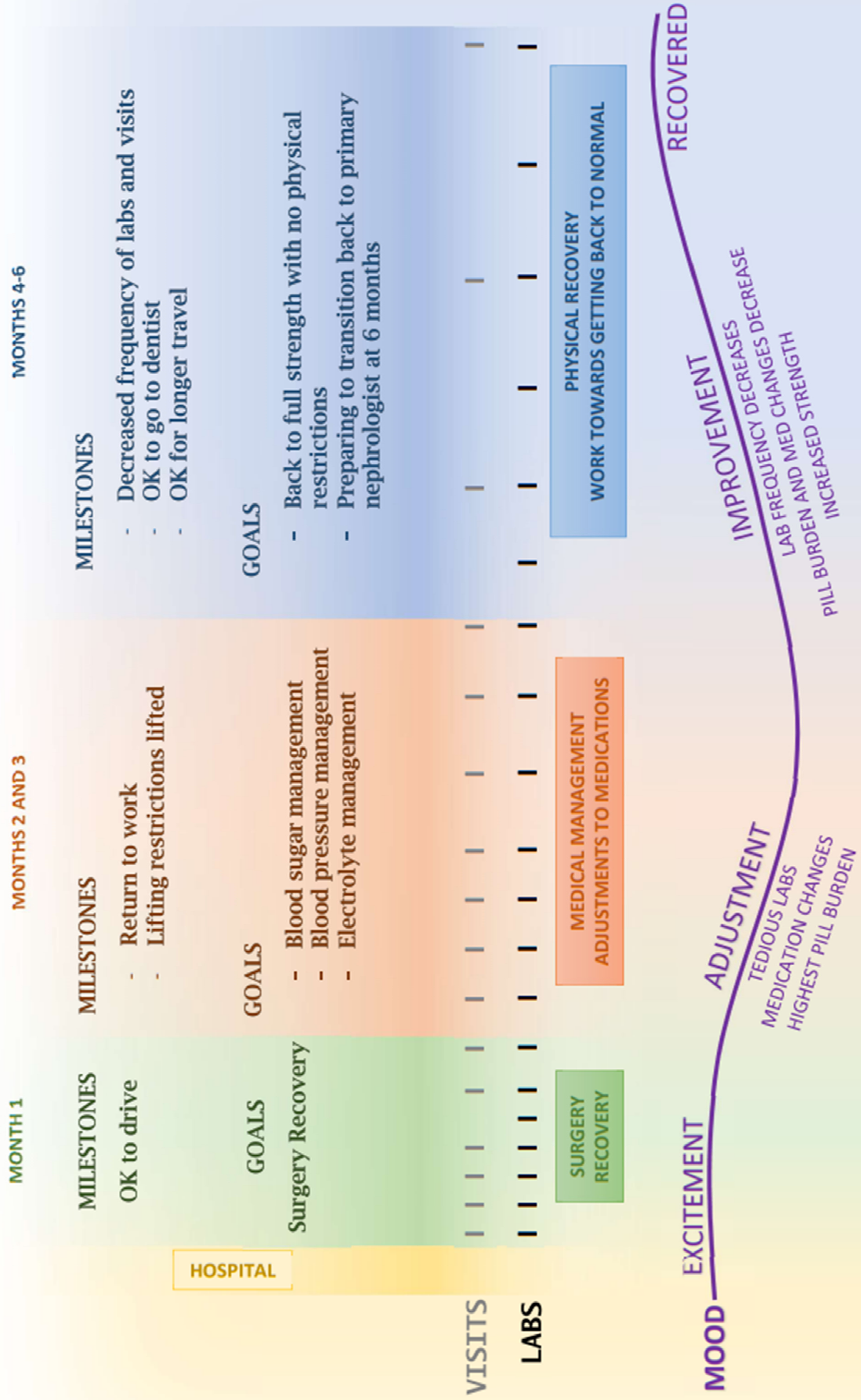
Contacting your transplant team:

- Transplant office phone number: 309-655-4101 (office hours are 8:00am to 4:00pm)
- A Transplant Nurse Coordinator and doctor are always available “on call” if you are ill after normal business hours, on weekends, or holidays. Patients who are ill should contact the On-Call Coordinator. To do so, call the direct paging service at 309-655-2000 and ask for the kidney transplant coordinator on call.
- Please do not call the on-call coordinator for routine requests, such as a prescription refill or lab results. Call during normal office hours from 8:00am to 4:00pm for those requests.
- If at any time you have a life-threatening emergency, call 911

Concerning signs and symptoms and when to call your transplant team:

- Fever greater than 100.5 °
- New pain or swelling over the transplant site
- Generalized sick or achy feeling
- Nausea, vomiting, or diarrhea
- Decrease urine output
- Shortness of breath
- Pain or burning with urination
- Rapid weight gain
- Sore throat, nagging cough, or hoarseness

POST TRANSPLANT TIMELINE



Kidney Transplant Patient Education Guide

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RECORD SHEETS

