



After Your Kidney Transplant

Patient Teaching Manual

INTRODUCTION

The goal of kidney transplantation is to restore your state of health to what it was before your kidneys failed. In time, you should be able to return to your normal activity level.

This guide has been developed to help you and your family understand your needs and to encourage you to become an active participant in your care. It is meant to serve as a reference, which, in conjunction with the Boston Medical Center Transplant Team, will help you to understand and learn about kidney transplantation. We hope that you will find it useful and that it will answer many questions you may have as a new transplant recipient.

Please read the manual with your family and let it guide you through this time. Never hesitate to contact the members of the Transplant Team should you have comments, questions, or concerns. A member of the transplant team is accessible during business hours for routine medical issues or questions at **617.638.8430**.

For emergencies or after hours, call the page operator at **617-638-8000 and ask to speak with the transplant surgeon on call.**

Boston Medical Center – Transplant Web site:
www.bmc.org/transplant-surgery

The Boston Medical Center Transplant Program has a team of experts from a variety of practice areas – all dedicated to your care.

TEAM MEMBERS

Transplant Surgeons

Transplant Operations Administrator

Clinical Administrator

Living Donor Coordinator

Pre-Transplant Clinical Coordinators

Post-Transplant Clinical Coordinator

Transplant Social Worker

Transplant Pharmacists

Transplant Nutritionist

Transplant Medicine/Nephrology Team

Transplant Psychiatry

Transplant Infectious Disease Team

Transplant Urology Team

Transplant Cardiology

YOU – The Most Important Part!

Multidisciplinary Transplant Clinic:

Shapiro 7A
725 Albany Street
Boston, MA 02118
617.638.8680

Blood Drawing Areas:

Shapiro Lower Level
725 Albany Street
Boston, MA 02118

Menino Building – Inpatient Rooms, Operating Rooms, SICU

840 Harrison Ave.
Boston, MA 02118

THE KIDNEYS, KIDNEY DISEASE, AND TRANSPLANTATION

What are the kidneys?

The kidneys are the master chemists of the body. Normally, you have two kidneys: one on either side of your spine under your lower ribs. They are pink and shaped like kidney beans. Each kidney is about the size of a closed fist.

Why are the kidneys important?

Kidneys remove wastes from the blood and excrete them into the urine. They regulate the levels of water and different minerals needed by the body for good health. They also produce hormones that control specific body functions.

Many other organs depend on the kidneys in order to work properly. When kidney function is no longer adequate, dialysis treatment or a kidney transplant is required.

What is renal disease and why do I need treatment?

Another name for kidney disease is renal disease. You can be healthy with one kidney. Renal disease usually affects both kidneys at the same time. When both kidneys do not work, waste materials and water stay in your body. Your body's chemical balance becomes upset. You become ill and need treatment to do the work your kidneys can no longer do. End-stage renal disease, or ESRD, means that you must have some form of dialysis treatment or a kidney transplant in order to stay alive.

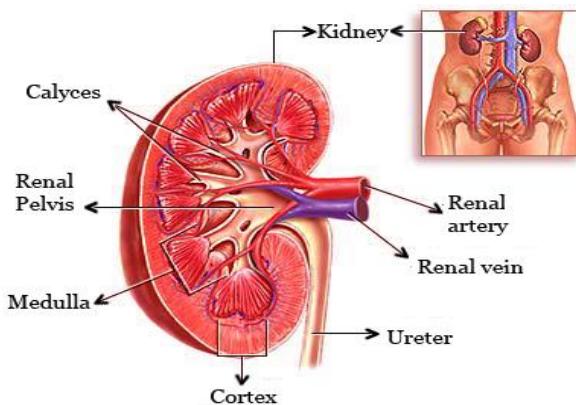
What is a kidney transplant?

A kidney transplant is a surgical procedure in which a healthy kidney from either a living or deceased donor is placed in your lower abdomen. It is not a cure, but a treatment for chronic kidney failure. It is the treatment of choice for those who are considered suitable candidates for a transplant.

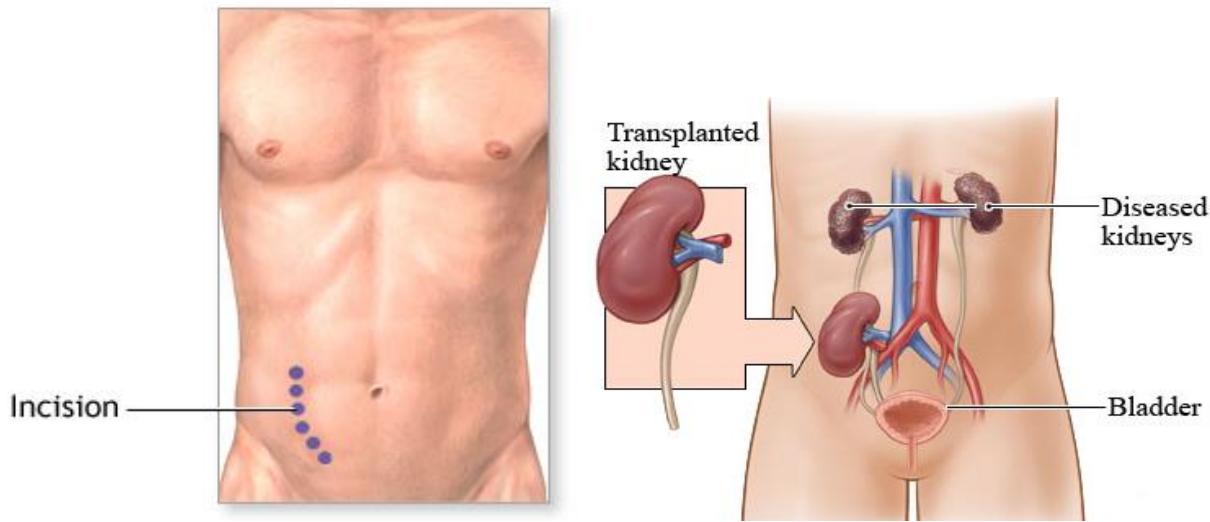
How does transplantation compare to dialysis treatment?

Transplantation has many advantages. It can treat your kidney failure, give you back your health, and give you a lifestyle free from dialysis. Usually, you will have fewer fluid and diet restrictions after getting a "new kidney." We expect you may feel well enough to return to work.

Transplantation can have some disadvantages. For your new kidney to work, you must take medications every day, exactly as taught, for as long as the kidney is working, and perhaps for your whole life. These medications can have side effects. Complications may arise, such as rejection of your new kidney or an infection.



THE OPERATION



The kidney transplant surgery can take anywhere from 4 - 6 hours. You will be given general anesthesia to put you to sleep during surgery. Once you are asleep, a catheter will be placed into your bladder in order to accurately measure your urine output. This catheter will stay in for 3-5 days after your surgery. The new kidney will be placed low in your right or left lower abdomen, in the front. Unless your doctor feels it is necessary, your diseased kidneys will not be removed.

You may have a 'stent' placed during the surgery, where the transplanted ureter is attached to your bladder. This stent helps to prevent scarring from tightening (stricturing) around the opening and may help prevent urine from leaking while the connection heals. If you have a stent, an appointment will be made for you and the stent will be removed. This stent is usually removed 2 weeks after the transplant in a simple cystoscopy procedure by our expert urologists.

THE RECOVERY

All Transplant Recipients remain in the SICU (Surgical Intensive Care Unit) the first night after surgery for monitoring of vital signs, urine output and fluid status. Once you are strong enough and your vital signs are stable you will be transferred to the Surgical Step Down Unit.

The staff in the SICU and Step Down Unit have special expertise in the care of transplant patients. They are knowledgeable about the transplant medications and will help you thoroughly learn them. They will educate you on the signs and symptoms of infection and rejection and provide you with follow-up instructions.

Nutrition support personnel will be available to provide you with dietary guidelines and assistance. You may also be seen by a physical therapist that will provide you with exercises, assist you with ambulation, help you climb stairs and assess your individual needs.

If you have staples in your incision, they are usually removed a few weeks after transplant at one of your clinic visits. Steri Strips (little white strips of tape) will fall off on their own over time.

You may have several IV lines in place when you wake up after surgery. These lines allow us to give you medications, vital fluids, and to draw blood for lab tests without have to stick you repeatedly while you are in the hospital. As you recover, they will slowly be capped or removed.

You will be encouraged to get out of bed as soon as your team feels this is safe, usually within 24 hours of transplant. Walking will help prevent post-op complications like blood clots and pneumonia, and will help wake up your bowels after anesthesia.

You can expect to be in the hospital after your surgery for 5-7 days on average.

You and your caregiver will work with members of the Transplant Team while you are in the hospital to learn your medication regimen, and the do's and don'ts of life after transplant. We are always available to answer any questions you may have.

PRECAUTIONS

Your immune system will try to attack your new kidney as if it were bacteria or a virus. Therefore, you will be given medication to suppress your immune system (immunosuppression). The first doses of medications will be given in the operating room. As a result of this immunosuppression, you will be at risk for infection. Because infections are contagious and other patients in the hospital are sick, you will need to wear a mask when you are outside of your room and walking around the hospital floor. This is to protect both you and other patients. You also may be placed on "precautions." Precautions are extra measures taken when you need extra care to take care of yourself and others. You will be advised if this situation should occur. Please do not be alarmed if you are placed on precautions.

To further protect you from possible infections, we ask that you adhere to the following recommendations both here in the hospital and once you are home. These recommendations have been devised by members of the Transplant Infectious Disease Team to limit exposure to bacteria that may be harmful to transplant recipients.

- You will be instructed to wear a mask for the first six weeks post-transplant, whenever you are somewhere you may be exposed to sick people. For example, any doctor's office, getting your blood drawn, anytime you are in the hospital corridors or waiting rooms.
- Good hygiene should always be maintained in order to avoid infections. Frequent hand washing and hand sanitizers should be used frequently by you and your family.
- Anyone entering your hospital room (including your care team members) should use hand sanitizer or wash hands thoroughly as they enter.
- Raw or undercooked fish, seafood, meat, and poultry are strongly discouraged.
- Avoid crowds. In the first month or so after your transplant, while you are taking high doses of immunosuppressive medications, you are more likely to get an infection. Stay away from people who have measles, mumps, chickenpox, shingles, or the flu.
- **NEVER STOP TAKING YOUR TRANSPLANT MEDICATIONS!** If you are having side effects, call us immediately, do not miss any doses!

Although these sound like strict recommendations, they are for your benefit. Please speak with a member of the transplant team for further clarification.

DISCHARGE PLANNING AND FOLLOW-UP CARE

Once you arrive on the Step Down Unit the Transplant Team and floor nurses will begin to discuss your potential discharge needs. Unless otherwise indicated, all visits after your transplant will take place in the Transplant Surgery clinic at the Shapiro Ambulatory Care Center, 725 Albany Street on the 7th floor. Your Wednesday appointments with transplant surgery and all your nephrology appointments will take place here. You **must** bring your support person to all these visits for the first year after transplant.

You will leave the hospital with a RED Transplant Binder which includes a list of your medications and doses on a **MedActionPlan**, a **vital signs log** to record your vital signs at home, and your Discharge Education information, which, includes all the contact information for the members of your Transplant Team. Your Binder, **MedActionPlan**, **all medications**, **pill box** and **vital signs log** should be with you at all clinic visits to allow us to review your medications and make any necessary changes and to allow us to review your weight and blood pressure results and to look for subtle changes that may need attention.

Blood work should be drawn before your visits with the doctors here at BMC. The blood will be drawn in the lab drawing station at the Shapiro Center, Lower Level, 725 Albany Street. Please arrive a bit early for your appointment to allow time for this. Your lab order will be in the computer when you arrive at the lab. Don't forget that blood **must be drawn before your morning Prograf (Tacrolimus) dose**. See the Medications section for more information.

After your blood is drawn, you will be seen by either your Surgical Team (Surgeon, Transplant Pharmacist, and Transplant Coordinator), or your Transplant Nephrology Team (Nephrologist and Nephrology Fellow, Nurse or Coordinator). It is very important that you bring the **RED Binder** with you to each clinic visit. It will be helpful to keep a list of any questions or concerns that arise over the week to ask when you are in clinic. You should not leave the clinic until you are given a follow up appointment.

In addition to the weekly clinic visits you will be asked to have your blood drawn at BMC or a hospital or laboratory close to your home once or twice a week (usually Monday and Friday), for the first 4 few weeks after discharge. This will continue until the laboratory values are stable. The transplant team and your nephrologist will advise you when to reduce your visits to the lab. When you go to your local laboratory, you will have a Prograf (Tacrolimus) blood level drawn, so please do not take your morning dose of this medication until after your blood is drawn. If you choose to go to a local lab for these draws, we will provide you with a lab order form to use.

It is very important for the transplant team to know where you plan to have your lab tests done once you are home. We will provide you with information about several local Quest Lab drawing sites near your home, if you like, as this lab can always process your blood tests and get us the results the same day. We will provide you with two written STAT lab order slips to use at the local lab. One should be given to the lab and they add it as a permanent record in your profile at that lab. This is considered a "standing order." With a standing order in place, .you will not need a new lab order every time you go to the laboratory. Please keep the second lab order slip with you as a back-up in case your lab loses or misplaces your standing order.

We ask that you have your blood drawn as early in the morning as possible so that we can receive the results the same day. Be sure that the laboratory personnel understand that they must fax or call the results to Boston Medical Center the SAME DAY your blood is drawn. Your laboratory results will be faxed to 617-638-8427. This information is included on the lab order form.

TESTS AND PROCEDURES

This section describes the common tests and procedures after your transplant. The tests may be done on either an inpatient or outpatient basis, depending on your circumstances.

ROUTINE BLOOD WORK

The tests listed below help us monitor your kidney function, detect medication side effects due to your medications, and help us monitor your overall health.

Blood Chemistries:

We order a test called a “CMP” that includes:

- Glucose (Glu)
- Sodium (Na)
- Potassium (K)
- Chloride (Cl)
- Carbon Dioxide (CO₂)
- Calcium (Ca)
- Phosphorous (Phos)
- Magnesium (Mg)
- Blood urea nitrogen (BUN)
- Serum creatinine (SCr)
- Liver function tests

Hematology:

We order a test called a “CBC with differential” that includes:

- Hemoglobin (Hgb)
- Hematocrit (Hct, “crit”)
- White Blood Cell Count (WBC, “white count”)
- Platelet Count (Plt)
- Absolute neutrophil count (ANC)

Drug Levels

We order a blood concentration of specific drugs. If you are taking one or more of these drugs, please be sure blood is drawn before you take your morning dose. You will also need to adjust the timing of your evening dose the night before your labs are drawn, so that the blood level is drawn 12 hours after your evening dose (and right before your morning dose). The result helps us ensure that you are on the correct dose.

- Prograf (Tacrolimus)
- Neoral (cyclosporine, CSA)
- Rapamune (sirolimus, Rapa)

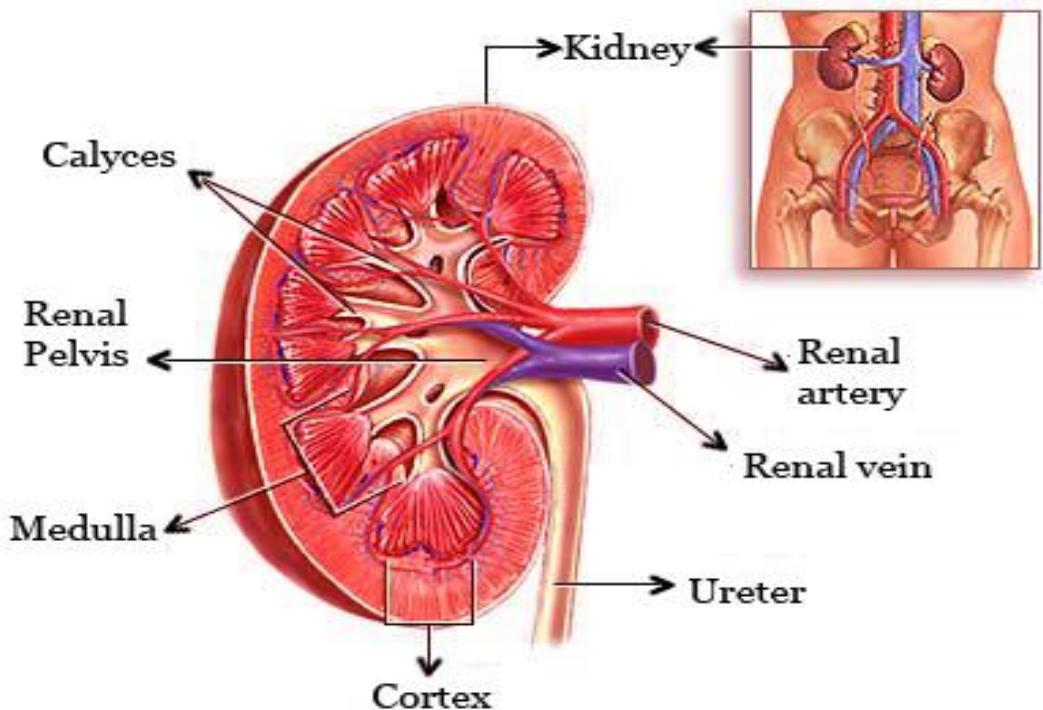
POST-TRANSPLANT COMPLICATIONS

After your transplant, it is not uncommon to experience one or more episodes of rejection, infection, and/or side effects from the medications.

ACUTE TUBULAR NECROSIS (ATN)

With transplants from a deceased donor, it is not unusual for kidney function to be sluggish initially, or to start and then suddenly stop. This passing delay in function is usually caused by temporary damage to the kidney, like a bruise that will heal. Referred to as acute tubular necrosis (ATN), this condition has been likened to “hibernation” by some experts, and may take a few weeks to pass. In either type of transplant (living or deceased donor), poor function right after surgery does not mean that your kidney will not function adequately in time. As a temporary measure, dialysis may be performed to do the job of a sluggish kidney. **OBSTRUCTION**

Mechanical complications can occur at any time after the transplant. The most common problem is scarring and narrowing of the ureter, which is the tube draining urine from the kidney and putting it into the bladder (see the picture below). If the transplant team suspects obstruction, they will order an ultrasound. An ultrasound is a sound wave test where gel is placed over the kidney and a probe is passed back and forth over the transplant. The ultrasound allows your doctor to look for swelling around the kidney (hydronephrosis) which is an indication of obstruction. In most cases, obstruction is caused by narrowing of the ureter. This is easily fixed by a procedure where a stent (plastic tube) is placed into the kidney, through the ureter, and into the bladder. This stent is left in place for approximately two months. After removal, another ultrasound may be performed so your doctors can look for recurrence of swelling.



REJECTION

The immune system's normal response to anything foreign is to attack and try to destroy the foreign object. Normally, this is a good thing, as it helps your body fight off infections caused by bacteria, viruses, or other unwelcome material. This is true after transplantation as well – the normal immune response is to recognize the transplanted organ as foreign and try to destroy (reject) it. To combat this immune response against the transplanted organ, you will need to take immunosuppressive (anti-rejection) medications. The goal is to prevent rejection without eliminating your body's ability to fight infections. The risk from too little immunosuppression is a rejection episode. Rejection is almost always easily treated, as long as it is caught early. The risk of too much immunosuppression is infection, which can be very serious. For more information on the immunosuppressive medications you will be taking, see the "Medications" section.

You will never be completely taken off your immunosuppressive medications because your body will never completely stop trying to reject the transplanted organ. However, as time passes, the amount of immunosuppression that your body needs will decrease. Thus, your immunosuppressive medication doses will be decreased over time.

In spite of the immunosuppressive medications, it is possible that you will experience at least one episode of rejection. This most often occurs during the first two weeks after transplantation and almost always within the first three months. It is possible for rejection to develop much later, but as long as you continue to take your medications as prescribed, it is rare to have rejection more than one year after surgery. An episode of rejection is a period of time where the kidney function is abnormal and requires intervention because the immune system is attacking it. Ninety-five percent of all rejections are cured with temporary increases in immunosuppressive medications. Usually there are no symptoms associated with a rejection episode. Your doctors will detect it via a change in the kidney function on your lab tests. An ultrasound and a biopsy may be done to confirm the diagnosis of rejection.

You will be getting blood tests frequently and you will be monitored very closely, especially during the first 4 months after your transplant. In most cases, the first sign of a rejection episode is a change in your blood tests without your experiencing any symptoms. However, you may experience one or more of the following symptoms:

- **Fever, chills, sore throat**
- **Ankle swelling**
- **Pain over the kidney**
- **A rise in blood pressure**
- **Weight gain (sudden large amount, 4 to 5 pounds in one day)**
- **Generally not feeling well, fatigue**
- **A decrease in urine output**

If you develop any of these symptoms, you should contact a member of the transplant team.

There are a number of ways to treat a rejection episode. These treatments may require admission to the hospital and may include intravenous steroids and adjustment of immunosuppression.

REMEMBER, REJECTION IS AN EPISODE WHICH CAN BE TREATED AND DOES NOT MEAN YOU WILL LOSE YOUR KIDNEY.

INFECTION

Your immune system will be most active in trying to reject the new kidney for the first few months after transplant. You will be given higher doses of the immunosuppressive medicines to prevent rejections during this time. For this reason, you will be most at risk for infections early after transplant.

Infections are common after transplant. Normally, your immune system helps you to fight infections. However, as a result of the immunosuppressive medications you must take for a successful transplant, your immune system is less able to respond to infections. Therefore, we will prescribe you certain medications to help prevent infections. These medications are discussed in the medication section.

In this section, you will learn about certain infections that can occur in transplant recipients. The more obvious signs and symptoms of infection include fever, headache, shortness of breath, persistent cough, urinary frequency, urgency or burning, vomiting and diarrhea. Sometimes these symptoms are subtle in transplant patients. If at any time you experience one or more of these symptoms you should contact the transplant team.

Cytomegalovirus (CMV)

One of the most common infections in the general population and after transplantation is cytomegalovirus, or CMV. About 80% of the general public has been exposed to CMV and carries this virus. CMV does not cause illness in most people. However, it can cause a syndrome called CMV disease in people who are immunosuppressed, like transplant patients. Although it can occur at any time, CMV most commonly develops during the first 3-6 months after transplant. If you or your donor has ever been exposed to CMV, we will give you medications to help prevent you from developing the infection.

If you do develop CMV disease, you may have a fever, feel tired and have flu-like symptoms including shaking chills, diarrhea, nausea, and joint, bone, or muscle aches. Certain lab tests may be elevated and your white blood cell count may be decreased. Blood tests can usually detect CMV; however, sometimes further testing is needed.

Herpes

Herpes simplex (cold sores) and Herpes zoster (shingles) are two other viral infections that transplant patients may experience. Similar to CMV, many people have been exposed to the herpes virus (usually in the form of chicken pox during childhood). We will prescribe antiviral medication to help prevent these infections. You should contact the transplant team if you think you have been exposed to any person with chicken pox or shingles. If you do develop one of these infections, they are usually not too severe and can be treated on an outpatient basis.

BK Virus

The BK virus is another viral infection that you may be at increased risk for because of your immunosuppressive medications. This virus usually affects the kidneys and urinary tract. There are currently no medications available to prevent or treat infection with the BK virus. If you become infected with the BK virus, the transplant team may decide to decrease the dose of your immunosuppression, or one of your immunosuppressive medications may be stopped altogether. This is to allow your immune system to try to fight the virus on its own.

Pneumocystis Jiroveci Pneumonia (PJP)

Pneumocystis Jiroveci pneumonia is a lung infection that has been seen in the past in the immunocompromised patient. Today, this is a rare infection that only occurs in very complicated cases. To help prevent this infection you will be placed on an antibiotic medication for the first 12 months.

Urinary Tract Infection (UTI)

UTIs are not unusual after kidney transplantation. We will treat you with antibiotics if you have a UTI

Thrush

Thrush is an oral fungal infection that occasionally occurs in immunosuppressed patients. You will be given an antifungal medication for the first 3 months after transplant to prevent oral thrush.

MEDICATIONS

This section will provide you with an overview of the medications that are commonly prescribed after transplant. Each person's medications will be individually determined by the transplant team. Doses are often changed based on blood levels and side effects. **PLEASE DO NOT CHANGE ANY OF YOUR MEDICATIONS UNLESS DISCUSSED WITH A MEMBER OF THE TRANSPLANT TEAM.** Please do not take any medications prescribed by any doctor or over the counter medications without first checking with the transplant team.

You and your family/support person must have a good understanding of the medications. Not only should you know the names of the medications prescribed, but also the doses you are taking, the time you take it, and any side effects you are having. Shortly after your surgery, you will be provided with a personalized medication information sheet called a **MedActionPlan**. Your nurse will begin teaching you about the medications as she/he gives them to you and a pharmacist will teach you about your medications before discharge. You should study the medications in addition to the information included in this manual so that you have a good understanding of them and feel comfortable leaving at discharge.

As described earlier, your body's natural response to a foreign object (i.e. the transplanted organ) is to destroy it. To help block your immune system's natural response, we will prescribe medications that suppress your immune system, so that the immune system does not try to destroy your new kidney. As time passes, your immune system's response will become less powerful. We will slowly reduce the doses and/or number of your immune suppressant medications. When your immune system is suppressed, you are at a higher risk of getting infections from bacteria or viruses. You will also take new medications to prevent infections, but they are usually only needed for the first 6 months after your transplant.

You will notice as you read through this section that many of the medications have side effects. Some people do not experience any side effects, some experience just a few, and some may experience many side effects. Everyone's response is different to these medications. The side effects of the immunosuppressive medications are generally related to the dose. Therefore, as the dose is decreased, the side effects also decrease. It is important for you to be familiar with the side effects and to be aware of measures that can help reduce them.

Many other medications, including over the counter, non-prescription, and herbal medications have interactions which can dangerously change the amount or effect of your immunosuppressive medications.

**PLEASE REMEMBER NOT TO TAKE ANY MEDICATIONS, HERBAL SUPPLEMENTS,
VITAMINS, OR OVER THE COUNTER PRODUCTS OTHER THAN THOSE PRESCRIBED
BY THE TRANSPLANT TEAM, UNLESS THE TEAM IS AWARE.**

IMMUNOSUPPRESSIVE MEDICATIONS

Your body's defense system (your immune system) fights off bacteria and viruses that try to attack you and make you sick. Unfortunately your body and immune system will think that your new kidney is also an invader trying to attack you, and this is called "rejections". Your body will never completely adjust to the new organ. Therefore, you will be taking medications to block your immune system for the life of your kidney after your transplant so that they don't cause harm to the kidney or cause rejection. These medications are called "immunosuppressants" or anti-rejection medications.

INDUCTION THERAPY:

Your immune system's response against your new kidney will be the strongest immediately after your surgery. Therefore, you may receive very powerful immunosuppressive medications while you are in the hospital. These strong medications are a part of what is called "induction therapy". Induction therapy ensures that your immune system is suppressed enough so that it will not reject your new organ while we get you on the right amount of medication. Depending on how strong the transplant team expects your immune response to be, you will receive induction therapy with high dose steroids and either Thymoglobulin or Simulect.

MAINTENANCE MEDICATIONS:

Anti-rejection medications work best when we use them together. In most cases we will prescribe two or three different anti-rejection medicines, and over time you will need less medicine. Your team will work with you to find the best combination of medications to protect your kidney and have few side effects. **If you miss taking your anti-rejection medicines even ONCE or skip taking them, this can cause rejection and may cause your new kidney to stop working.**

Example:

Take this medicine	8:00 am	12:00 pm	6:00 pm	8:00 pm	Purpose
 Tacrolimus 1 mg Oral Capsule Take by mouth	4 capsules			4 capsules	Prevents rejection
 Mycophenolic acid 180 mg Oral Tablet Take by mouth		4 tablets		4 tablets	Prevents rejection
 Prednisone 5 mg Oral Tablet Take by mouth		1 tablet			Prevents rejection

Prograf®/Envarsus XR®/Astagraf XL® (tacrolimus)

Tacrolimus is one of the main anti-rejection medications that you will take after your transplant. Tacrolimus is sometimes called "tacro" for short. It helps to stop your body from rejecting your new kidney. Your transplant team will use blood tests to monitor the level of your tacrolimus to make sure that it's not too high and not too low. You may have extra side effects if it's too high. If it's too low, you could reject your kidney. **When you go for a blood test, do NOT take tacrolimus in the morning before the test. Take it after you have your blood drawn.**

There are 3 different forms of tacrolimus:

- Prograf®/generic tacrolimus - immediate release capsules – you take every 12 hours
- Envarsus XR® - extended release tablets – you take once a day in the morning
- Astagraf XL® - extended release capsule – you take once a day in the morning

- Do NOT switch between versions unless your team tells you to
- Do NOT switch between different generic versions unless you let your team know and you schedule to get lab work done

PLEASE REMEMBER, NEVER STOP TAKING YOUR TACROLIMUS (PROGRAF) OR CHANGE THE DOSE WITHOUT SPEAKING WITH A MEMBER OF THE TRANSPLANT TEAM.

How Much	Your transplant team will tell you how much you need to take (usually 1mg capsules)
How Often	Every 12 hours for immediate release tacrolimus, every 24 hours for extended release tacrolimus
How Long	Lifelong
Side Effects	<ul style="list-style-type: none"> • Low magnesium levels • High potassium levels • High blood pressure • High blood sugar/developing diabetes • Decreased kidney function • Tremors/shakiness • Headache • Trouble sleeping
Special Instructions	<ul style="list-style-type: none"> • You should always take tacrolimus at the same time • Be consistent with how you take it (always before or always after you eat) • Avoid grapefruit and any drinks that contain grapefruit juice (Fresca, Sunny Delight) and pomegranate

Myfortic® (Mycophenolic acid)

Myfortic® (mycophenolic acid) is an anti-rejection medication to prevent your body from rejecting your new kidney. . . Myfortic® is supplied as 180 mg or 360 mg tablets. If you are prescribed this medication, you will take it in the morning and in the evening along with your tacrolimus.

FDA warning: this medication is linked to increased risk of loss of pregnancy and birth defects. Females of child bearing age must be counseled about preventing pregnancy and planning

- If you become pregnant while taking this medication, let your doctor know immediately
- Before taking the medication, talk to your team about birth control options

PLEASE REMEMBER, NEVER STOP TAKING YOUR MYCOPHENOLIC ACID (MYFORTIC) OR CHANGE THE DOSE WITHOUT SPEAKING WITH A MEMBER OF THE TRANSPLANT TEAM.

How Much	Your transplant team will tell you how much you need to take (usually 180mg tablets)
How Often	Every 12 hours
How Long	Lifelong
Side Effects	<ul style="list-style-type: none"> • Stomach upset (nausea, vomiting, diarrhea) • Low white blood cell count
Special Instructions	<ul style="list-style-type: none"> • If you take anything with calcium, magnesium, or aluminum hydroxide (Maalox, Mylanta, Tums, or Phosphate Binders) you should take them 1 hour before or 2 hours after taking your Myfortic®

Prednisone

Prednisone is a corticosteroid used to help both prevent and treat rejection by further suppressing the immune response. Initially after your transplant, you will be given the intravenous (IV) form of prednisone, called Solu-Medrol or methylprednisolone. This IV treatment will continue for 5 days when you're in the hospital. If your doctor thinks you need prednisone long-term, you will start oral prednisone at the end of the IV treatment. .

How Much	Your transplant team will tell you how much you need to take (usually 5mg tablets)
How Often	Usually once a day
How Long	Your transplant team will tell you how long you need to take this medicine for
Side Effects	<ul style="list-style-type: none"> • Trouble sleeping, mood swings, night sweats • High blood sugars • Water retention, high blood pressure • Acne • Increased appetite, heartburn • Osteoporosis

MEDICATIONS TO PREVENT INFECTION

After you receive your new kidney, your immune system will be low because of the anti-rejection medicines. This will mean that your body won't be able to fight off infections as easily as it did before. Your transplant team will prescribe you medicines to protect you from some infections for the first few months after the transplant.

Valcyte® (Valganciclovir)

Valcyte® is an antiviral medication used to prevent or treat cytomegalovirus (CMV), herpes, and chicken pox infections.

How Much	1-2 tablets (450mg)
How Often	Usually once a day, may also be given 2-3x per week. Based on kidney function
How Long	3-6 months
Side Effects	<ul style="list-style-type: none"> • Low white blood cell count • Low red blood cell count • Low platelets

Mepron® (Atovaquone)

Mepron® prevents pneumonia caused by the fungus *Pneumocystis jirovecii* (PCP). Mepron® is a bright yellow liquid with a citrus/tutti frutti flavor.

How Much	10mL (1500mg)
How Often	Usually once a day
How Long	12 months, some people may have to take for the rest of their life
Side Effects	<ul style="list-style-type: none"> • Stomach upset

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Mycelex® (Clotrimazole Troche/lozenge)

This medication is used to help prevent a fungal infection in your mouth and throat called “thrush” which is from *Candida*. . You should let one lozenge melt in your mouth three times a day after meals. You should not eat or drink anything for 15 min after taking the medication to allow the medication to absorb into your mouth and throat where it needs to work. In most cases we will instruct you to discontinue this medication 3 months after your transplant.

How Much	1 tablet (10mg) lozenge
How Often	Three times a day
How Long	3 months
Side Effects	<ul style="list-style-type: none">• Stomach upset
Special Instructions	<ul style="list-style-type: none">• Let the medicine dissolve so that it can coat your mouth• You should not eat or drink for 30 minutes after doing this

ANTI ULCER/HEARTBURN MEDICATIONS

Some medications (like steroids) are hard on your stomach. You may need to take some medication to treat heart burn, indigestion, or prevent stomach ulcers. Some of these are available over the counter. Some of the medications may interact with your transplant. Please discuss with your transplant team before you start taking these medications . . . Listed below are medications that we may prescribe to help minimize this problem.. .

Pepcid® (Famotidine) - Pepcid® comes in 20 mg tablets which can be taken once or twice a day.

Protonix® (Pantoprazole) - Protonix® comes in 40 mg tablets and is taken once or twice a day.

Prilosec® (Omeprazole) - Prilosec® comes in 20 & 40 mg capsules that can be taken once or twice a day.

ELECTROLYTE TREATMENTS

Some of the medications you are taking may change the normal levels of electrolytes in your body. You may be given supplements to increase or decrease levels of these electrolytes, depending on what you need. Listed below are some medications that we may prescribe to help.

Magnesium Oxide - Magnesium oxide may be given to increase your magnesium levels.

K-Phos Neutral (Phospa 250) - K-Phos Neutral is a phosphorus supplement that may be given to increase your phosphorus levels

Kayexalate (Sodium polystyrene sulfonate) - Kayexalate is a drug given to lower your potassium levels

PAIN MEDICATIONS

Sometimes patients need to take medications after transplant for pain from the surgery. . . If you need to take pain medications at home, you must discuss this with the transplant team. Oxycodone and Tylenol® (acetaminophen) are pain medications that you can take if needed for pain.

Some pain medications like non-steroidal anti-inflammatory drugs (NSAIDs) can be harmful to your new kidney. You should not take Advil®, Motrin®, Aleve®, or any medications that contain ibuprofen or naproxen unless the transplant team tells you to take them. Aspirin is also an NSAID and should only be taken to protect your heart if the transplant team tells you to take it.

CONSTIPATION

After transplant you may have difficulty moving your bowels. This can be a side effect of pain medications, surgery, and laying down while recovering. If it hurts to move your bowels or if you have not moved them after transplant, you should tell the transplant team. The team may tell you to take medications to help you move your bowels. Docusate (Colace®), Senna (Sennakot®), and Polyethylene glycol (Miralax®) are laxative medications that will help you move your bowels. If you're having diarrhea, stop taking these medications.

GENERAL PHARMACY INFORMATION

The number, type, and cost of the medications that you take after transplant can be overwhelming. Many local pharmacies do not carry immunosuppressive medications and must special order them for you. In addition, depending on your insurance carrier and their prescription plan, you may be required to use a specific pharmacy or a mail order pharmacy. Our Transplant Pharmacist will work with you, after the transplant, to arrange monthly fills of your medicine at a BMC pharmacy. This allows us to help you with refills, insurance issues, and making sure you have all of the medicines you need at all times.

..

IF YOU EVER ENCOUNTER PROBLEMS TAKING OR OBTAINING YOUR MEDICATIONS, PLEASE TELL US IMMEDIATELY. WE CAN HELP!

..

1. NEVER stop taking your medicines without talking to your transplant team
2. Bring your medications to all appointments
3. Show your team how and when you're taking your medicines
4. Tell your team if you think you're having any side effects from your medicines
5. Keep a list of your medicines on you at all times
6. Make sure that you and your caregivers know what medicines you're on and how you're taking them
7. Take your medicines as instructed
8. Be consistent with timing of your medicines
9. ALWAYS have enough medicines available. Talk to the pharmacy if you're close to running out.
10. If you cannot afford your medicines, tell your transplant team immediately.
11. Call your transplant team if you miss a dose, another doctor prescribes you a medicine, you want to take something over the counter, if you lose insurance, your copays are too high, or you don't have insurance.
12. Continue to take the same version of your medicine. If your pharmacy changes your medicine to a different manufacturer (different size, shape, color), you may need to have your labs checked to see if you need a change in your dose

GENERAL HOME CARE

BATHING

Whether you have Steri Strips or staples on your incision, you can shower when you get home. The transplant team will recommend differently if this is not the case for you. When you do shower, do not rub your incision. The soapy water from your head and torso running over the incision will keep the area clean. Pat dry gently. Soaking in a bathtub, hot tub, or swimming in a pool is not advised for at least 6 weeks.

HOME MONITORING

BLOOD PRESSURE, TEMPERATURE AND WEIGHT

Once you are in the hospital and for the next several months, you will be required to keep a daily log of your blood pressure, temperature, and weight. This will enable the transplant team to follow trends, adjust your medications as needed, and notice subtle changes that may reflect an ongoing process that needs attention. You should take and record your vital signs at the same time every day, approximately one hour after you have taken all your morning medications. Please record these data in your vital signs log.

Blood Pressure

A blood pressure cuff will be given to you at discharge. By the time you are discharged, you or caregiver should know how to take your blood pressure and what the numbers mean. Blood pressure varies with gender, age, fatigue, anxiety level and state of health. Check with your transplant team to determine what should be your blood pressure range. We will be asking you to take your blood pressure daily and record it in your green log book. By monitoring your blood pressure at home, you can have a better idea of whether your blood pressure is under control. High blood pressure has many causes but usually reflects changes in your kidney function or side effects of your medications. It can even be increased by too much sodium (salt) in your diet. Be sure to report elevated blood pressure to your transplant team so they can determine the cause and begin the necessary treatment. Also be sure to report low blood pressures if you feel dizzy or lightheaded.

Temperature

A digital thermometer will be given to you. After discharge you will be required to check your temperature daily. You should write the result in your vital signs log and notify the transplant team if you have a temperature greater than 101 degrees Fahrenheit or 38 degrees Celsius.

Weight

We ask you to weigh yourself every morning. It is best to use the same scale and to do it at the same time of day. Record the weight in the vital signs log and alert the transplant team if your weight changes (up or down) by 5 or more pounds in one day.

Glucose Monitoring

Some recipients develop diabetes as a side effect of medications. These patients may require oral agents or insulin to control their blood sugar. If this occurs, you will also need a glucometer. A glucometer is a device used to check the sugar levels in your blood. You will be further instructed if this becomes necessary.

WOUND CARE

Wound infections can occur after your transplant. Infected wounds are generally tender or have foul smelling drainage. You may also develop a fever. Should you identify any of these symptoms, please notify the transplant team at once.

Observe wounds and drain sites for signs of infection (redness, swelling, tenderness, drainage) or dislodgment. Notify the transplant team at once if any one of these should occur. Any new illnesses or hospitalizations not at Boston Medical Center should be reported to your transplant team.

Treatment for wound infections usually requires opening the superficial skin so that it can be drained. Cleaning and dressing changes on a regular basis may be required to promote wound healing. If necessary, a visiting nurse may be enlisted to assist with the dressing changes when you are home. In addition, oral or intravenous antibiotics may be indicated.

Individual Wound Care Notes:

Nutrition – Healthy Eating and Activity after Kidney Transplant

Lifestyle choices are an important part of living well after a kidney transplant. In addition to taking your medications correctly, healthy eating and physical activity help with the success of your transplant. Health goals after transplant include:

- ✓ Wound healing
- ✓ Minimizing side-effects from anti-rejection medications such as
 - High cholesterol levels and heart disease
 - High blood sugar levels and Diabetes
 - Bone thinning and Osteoporosis
- ✓ Achieving or maintaining a healthy weight
- ✓ Prevention of muscle wasting and weakness
- ✓ Maintaining adequate fluid intake

Nutrition

The following nutrition guidelines apply to most people who receive a kidney transplant. You will work with your transplant nutritionist to review your individual nutrition needs before and after your transplant. *Your diet goals should be as follows:*

- ✓ Food that is prepared and stored in a safe manner
- ✓ Healthy eating for Weight Control
- ✓ More Calcium for bone health
- ✓ Less sodium for blood pressure control
- ✓ Less sugar for blood sugar control
- ✓ Less Cholesterol/Saturated Fats and no trans-fat to reduce your risk of heart disease
- ✓ Safe water drinking

Food Safety Guidelines

What is it?

- Food should be cleaned, cooked, and stored properly. Avoid foods that are high-risk for bacterial contamination.

Why do I need to follow Food Safety Guidelines?

- Some of your drugs reduce your immune system. A reduced immune system increases your risk of developing food borne illness.

How long will I need to avoid the “high-risk for bacteria” foods?

- For the first 6 months after transplant or per the recommendation of your doctor.

Foods that are “High-risk for bacteria:”

- All raw and undercooked meats (especially ground), poultry, fish, game
- Sushi, raw oysters, and raw shellfish
- Raw or undercooked eggs and foods that contain them. (i.e., cookie dough, cake batter, Caesar dressing, etc)
- All fresh sprouts (bean, alfalfa, etc.)
- All unpasteurized milk and dairy products, including cheeses
- All unpasteurized juices and ciders
- Raw or spoiled foods items
- Foods contaminated with a food borne illness

Always practice the following:

- Keep kitchen and food storage areas clean.
- Remove jewelry and scrub hands with soap under warm, running water for 20 seconds before preparing food and after handling raw meat, poultry, or eggs. Use a clean towel to dry hands.
- Defrost all foods in a refrigerator or microwave, not on the counter.
- Use separate cutting boards for raw meat and fruits or vegetables (Replace cutting boards that have cracks or deep grooves).
- Wash fruits and vegetables under running water just before eating. Scrub firm produce like melons and potatoes with a clean produce brush. Cut away any damaged or bruised areas and peel before using. Bacteria can build up in damaged areas of produce. Berries are harder to wash properly, so you may want to avoid these.
- Start with a new food stock. Discard any opened jars or packages (including condiments), expired foods, food with mold, dented cans, and cracked eggs.
- Keep cold foods COLD and hot food HOT!!!
 - ✓ Cold: Check the thermometer on your refrigerator. It should be 34-40 degrees F. The freezer should be less than 5 degrees F.
 - ✓ Hot: Food should be cooked and reheated at least 165 degrees F. Whole poultry (like Thanksgiving turkey) should be cooked to 180 degrees F.
 - ✓ You should invest in a food thermometer to ensure you are keeping your refrigerator and foods at the correct temperature.
- Store Food Promptly and appropriately:
 - Store raw meat, poultry, and eggs *below* ready-to-eat foods.
 - Put leftovers in the refrigerator as soon as possible. For foods that are still hot, store them in a shallow dish, and throw away any food that is left out of the refrigerator for over an hour.
 - Eat refrigerated leftovers within 24 hours and reheat only once (freeze any extra).
- Wash dishes with hot water and liquid dish detergent. Allow dishes to air dry.
- When eating out, avoid foods containing uncooked ingredients, such as eggs, meat, poultry, or fish.

- Avoid buffets, salad bars, potlucks, etc., which may contain undercooked foods or foods that have been at room temperature too long.

Higher Protein

What is it?

- Protein is found in meat, dairy, nuts, beans, and fish.

Why do I need to eat more protein?

- To heal from surgery! Protein helps you heal after surgery. It builds and repairs muscles and tissues.
- The steroids that you are on after transplant can break down muscle. Protein helps build up muscle that may be broken down.

What should I do?

- Eat low fat, protein-rich foods
 - Lean meat, poultry, and fish
 - Eggs (no runny yolks)
 - Low fat milk, yogurt, and cheese
 - Dried or cooked beans and peas
- Your dietitian can help you figure out how much protein you need every day.
- A higher protein diet is temporary. Eventually you can return to a normal amount of protein.

Less Sodium: Read food labels! *Aim for less than 140 mg of sodium per serving*

What is it?

- Less than 2000 mg (2 g) of Sodium per day. Sodium is found in salt and other preservatives.

Why should I follow a lower salt diet?

- Some transplant medications (like steroids) can cause your body to hold fluid. A diet high in sodium can cause the body to hold more fluid, putting stress on the body, and raising blood pressure.

What should I do?

- Avoid foods that are commonly high in sodium. These include:
 - Table salt or seasoning salt
 - Cured meats like ham, bacon, sausage
 - Lunch meats/cold cuts
 - Canned or dehydrated soup
 - Commercially frozen meals
 - Condiments like pickles

Less Sugar

What is it?

- Sugar is found in sweets and candy, fruit juices, refined carbohydrates.

Why should I eat less sugar?

- Surgery and immunosuppressant medications, such as prednisone, can increase blood sugar. If not controlled, diabetes can develop.

What should I do?

- Eat less candy, dessert, and pastries.
- Limit fruit juice. Choose fresh fruit instead.
- Avoid sweetened drinks like juice and soda.
- Drink more water and calorie free beverages.
- Choose whole grains instead of refined white grains.

Less Cholesterol/Saturated Fat

What is it?

- Foods high in cholesterol and saturated fat can raise your cholesterol levels. Saturated fat should be limited to < 2 grams per serving. Trans fat can also raise cholesterol, and should be avoided completely. Saturated fat and cholesterol are found in animal products like meat, cheese, and ice cream.

Why do I need to follow a low cholesterol/saturated fat diet?

- The medications you are taking can also raise your cholesterol. High cholesterol increases the risk for heart disease. By controlling the fat and cholesterol you eat, it can help decrease the risk of developing high cholesterol. Healthy cholesterol levels are below 200 mg/dL.

What should I do?

- Avoid fatty meats like cold cuts, sausage, bacon, and liver.
- Choose skim or 1% milk.
- Eat no more than 3-4 egg yolks per week.
- Select baked, broiled, or poached seafood, chicken, and turkey.
- Eat less beef, lamb, pork and cheese.
- Use spray or soft tub margarine instead of stick butter.
- Use canola or olive oil instead of butter. These contain healthy oils and are good for your cholesterol.
- Avoid baked, processed foods that tend to be high in trans-fat.

Healthy Eating for Weight Control

What is it?

- Weight control is all about balance. The calories you take in should equal the calories you expend. If you need to lose weight, then you should eat fewer calories than you need.

Why do I need to watch my weight?

- After transplant, it is common for people to gain weight. You are feeling better! And there are fewer restrictions to your diet. Steroids can make you hungrier, making you eat more, thus gaining weight.

What should I do....Follow healthy eating tips:

- Eat more high fiber foods (fruits, vegetables, whole grains, cereals, and brans).
- Eat high protein, low fat foods (chicken, turkey, seafood, lean red meat, low fat dairy).
- Eat balanced meals throughout the day.
- Stop eating when you are full! Listen to your body.
- After talking with your doctor, start exercising.
- Meet regularly with your dietitian. They can help make sure that you are at a healthy weight.

Engage in regular physical activity. This is one of the most powerful things you can do to stay well after your kidney transplant.

More Calcium

What is it?

- Calcium is needed for bone strength and health.

Why do I need to eat more calcium?

- Some of the medications you may be taking can cause bone thinning and osteoporosis. Transplant patients can lose as much as 10% of their bone calcium during the first 5 months after surgery!

What should I do?

- Eat 4 servings of calcium rich foods a day. These include:
 - Low fat dairy: 1% or skim milk, low fat yogurt, and low fat cheese
 - Canned salmon (with bones)
 - Dark leafy green vegetables, such as beet greens, turnip greens, kale, collard greens, and spinach
 - Foods fortified with calcium, such as soymilk, rice milk, and some cereal
- If you don't eat these foods, talk to your dietitian and/or to see if a calcium supplement would be beneficial for your individual needs.

Safe Water Drinking

Why do I need to be careful with my water?

- Unsafe water may contain bacteria and impurities that may be harmful to you due to your decreased immune system.

What should I do?

- Do not drink from public water fountains.
- If you prefer drinking bottled water, chose a major brand of bottled water whenever possible.
- Only drink city water if it is safe to drink.
- Filters can reduce many water impurities but cannot be relied on if city water is unsafe to drink.
 - Look for a filter that uses reverse osmosis, is certified by the National Sanitation Foundation International under standard 53 for “Cyst Removal”, and is an “absolute” 1- μm filter.
 - Only drink well water if it is boiled to remove any bacteria and impurities.

Other Things to Note:

Some of these diet needs are different from your normal diet regimen due to post-transplant medications you may now be taking.

- ✓ **Potassium** restriction is usually not necessary after transplant. However, depending on your future lab draws, you may be told to restrict potassium.
- ✓ **Your phosphorus** level may fall too low after transplant due to how well your kidney is doing its job. Include a lot of phosphorus foods in your diet, such as milk, yogurt, low fat cheese, and beans to help maintain a normal phosphorus level.
- ✓ **Your magnesium** level may fall too low after transplant due to the side effects of the medications. Include a lot of magnesium-rich foods in your diet, such as legumes, nuts, whole grains, and certain vegetables
- ✓ **Vitamin supplements** are typically not necessary after transplant if you are eating a balanced and varied diet. Before starting any supplement, including herbal supplements, discuss it with your doctor to avoid any possible interactions with your medications.
- ✓ **Alcoholic beverages** should be avoided in the early post-transplant period. Later, an occasional drink *should* be fine, but check with your doctor first.
- ✓ **Grapefruit and grapefruit juice** should be avoided. Grapefruit and grapefruit juice can interact with your Prograf, which can be very dangerous.

PUTTING IT ALL TOGETHER

Now that you know that you should eat a healthy diet, eat a lot of protein, watch your sodium, sugar, saturated fat, and cholesterol intake, what can you eat?? This chart lists foods to choose and avoid that combine all of the guidelines previously discussed.

	<u>Foods to Choose More Often</u>  Low salt, heart healthy	<u>Choose Less Often</u>  Higher in salt, sugar, fat	<u>Food Safety</u>  High-risk for bacteria
Milk and Dairy	<ul style="list-style-type: none"> • Low Fat milk (1% or fat free) • Low fat/light cheese, fat free cottage cheese (choose low sodium) • Fortified light soymilk, rice milk 	<ul style="list-style-type: none"> • Soft serve ice cream, frozen yogurt • Restaurant milkshakes • Party dips 	<ul style="list-style-type: none"> • Unpasteurized milk and dairy products • Soft cheese, deli cheese, aged cheese, cheese with mold (ie. Blue cheese)
Meat, Fish, Poultry (and other protein)	<ul style="list-style-type: none"> • Well-cooked lean meat, poultry, fish, seafood • Eggs (<3-4 egg yolks per week) • Low sodium cold cuts, hot dogs (heat until steaming) • Unsalted nuts • Canned tuna, salmon (with bones) • Beans and peas • Cooked tofu • Low sodium frozen foods, <500 mg sodium per serving 	<ul style="list-style-type: none"> • Deli cold cuts • Canned or dehydrated full salt soups • Breaded or fried meat and poultry • Sardines and anchovies • Bacon • Baked beans • Chocolate milk • Salted nuts • Frozen meals with over 500 mg sodium per serving 	<ul style="list-style-type: none"> • Undercooked or raw meat, fish, seafood, poultry, eggs, tofu • Raw seafood (clams, mussels, oysters) • Sushi, sashimi • Refrigerated pates, meat spreads, smoked fish, jerky • Raw nuts, or nuts with shells

	<u>Foods to Choose More Often</u>  Low salt, heart healthy	<u>Choose Less Often</u>  Higher in salt, sugar, fat	<u>Food Safety</u>  High-risk for bacteria
Fruits and veggies	<ul style="list-style-type: none"> Well washed fruits and vegetables Frozen vegetables without sauce Cooked/canned/frozen fruits Low sodium canned vegetables Dried fruits Low sodium tomato and vegetable juice Canned salsa 	<ul style="list-style-type: none"> Grapefruit, grapefruit juice (interacts with meds Cyclosporine and Prograf) Full salt tomato juice Full sodium canned vegetables Sauerkraut, relish, pickles 	<ul style="list-style-type: none"> Unpasteurized juices Raw vegetable sprouts Deli salads, fruits, veggies Fresh, raw salsa
Grains and Starches	<ul style="list-style-type: none"> Whole grain pasta Brown rice Potatoes Low sugar cereals Oatmeal Baked whole grain breads and rolls Unsalted crackers, popcorn, and pretzels Low sodium pancake mix Whole grain cereal Low sodium snacks 	<ul style="list-style-type: none"> Sugary cereals Salted bread, rolls, crackers, pretzels, popcorn Commercial bread stuffing French fries Regular Pancake mix 	<ul style="list-style-type: none"> Unrefrigerated cream and custard desserts/pastries Deli prepared potato, pasta salad Deli prepared baked goods (muffins, cookies, donuts, croissants)

	<u>Foods to Choose More Often</u>  Low salt, heart healthy	<u>Choose Less Often</u>  Higher in salt, sugar, fat	<u>Food Safety</u>  High-risk for bacteria
Beverages	<ul style="list-style-type: none"> • Tap water (city or municipal) • Bottled water • Low fat/skim milk • Coffee and tea-bags 	<ul style="list-style-type: none"> • Whole milk • Soft drinks • Fruit juices with sugar • Grapefruit Juice • Sports drinks 	<ul style="list-style-type: none"> • Well water • Loose tea
Fats, Oils, Spices, Herbs, Condiments		<ul style="list-style-type: none"> • Table salt, kosher salt, sea salt • Regular salad dressing • Herbal supplements • Stick margarine and butter • Fresh herbs • Soy sauce • Large amounts of ketchup and mustard • Monosodium glutamate (MSG) • Steak sauce, gravy • Shortening/Lard • Margarine with trans fat 	<ul style="list-style-type: none"> • Salad dressing made with aged cheese, raw eggs • Raw untreated honey • Raw peanut butter

EXERCISE AND LIFTING

With doctor-approved exercise programs, transplant patients often see an increase in strength, stamina, and energy. Exercise helps control blood pressure, reduce sleeplessness, and control weight. Exercise has also been shown to decrease the incidence of depression, decrease anxiety, and increase the sense of well-being. Discuss an exercise program with your transplant team.

For the first 12 weeks post-transplant, exercise should be limited to aerobic activity that does not place strain on abdominal or ‘core’ muscles. An example of an approved exercise would be daily walking, slowly increasing speed and duration.

When discharged, you should not lift anything heavier than a gallon of milk (approx. 8 lbs.) and over the course of the first six weeks, gradually work up to 15 lbs. From week 6 to week 12, you can slowly increase the weight you lift to 30 lbs. Avoid lifting, pushing, or pulling heavy objects and performing strenuous physical work for at least twelve weeks. These guidelines are meant to help you avoid developing a hernia in your incision.



GENERAL HEALTH

Eye Health

Ophthalmology examinations are recommended on a yearly basis following your transplant. Certainly if blurred vision and/or pain occur, you should have an ophthalmologist examine you before the annual appointment.

Prednisone may cause cataracts. Blurred vision may be a result of elevated blood sugars and certain types of viral infections. If you currently wear glasses, you may notice a change in your prescription requirements.

Dental Health

It is essential for you to maintain dental hygiene in order to prevent tooth decay and gum infections. You should have routine dental care every six to twelve months. However, we ask that you avoid dental visits for the first 6 months after transplant, unless you are experiencing a dental emergency.

When you do need dental work done, you will need to get an antibiotic to take 1 hour before the appointment from your doctor. Please contact the transplant team if you are having a dental procedure.

OB/GYN

OB/GYN examinations are advised for women on a yearly basis including cervical cancer screenings (Pap smear) every 3 years for women age 21-65 or cytology with HPV testing every 5 years for women age 30-65. You should also perform self breast exams monthly (after your menstrual period if applicable). Women between the ages of 50-74 should have a mammogram every other year.

Vaccinations/Flu Shots

Vaccinations should be discussed with your transplant team. Vaccinations given within the first year after transplant may not be effective. Live virus vaccines should **never** be given to an immunosuppressed patient. The tetanus shot should be given every ten years. For any other vaccinations, please discuss with a member of the transplant team. The flu shot vaccine should be given annually.

- **Live vaccines include:** measles/mumps/rubella (MMR), rotavirus (oral and injection), smallpox, chicken pox, yellow fever, flu (nasal mist), oral polio, shingles (Zostavax®), oral typhoid

Skin Care

Careful skin care is a necessary part of your routine. The immunosuppressive medications put you at increased risk for developing skin cancers. This risk is made worse by unprotected sun exposure. Following these suggestions may decrease the chances of this happening. Always use sunscreen when you are outdoors. Apply it liberally prior to going out in the sun and remember the sun is at its strongest between the hours of 11 AM and 3 PM. Examine your skin regularly and note any changes. We strongly recommend annual skin cancer screenings with a dermatologist. Please let the transplant team know if you notice anything that appears suspicious to you.

Smoking

Smoking is Strictly Prohibited. Please speak with a member of the transplant team if you have any questions or need clarification on this subject.

MISCELLANEOUS

RETURNING TO WORK

Depending on your profession/occupation, we expect that most of you will return to work after your transplant. The time that you return to work depends on the type of work you do and your stamina. Once you do return to work, you should probably begin with half days and/or shortened weeks to be increased gradually. Please discuss your return to work plans with a member of the transplant team.

MEDIC ALERT

A medic alert tag is an essential item that you should obtain and wear after transplant. The emblem can be worn as a necklace or a bracelet and comes in many different metals. It will identify you as a transplant recipient and should list your medications and any drug allergies you may have. Your information at Medic Alert can be updated as often as needed online from home. An application is included in your discharge materials. Any member of the transplant team can advise you on what you should have written on the tag and how to obtain one.

www.medicalert.org

DRIVING

Together we will determine whether you are at a safe point to get behind the wheel. Try to avoid long trips for four weeks, and don't forget to buckle up. It is unsafe to drive or operate any machinery while taking narcotic pain medications.

SEX

You may resume your normal sexual activity as soon as you feel comfortable after your discharge from the hospital. Please remember that safe sex measures including the use of a latex condom are strongly recommended, especially for those of you who are not in long-term monogamous relationships. Condoms may help to prevent sexually transmitted diseases.

Women should discuss their method of birth control with the transplant team. Although your menstrual cycle may not be regular during the first few months after your transplant, you may still ovulate and even become pregnant. If you or your spouse is considering having children, please discuss it with your nephrologist. We recommend that females avoid pregnancy and males avoid fathering a child for at least two years after transplant.

Male patients may experience some degree of sexual dysfunction early after the transplant, which resolves with time. If you continue to experience this for an extended period of time, please let us know.

GARDENING

Gardening/mowing/raking should be avoided for at least 6 months after transplant. There can be mold and/or fungus in the earth or plant materials that may make you ill.



GENERAL GUIDELINES

Now that you have had a transplant, you are not a sick patient but a normal, healthy recipient. This applies to your relationship with family and friends just as it does to your professional and recreational activities. You can resume your previous activities, and you may even feel good enough to add some new ones. You may need extra rest the first day or two after leaving the hospital, but a daily exercise program will improve and maintain your health. You will not damage, hurt, bump, or strain your kidney as long as you follow your transplant team's recommendations. Here are some general guidelines:

- Avoid lifting, pushing, or pulling heavy objects and performing strenuous physical work for at least twelve weeks. When discharged, you should not lift anything heavier than a gallon of milk (approx. 8 lbs.) and over the course of the first six weeks, gradually work up to 15 lbs. From week 6 to week 12, you can slowly increase the weight you lift to 30 lbs. These guidelines are meant to help you avoid developing a hernia in your incision.
- If you intend to return to work, including heavy physical labor, get your doctor's OK first.
- Avoid dark, dusty, damp areas where mold or fungus may grow (attics, wet basements, ...)
- Avoid contact sports.
- Students should check with the transplant team before returning to school.
- If you plan to go away on vacation or for business, you MUST let the transplant team know ahead of time. Take all your medications with you. When traveling by plane, carry your medications with you. Do not check them with your luggage. Also, take your physician's name and number where he or she can be reached. You should also find out the location of the Transplant Center nearest to your travel destination before you leave home.

<http://optn.transplant.hrsa.gov/members/search.asp>

PET SAFETY TIPS

Patients who have received organ transplants are more likely than most people to get diseases from animals. However, simple tips can be followed to reduce their risk of getting sick after contact with animals. These recommendations were originally made for bone marrow transplant patients, but they also may be useful for other organ transplant patients. Although this section focuses on how to protect organ transplant patients from pet related diseases, many groups support the health benefits of pets.



Keep Clean!

Wash your hands thoroughly with running water and soap after handling animals and their feces (stool). If possible, you should avoid direct contact with animal feces. Adults should supervise the hand washing of children.

Caring for Your Pet

If your pet is ill, seek veterinary care as soon as possible. Any cat or dog that has diarrhea should be checked by a veterinarian for infection with *Cryptosporidium*, *Giardia*, *Salmonella*, and *Campylobacter*.

Caring for Birds: Bird cage linings should be cleaned daily. Wear gloves whenever handling items contaminated with bird droppings.

Caring for Fish: Avoid cleaning fish tanks by yourself; ask a family member or friend for assistance. If this task cannot be avoided, you should wear disposable gloves during such activities. Wash your hands thoroughly with running water and soap afterwards.

Caring for Cats: If you have a cat, try to have another person clean out litter on a regular (daily) basis. Do not place litter boxes in kitchens, dining rooms, or other areas where food is prepared and eaten. Keep your cat indoors. Avoid handling stray cats. Pet cats do not need to be tested for toxoplasmosis.



Feeding Your Pet

Just like people, pets can get diseases from eating contaminated food. By protecting your pet from food borne diseases, you can protect your own health as well. Pets should be fed only high-quality commercial pet foods. If eggs, poultry, or meat products are given to your pet as supplements, they should be well-cooked. Any dairy products given to your pets should be pasteurized.

Additionally, pets should be prevented from drinking toilet bowl water and from having access to garbage. Do not let your pet scavenge for food, hunt, or eat other animals' feces.

Getting a New Pet

When getting a new pet, avoid animals that are ill, stray, or young (cats and dogs less than 6 months old). These animals are more likely to carry diseases that can make you ill.

Animals to Avoid

The following animals are considered high-risk animals for immuno-compromised people (including organ transplant patients):

- Reptiles, including lizards, snakes, and turtles.
- Baby chicks and ducklings, many types of birds.
- Exotic pets, including monkeys. Note: All persons should avoid direct contact with wild animals. Do not adopt wild animals as pets or bring them into your home.

Contact with these animals and their environments should be avoided by people with compromised immune systems. If you do touch these animals or their environment (their food or cage, for example), wash your hands thoroughly with running water and soap. Additionally, organ transplant patients should be extra cautious when visiting farms and when in contact with farm animals, including animals at petting zoos and fairs.

RESEARCH

Kidney transplantation is a constantly evolving field. The Boston Medical Center's Kidney Transplant Program is always trying to improve results through various research projects. You may be asked to participate in research protocols or studies. Research protocols may involve looking at new immunosuppressive medications or drugs that may be helpful in the prevention of postoperative infections. Participation in research is always voluntary and in no way affects your care. Individual research studies will be discussed with you by a member of the transplant team.

REACHING OUT

If you have received a deceased donor kidney transplant, after time you may wish to write a letter to the donor family for the gift of life you received. If you choose to write, you should not make direct mention of your name or the transplant center. The letter should be anonymous. Once completed you may give it to one of the transplant coordinators who will then forward it to the Aftercare Coordinator at the appropriate procurement agency. If the donor family wishes to respond, the letter will be forwarded to one of the coordinators who will then pass it on to you and your family. While writing to your donor family is not required, it has been a positive experience for many recipients as well as donor families. Please ask your coordinator for more information.

We hope this manual has provided you with some useful information. You, too, through your experiences can continue to serve as a resource. Share your experiences with family, friends and colleagues. Many people don't know about transplantation and organ donation until it touches their lives directly. If you choose to reach out in your community there are many organizations that you can be a part of including but not limited to the New England Organ Bank, The National Kidney Foundation and The Transplant Recipient International Organization (TRIO). Please ask any member of the transplant team if you wish to have any more information on these or any other organizations.

<http://www.neds.org/>

<http://www.unos.org/>

<http://www.kidney.org/patients/>

<http://www.trioweb.org/>

<http://www.transplantliving.org/>

<https://www.aakp.org/>

<http://www.rsnhope.org/>

<http://www.kidney.org/>

TRANSPLANT ORGANIZATIONS from NKF

American Academy of Dermatology helps educate transplant recipients, who are on anti-rejection meds and therefore at greater risk for skin cancer, learn how to prevent and detect skin cancer.

American Liver Foundation is a national voluntary health organization that has established a Transplant Fund to assist patients and families in fundraising efforts for liver transplantation. The Foundation acts as a trustee of funds raised on behalf of patients to help pay for medical care and associated transplantation expenses, which may include expenses related to a living liver donation. (800) GO-LIVER / (800) 465-4837, webmail@liverfoundation.org

The American Organ Transplant Association offers transportation assistance through the Greyhound Corporation. Helps patients with free transportation to and from their transplant center, many times hundreds of miles away. (832) 930-2682

American Society of Transplantation is a group of transplant professionals dedicated to research, education, advocacy and patient care in transplantation science and medicine.

American Transplant Foundation offers grants up to \$300 for transplant recipients (for medication and insurance premiums) and up to \$700 for living donors (for essential living expenses, like rent, electricity, etc.).

Arbor Research Collaborative for a health calculator and to compare waiting times by transplant hospital.

The mission of the Association for Multicultural Affairs in Transplantation (AMAT) is to support our partners in the donation and transplant field as they save and heal lives in our diverse communities. (877) 742-2630

Children's Organ Transplant Association helps children and young adults who need a life-saving transplant by providing fundraising assistance and family support. (800) 366-2682

Division of Transplantation is a Government organization that provides Federal oversight and funding support for the nation's organ procurement, allocation, and transplantation system; coordinates national organ and tissue donation activities and funds research to learn more about what works to increase donation; administers the national bone marrow registry program.

Donate Life America is a not-for-profit alliance of national organizations and state teams across the United States committed to increasing organ, eye and tissue donation.

Georgia Transplant Foundation is focused on providing both financial and educational assistance for those undergoing or waiting for a solid organ transplant in the entire state of Georgia. GTF also provides assistance for expenses related to living donation. (770) 457-3796

Gift of a Lifetime is a photo-documentary journey about organ donation and transplantation.

HelpHOPELive (formerly called National Transplant Assistance Fund) works with families and volunteers throughout the United States to establish successful grass-roots fundraising campaigns in honor of individuals facing transplantation or for persons who have sustained a catastrophic injury (incl. spinal cord or traumatic brain). (800) 642-8399 or (610) 727-0612

Israel Penn International Transplant Tumor Registry provides information for organ recipients who develop transplant-related malignancies.

Kidney Transplant/Dialysis Association, Inc. is dedicated to providing financial aid, information, and emotional support to chronic renal disease patients and their families.

Lotsa Helping Hands is a simple, immediate way for friends, family, colleagues and neighbors to assist loved ones in need. It is an easy-to-use, private group online calendar, specifically designed for organizing helpers, where everyone can pitch in with meal delivery, rides, and other necessary tasks. There is no cost to your family to use this system.

NATCO, The Organization for Transplant Professionals is a professional society representing the largest group of transplant professionals in North America.

National Foundation for Transplants offers fundraising assistance for organ and tissue transplant patients across the country, tailoring efforts to best suit each individual. (800) 489-3863 or (901) 684-1697, info@transplants.org

The National Living Donor Assistance Center is a new program funded by the US government that allows transplant programs to file an application on behalf of an eligible living donor for travel and lodging reimbursement.

National Minority Organ Tissue Transplant Education Program (National MOTTEP) educates and empowers minority communities to learn about organ and tissue transplantation and addresses the diseases and behaviors which lead to the need for transplantation such as diabetes, hypertension, alcohol and substance abuse, poor nutrition and lack of exercise.

National Transplantation Pregnancy Registry studies the outcomes of pregnancies in female transplant recipients and those fathered by male transplant recipients.

Alliance for Paired Donation has a program called OPT (Options Post-Transplantation) for a New Start that provides an opportunity for kidney transplant recipients to acquire a college degree, maintain the health of their kidney, increase their return-to-work rate and begin to enjoy life again after transplantation.

The Organ Procurement and Transplantation Network (OPTN) is the unified transplant network established by the United States Congress under the National Organ Transplant Act (NOTA) of 1984. The act called for the network to be operated by a private, non-profit organization under federal contract. The OPTN is a unique public-private partnership that links all of the professionals involved in the donation and transplantation system. The primary goals of the OPTN are to: increase the effectiveness and efficiency of organ sharing and equity in the national system of organ allocation, and to increase the supply of donated organs available for transplantation. [Find a transplant center.](#)

Scientific Registry of Transplant Recipients is a national database for transplant statistics.

Transplant Café allows individuals in the transplant community to connect online to create friendships, get & give support, increase awareness through advocacy & much more.

Affordable Transplant Housing may be available for you and your family if you are traveling to a transplant center that is far from your home and need a place to stay while you are receiving care. This list is of transplant centers that have "transplant houses," however this list is not exhaustive and you should contact your transplant coordinator or social worker for more information about these and other programs. Some transplant centers offer a discount at area hotels.

Transplant Recipients International Organization (TRIO) has a scholarship program that gives thousands of dollars in academic grants to members and their families each year.

TRIO/United Airlines Travel Program is a cooperative arrangement between TRIO and the United Airlines Charity Miles Program, providing cost-free air transportation for transplant recipients, candidates, living donors and care-givers for transplant-related travel. (800) TRIO-386, info@trioweb.org

The United Network for Organ Sharing (UNOS) manages the waiting list for a transplant in the U.S. and matches donors to recipients. Each transplant center's waiting list is part of the "national waiting list" that UNOS manages. UNOS administers the OPTN under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Their patient-centered Transplant Living site offers an easy-to-navigate collection of information and resources that help transplant patients and their families make the best possible decisions about their treatment and future health. View their list of support groups to see if there is one in your area.

U.S. Department of Health and Human Services (HHS) U.S. Government information on Organ and Tissue Donation and Transplantation.



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