



## **Kidney Transplantation**

*A Manual for Patient Education*

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**

Matthew Nuhn, MD, *Chief*, Division of Transplant Surgery  
Amitabh Gautam, MD

### **Transplant Administrator**

Greg Bloom

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### **Living Donor Coordinator**

Karen Curreri, RN, CCTC

### **Post-Transplant Clinical Coordinator**

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Isabelle Kilfoyle, LCSW

### **Transplant Pharmacist**

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### **Transplant Nutritionist**

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### **Transplant Medicine/Nephrology Team**

Jean Francis, MD, *Medical Director*, Kidney Transplantation; *Director of Quality and Practice Improvement*, Transplant Surgery  
Sandeep Ghai, MD, Transplant Nephrologist  
Elaine Sutton, RN

### **Transplant Infectious Disease Team**

Iona Bica, MD

### **Transplant Urology Team:**

David Wang, MD

**General Information**

**Multidisciplinary Transplant Clinic:**

Shapiro 7A  
725 Albany Street  
617.638.8680

**Blood Drawing Areas:**

Shapiro Lower Level  
725 Albany Street

East Newton Campus – Inpatient Rooms, OR, SICU  
88 East Newton St.  
East Newton Pavilion

## **The Kidneys:**

### **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. Your kidneys also regulate certain electrolytes such as sodium and chloride, which are responsible for fluid balance; potassium, which is vital to your heart activity; and calcium and phosphorous, which are necessary for healthy bones and muscles. Your kidneys also produce hormones that assist with the production of red blood cells and the regulation of blood pressure. Many other organs depend on the kidneys in order to work properly.

### **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. Kidney transplantation is currently the best way to restore renal function and is recommended for most individuals.

### **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, improve your health, and provide a lifestyle free from dialysis. Usually, you will have fewer fluid and diet restrictions after getting a "new kidney." Most people even feel well enough to return to work.

With transplantation comes responsibilities. 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.

### **Candidate Evaluation:**

Generally, to be eligible, you must be less than 80 years old. Any other medical problems you have must be well controlled. You will need to meet with the transplant team, including the transplant surgeon, transplant nephrologist, coordinator, dietician, pharmacist and social worker.

The surgeon will examine you to determine if you have any medical or surgical reasons why kidney transplant would not be appropriate. He will discuss the surgery itself, determine what additional tests need to be done and address any questions or concerns you and your family may have. The coordinator will set up the appointments and explain any additional tests the doctor may have ordered and also explain what takes place in the hospital when the transplant actually occurs. The social worker will address any emotional or financial concerns you may have. The Transplant Nephrologist works closely with the surgeon in completing the complete medical evaluation.

All candidates must undergo extensive testing before transplantation. The blood tests include blood grouping, kidney function, liver function, and viral studies such as hepatitis and HIV. Tissue typing is the determination of specific proteins that are on the cell surface. These proteins are called antigens. All people receive three antigens from their father and three from their mother. This test will allow us to better match a kidney to you.

Other routine tests are urine studies, chest x-ray, TB test, EKG and echocardiogram. You will also need to see a cardiologist and psychiatrist.

You must identify a Care partner/Support Person who will help you through the surgery and initial recovery. This Support Person will need to come to one of your evaluation appointments to learn what this role involves.

Once all the test results are reviewed by our Transplant Committee and the team has cleared you for a transplant, you will be placed on the active waiting list. To remain active you must send a blood sample to the organ bank each month. This is usually coordinated through your dialysis center or nephrologist.

### **Transplant Team Members**

- A **Transplant Surgeon** will conduct an evaluation, from a surgical standpoint, to ensure that you remain an acceptable candidate while you are on the list at BMC. The surgeon is available to discuss your case with your nephrologists should the need arise.
- A **Transplant Nephrologist** will conduct an evaluation, to ensure that you remain medically suitable to receive a transplant at BMC. The Transplant Nephrologist is available to discuss your case with your nephrologists should the need arise.
- The **Transplant Coordinator** provides reinforced education regarding the transplant process, listing for transplant and patient responsibilities before and after transplant. The coordinator is your **advocate** throughout the transplant process and will work with you to ensure all your needs are met. This coordinator is your contact person here at BMC and a resource for you. The coordinator is responsible for ensuring you fully understand the transplant process and your responsibilities in partnering with BMC for your continued care.
- A **Psychiatrist** and **Social Worker** are available to you throughout the waiting period and will meet with you to evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan, both before and after transplantation and address any additional concerns that may arise while you await your transplant.

- A **Dietitian** will evaluate you while you are on the wait list to ensure your nutritional status remains optimal for transplant. The dietitian is also available to you at any time while you wait for transplant.
- A **Pharmacist** will also evaluate your current med list and identify any possible drug-drug interactions that may occur after transplant and they will make recommendations to either avoid the interactions or decrease the potential side effects. The pharmacist will also teach you about your medications and assess compliance with your medication regimen.
- You may be required to see other specialists during your evaluation and follow up visits depending on your health conditions and age, like a cardiologist.

### **Types of Kidney Transplants:**

#### **Living Donor:**

A living donor kidney comes from a healthy adult. When a person comes volunteers to be a potential living donor, blood tests are performed to determine compatibility with the recipient. The pre-transplant tests performed are blood grouping, tissue typing and cross matching.

Blood group testing between the donor and recipient must be compatible before tissue typing and cross matching are performed. Once compatibility is confirmed the donor must undergo additional testing. This testing includes evaluations by a nephrologist, a surgeon, a social worker, a nutritionist, a pharmacist, blood tests for kidney and liver function, viral studies, urine studies, chest x-ray, EKG, ultrasound, and computerized tomography (CT) scan of the kidneys. The CT shows the kidney anatomy and is used to determine which kidney will be used for transplantation. Donors will meet with our Living Donor Advocate, who is not a member of the Transplant Team, but whose role is to be sure donors understand the risks and benefits of donor surgery and advocate for the rights of each donor. If all the tests results are acceptable, the surgery will be scheduled. At Boston Medical Center, laparoscopic donor kidney removal is routinely performed. This procedure is less painful for the donor and the recovery time is shorter. With this type of procedure donors spend an average of two days in the hospital and the recovery time is two to three weeks.

Statistics show that kidney transplants from live donors function longer and the survival rate for live donor kidneys is greater than 95 % for the first year. The average life of a kidney donated from a perfectly matched (tissue typing identical) sibling is 25 to 30 years and the average life of a kidney donated from a half matched or unrelated donor is 16 years. No live donor candidate is allowed to donate a kidney unless the transplant team is certain, to the best of their ability, that the donor will live a normal, healthy life with one kidney.

#### **Deceased donor:**

A deceased donor kidney comes from a person who has chosen to be an organ donor and has been declared deceased. Like the living donor, the deceased donor must have blood testing performed to show compatibility with the proposed recipient. The kidney transplant survival rate for the first year with a deceased donor kidney is 85 to 90 %. The average functional time period of a deceased donor kidney transplant is between 8-20 years.

### **Insurance Information:**

Most insurance companies including Medicare, Medicaid, private companies, and HMO's cover the costs of kidney transplantation. It is important for you to know exactly what your insurance company covers before the transplant surgery. Some companies require a pre-authorization for transplant procedures. You need to be aware of this to ensure that your insurance has approved the procedure before the surgery.

Medicare covers 80 % of the cost of the anti-rejection medications you will need after the transplant. You or your secondary insurance are responsible for the remaining 20%. This **Medicare coverage lasts for 36 months**, after the date of your transplant unless you remain eligible for Medicare based on disability or age. If you remain eligible, the medication coverage continues for as long as you have Medicare. If you are ineligible for Medicare, after 36 months, you will need another type of insurance to pay for your anti-rejection medications. If you have private insurance you need to be aware of their specific requirements for medication coverage.

It is essential that you discuss any concerns about insurance or payment with the transplant team. They can provide you with additional resources to help you determine the best way to manage the expenses associated with kidney transplantation.

**Waiting:**

Once all of the testing is complete and the transplant candidate is 'Listed' the candidate must wait (unless a living donor has been identified). It is the patient's responsibility to update any address, insurance or telephone number changes with the Transplant Team. If you move or are going away, let your coordinator know ahead of time. It is important during this waiting time to keep a positive attitude and take steps to deal with stress. The candidate will be seen in the transplant clinic annually or until the kidney transplant has taken place.

Most of all keep things in perspective. Realize that after kidney transplant your life will likely improve. Your health and independence are just around the corner.

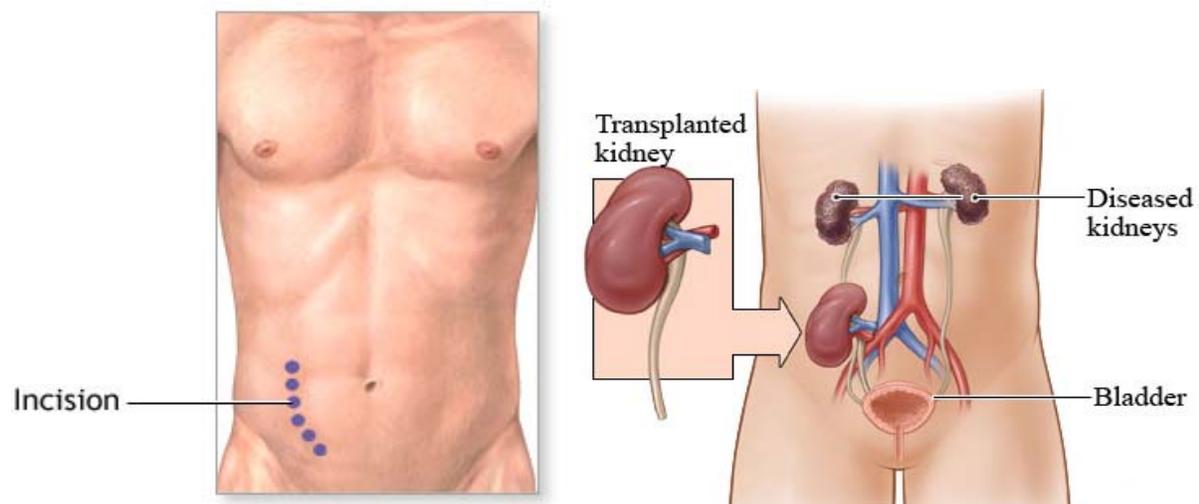
## **The Transplant Operation:**

You should plan to spend about five days in the hospital after your kidney transplant. Once you arrive at the hospital, many tests will be performed including another chest x-ray, EKG, urine studies and blood tests. You will not be able to eat or drink anything for eight hours before the surgery. Both the surgeon and the anesthesiologist will meet with you before the surgery and explain the procedure and how you will be put to sleep.

If you receive a living donor kidney, the transplant surgery will be scheduled in advance. If you receive a deceased donor kidney you will be called to the hospital when one becomes available.

The kidney transplant surgery will take anywhere from 3 - 4 hours to complete. 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. After you are asleep, an incision about eight inches long is either made on the right or left side of your lower abdomen. The new kidney is placed beneath the incision and the kidney blood vessels are attached to the artery and vein that supply your leg. The ureter of the donor kidney is sewn to your bladder. Unless your doctor feels it is necessary, your diseased kidneys will not be removed. You will be taken to the SICU once your surgery is completed.

You may have a 'stent' placed during the surgery, where the transplanted ureter is attached to your bladder. This stent can help prevent urine from leaking while the connection heals. This stent is usually removed 2 weeks after the transplant in our urologists' outpatient clinic.



## **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. When you awaken in the SICU, you will notice an IV in either your arm or neck. You will have a tube going into your bladder that drains your urine into a collection bag. This tube is called a Foley catheter and it will stay in for three days. You will have oxygen tubing in your nose to help you breathe easier. There will be a dressing over your incision on your abdomen. You will have a button to push to give yourself pain medication when you need it.

The nurses and doctors on this unit will be monitoring you very closely. They will be checking your vital signs (temperature, blood pressure and pulse) and your urine output every hour. To prevent pneumonia you will be instructed to take deep breaths and cough frequently. The nurses will also show you how to use a machine called an incentive spirometer. Proper use helps keep your lungs expanded.

Usually 24 hours after surgery you will be transferred to either 8 West or 8 East, the transplant floors. This is where you will stay until you are discharged from the hospital. The staff on the 8<sup>th</sup> floor has 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.

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. Once you are able to pass gas, you will be allowed to drink and eat. The nurses will be closely monitoring the amount of fluid you drink and the amount of urine you produce. Many factors influence when a new kidney begins to work. Do not be alarmed or disappointed if the new kidney does not make urine immediately. Sometimes a new kidney needs a few days or weeks to regain complete function. We call this delay in regaining the kidney function “Delayed Graft Function”.

Every morning while you are in the hospital you will have blood drawn and you will be weighed. These things help the transplant team understand how well the new kidney is working. You will begin taking new medications for anti-rejection. Your Post-Transplant Coordinator will give you a black binder with checklists to keep track of your medications once you are home. 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. You will leave the hospital with the Black Transplant Binder which includes a list of your medications and doses on a **Medication Card**, 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, **Medication Card**, 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.

You can expect to stay in the hospital for 4-5 days after your surgery.

## **PRECAUTIONS**

Your immune system will try to attack your new kidney as if it were a 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. You will need to wear a mask when you are outside of your room and walking around the hospital floor. This is to protect you.

To further protect you from infections we ask that you adhere to the following practices both here in the hospital and once you are home. These practices have been created 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.
- You should not have loose ice in your beverages.
- 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.
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Although these sound like strict recommendations, they are for your safety. Please speak with a member of the transplant team for further clarification.

## **Possible Complications:**

The two major complications that can occur after transplant surgery are infection and rejection.

### **Infection:**

Although very uncommon, an infection can occur in your surgical incision. It is very important that this site remains clean and dry. There will be a sterile dressing covering the incision most of the time while you are in the hospital. If you notice any redness, tenderness, or drainage at the incision site, you should notify your doctor or nurse.

Other infections include pneumonia, urinary tract infection, fungal and viral infection.

### **Rejection:**

Rejection occurs when your body tries to get rid of the foreign object (transplanted kidney). In this case, the foreign object is your new kidney. There are three types of rejection- *hyperacute, acute and chronic*.

*\*Hyperacute rejection* is very rare and occurs during the surgery or within the first few hours after the surgery. This rejection results in complete failure of the kidney. It can be avoided by careful matching the blood of the donor and the recipient.

*\*Acute rejection* is the most common. You are at the greatest risk for developing this type of rejection in the first three months after surgery. It is important that you recognize signs of rejection and contact your transplant team as soon as possible. If detected early, this type of rejection can be treated successfully.

*\*Chronic rejection* occurs gradually over a period of years and may be difficult to treat.

The following are possible signs of rejection:

- Fever greater than 100 degrees
- Sudden weight gain of three or more pounds overnight
- Decreased urine output
- Pain or tenderness over the kidney transplant site

The most important thing you can do to prevent rejection is to take your anti-rejection medications exactly as they are prescribed. You will need to take these medications for as long as you have your new kidney. Missing anti-rejection medications will put you at risk for rejection.

### **Medications After Transplant:**

It is your responsibility to learn about your new medications and to take them exactly as they are prescribed. It is important for you to know the following about each medication:

- Name
- Purpose
- Dose
- When to take each dose
- Main side effects

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 "Med Card". 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 OTHER THAN THOSE PRESCRIBED BY THE TRANSPLANT TEAM UNLESS THE TEAM IS AWARE.**

Your doctor, pharmacist and transplant coordinator are good resources to answer any questions you may have. You will be taking some, not all, of the following medications after your transplant.

**REMEMBER:** Never stop taking any of your medications without approval from your Transplant Team.

## **IMMUNOSUPPRESSIVE MEDICATIONS:**

Your immune system will never completely adjust to the new organ. Therefore, you will be taking medications to suppress your immune system for the life of your kidney after your transplant.

In most cases we will prescribe two or three different immunosuppressive medications so that each can be given in the lowest possible dose. By using a combination of different medications, we can maximize the overall immunosuppressive effect but minimize the individual drug side effects.

### **Induction**

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.

The following is a list of some of the medications that you may be required to take after your transplant. Your Transplant Team will determine the best medication combination for you.

#### ***Tacrolimus (Prograf®):***

Tacrolimus is used to prevent rejection of your new kidney. It comes in 0.5mg yellow capsules, 1mg white capsules, and 5mg pink capsules. The main side effects are:

- Headache
- Diarrhea/nausea
- Tremor
- Hair loss
- High blood sugar
- Changes in kidney function

You will take Tacrolimus twice a day; once in the morning and once in the evening. It is best to take the doses twelve hours apart, for example 8 AM and 8 PM. It is important that you take this medicine at the same time each day.

**BE CONSISTENT! DO NOT TAKE YOUR TACROLIMUS BEFORE ANY BLOOD DRAWS!**

**You should take this medication as soon as your blood test is drawn.**

#### ***Cyclosporine (Neoral®):***

Cyclosporine is used to prevent rejection of your new kidney. It is a gray capsule that comes in 100mg strength and 25mg strength. The main side effects of Cyclosporine are:

- High blood pressure
- Changes in kidney function
- Headache
- Gum overgrowth
- Tremor
- Hair growth

You will take Cyclosporine twice a day; once in the morning and once in the evening. It is best to take the doses twelve hours apart. It is important that you take this medicine at the same time each day. **BE CONSISTENT! DO NOT TAKE YOUR NEORAL® BEFORE ANY BLOOD DRAWS!**

**You should take this medication as soon as your blood test is drawn.**

***Mycophenolate mofetil (MMF, CellCept®):***

MMF is used to prevent rejection of your new kidney. It comes in large purple 500mg capsules tablet and smaller blue/orange 250mg capsules. The main side effects of MMF are:

- Nausea/vomiting
- Diarrhea
- Changes in white blood cell counts
- There is a risk of miscarriage and birth defects while taking CellCept® during pregnancy.

You will take MMF twice a day: once in the morning and once in the evening. Some patients who have problems with nausea take smaller doses of the MMF four times a day. It is important to take this medicine at the same time each day. **BE CONSISTENT!**

***Mycophenolic acid (Myfortic®):***

Mycophenolic acid is used to prevent rejection of your new kidney. It comes in a large orange 360mg tablet, and a smaller green 180mg tablet. The main side effects of Mycophenolic acid are:

- Nausea/vomiting
- Diarrhea
- Changes in white blood cell counts
- There is a risk of miscarriage and birth defects while taking Mycophenolic acid during pregnancy

You will take Mycophenolic acid twice a day, in the morning and evening. Mycophenolic acid should be taken one hour before eating any food and two hours after eating. It is important to take this medication at the same time each day. **BE CONSISTENT!**

***Sirolimus (Rapamune®):***

Sirolimus is used to prevent rejection of your new kidney. It comes in a 0.5 mg, 1 mg, or 2 mg, tablet. The main side effects of Sirolimus are:

- High cholesterol
- High blood pressure
- Nausea/diarrhea
- Rash

You will take Sirolimus once a day, in the morning. Take this medicine at the same time each day. **BE CONSISTENT! DO NOT TAKE YOUR RAPAMUNE® BEFORE ANY BLOOD DRAWS!**

**You should take this medication as soon as your blood test is drawn.**

***Prednisone (deltasone):***

Prednisone is used to prevent rejection of your new kidney. It is a small white tablet, 5mg or 10mg strength. Prednisone is a steroid. The main side effects of Prednisone are:

- Increased appetite
- Mood swings
- Acne
- Increased blood sugar
- Stomach upset
- Weight gain

You will take Prednisone once a day, usually in the morning. It is best to take Prednisone with food.

### **Anti-Viral Drugs:**

#### ***Valganciclovir (Valcyte®); Ganciclovir (Cytovene):***

Valganciclovir is used to prevent or treat a CMV infection. It can be given intravenously or as an oral capsule in 250mg or 500mg strength. It is most often given as a 450mg pink tablet. The

Valganciclovir comes in 450mg pink tablets. The main side effects of Valganciclovir are:

- Rash
- Reduction in white blood cell count

Your Transplant Team will instruct you in how to take Valganciclovir as it is different for different patients.

#### ***Acyclovir (Zovirax):***

Acyclovir is used to treat the herpes virus infection. It can be given intravenously or as an oral pill in 200mg, 400mg, or 800mg strength. The main side effects of Acyclovir are:

- Nausea/vomiting
- Diarrhea
- Rash

Your Transplant Team will instruct you in how to take Acyclovir, as it is different for different patients.

### **Other Medications:**

Most patients take the following medications in addition to the anti-rejection and anti-viral medications. It may be necessary for you to take one or all of these additional medications.

***Clotrimazole (Mycelex® Troche):*** To prevent a fungal infection in your mouth and throat

***Omeprazole (Zantac/Prilosec®) or / Pantoprazole (Protonix®):*** To reduce stomach acid and prevent ulcers

***Sulfamethoxazole/trimethoprim (Bactrim®):*** To prevent pneumonia and UTIs

### **Over-the-Counter Medications:**

The following is a list of common complaints and recommended over the counter medications you can take for these problems.

Do not take any other over-the-counter medications or herbal remedies without first consulting your Transplant Coordinator or Transplant Pharmacist.

- Constipation: Colace; Metamucil
- Diarrhea: Imodium
- Headache, Muscle aches, other aches and pains: Tylenol (Acetaminophen)
- Do not take Ibuprofen (Aleve, Advil, Motrin)
- Allergy/Cold symptoms: Benadryl, Robitussin

If any of these problems persist or if you develop a fever, notify the Transplant Team.

**IF YOU EVER ENCOUNTER PROBLEMS TAKING OR OBTAINING YOUR MEDICATIONS, PLEASE TELL US IMMEDIATELY.**

## **GENERAL HOME CARE:**

### **BLOOD PRESSURE, TEMPERATURE AND WEIGHT**

After you are discharged home, 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 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.

#### **Nutrition:**

Eating right is an important part of your recovery after transplant surgery. Good nutrition will help your body heal, fight infection and maintain a healthy weight. Certain medications you take may cause an increase in your blood pressure, blood sugar, cholesterol and weight. The following are some suggestions to help limit these side effects.

**Reduce Sodium (Salt) Intake:** Limiting the amount of salt you consume will help control your blood pressure and fluid retention. Do this by choosing not to add extra table salt to your meal. Good alternatives to salt are herb mixtures, onion and garlic powder, and other salt-free seasonings. Avoid processed foods. These foods have a lot of hidden sodium/salts.

**Protein:** It is important to eat plenty of protein. This helps your body heal. Good sources of protein are lean meats and fish, low fat dairy products, peanut butter and tofu.

**Fat and Cholesterol:** Too much fat and cholesterol can cause heart disease. You should follow a diet that is low in saturated fat and cholesterol. You should avoid eating butter, whole milk, skin of poultry and fatty cuts of meat. Instead, choose margarine, olive or canola oil and lean meats.

**Calcium:** Transplant patients are at a greater risk than other people for developing osteoporosis and bone fractures. Because of this, you should be sure to increase the amount of calcium and vitamin D in your diet. Good sources of calcium are low fat or skim milk, cheese, yogurt and calcium fortified orange juice.

**Sugars and Sweets:** If you are diabetic you should already be limiting the amount of sugar you eat. Even if you are not a diabetic, the medications you take may cause your blood sugar to increase. All transplant patients should limit their intake of sugars and concentrated sweets.

**Potassium, Phosphorous and Magnesium:** Your new medications may affect the levels of potassium, phosphorous, and magnesium in your blood. You may need to restrict **OR** supplement your diet to keep these levels in a desirable range. The following are examples of foods high in each category.

- **Potassium:** cantaloupe, oranges, orange juice, broccoli, tomatoes
- **Phosphorous:** milk, cheese, yogurt, whole grains, raisins
- **Magnesium:** shrimp, peanuts, beets, spinach, tofu

If you have any questions about these suggestions please notify your transplant team. They can arrange for you to meet with a nutritionist, who will help you develop a diet regimen that is right for you.

### **Exercise:**

To stay healthy, both mentally and physically, it is important for you to exercise on a regular basis. A good way to begin is by walking on a daily basis. Do not lift anything that weighs more than 10 pounds for the first four weeks after surgery. You should start out slow and gradually increase your activity. Remember to consult your doctor before starting on any kind of exercise plan. Your doctor will be able to advise you about an exercise plan that meets your individual needs.

## **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.

Neoral (cyclosporine) may cause gingival hyperplasia, which is swelling and overgrowth of gums. Please contact a member of the transplant team or mention this during a clinic visit if you feel it is happening to you.

## OB/GYN

OB/GYN examinations are advised for women on a yearly basis including yearly pap smears and clinical breast exams. You should also perform self breast exams monthly (after your menstrual period if applicable). Women over the age of 40 should have a mammogram every one to two years.

## 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.

## 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 Strongly Discouraged.** Please speak with a member of the transplant team if you have any questions or need clarification on this subject.

## **Follow-Up Visits:**

You will be given an appointment at discharge to return to clinic within one week after discharge from the hospital. We request that you do not take public transportation for the first 4-6 weeks due to the risk of exposure to illness.

**Blood work:** You will have blood work done at each clinic visit and 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 at the clinic desk on the 7<sup>th</sup> floor when you check in. Don't forget that blood must be drawn before taking your morning Prograf (Tacrolimus) or Rapamune (Sirolimus) dose. See the Medications section for more information.

**Clinic Visits:** 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) on Shapiro 7. It is very important that you bring the **Black 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.

## **REMEMBER: DO NOT TAKE YOUR Tacrolimus, Cyclosporine or Sirolimus BEFORE ANY BLOOD DRAWS!**

You should take these meds as soon as your blood test is drawn. You can expect to return to the clinic weekly for about 4 weeks and then less frequently as time goes on.

It is important for you to reinitiate contact with your primary nephrologist after you are discharged from the hospital. Eventually you will be referred back to your primary nephrologist for long-term, routine follow-up care, along with the transplant team.

### **GENERAL GUIDELINES**

Once you have had a successful transplant, you are no longer a sick patient but a healthy person living a normal life. 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 six 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. These guidelines are meant to help you avoid developing a hernia in your incision.
- Avoid dark, dusty, damp areas where mold or fungus may grow (attics, wet basements, ...)
- Avoid contact sports.
- If you plan to go away on vacation or for business let the transplant team know ahead of time. Take all your medications with you. When traveling by plane carry your medications with you and do not check them with your luggage. Also, keep your physician's name and number with you. 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>



## **Additional Resources:**

### **American Kidney Fund**

Website: [www.akfinc.org](http://www.akfinc.org)

Phone: 800-638-8299

### **American Association of Kidney Patients**

Website: [www.aakp.org](http://www.aakp.org)

Phone: 800-749-2257

### **National Kidney Foundation**

Website: [www.kidney.org](http://www.kidney.org)

Phone: 800-622-9010

### **Transplant Living**

Website: [www.transplantliving.org](http://www.transplantliving.org)

Phone: 888-894-6361

### **United Network for Organ Sharing (UNOS)**

Website: [www.unos.org](http://www.unos.org)

Phone: 888-TXINFO-1

### **National Living Donor Assistance Center (NLDAC)**

Website: <https://www.livingdonorassistance.org/Home/default.aspx>

Phone: (703) 414-1600 Toll Free: (888) 870-5002

### **Donate Life America**

Website: <https://www.donatelife.net/>

Phone: 804-377-3580

### **Scientific Registry of Transplant Recipients (SRTR)**

Website: <http://www.srtr.org/>

Phone: 877-970-SRTR

### **Organ Procurement and Transplantation Network (OPTN)**

Website: <https://optn.transplant.hrsa.gov/>

**Reading: The following 7 brochures are available from our Transplant Coordinators:**

*“United Network for Organ Sharing (UNOS) Patients Guide to Transplantation”*

*“What Every Patient Needs To Know” - United Network for Organ Sharing (UNOS)”*

*“Questions and Answers for Transplant Candidates about Multiple Listing and Waiting Time Transfer”*

*“Questions and Answers for Transplant Candidates about Kidney Allocation Policy”*

*“Living Donation | Information you need to know”*

*“Transplant Living Brochure”*

*“Kidney Transplant Evaluation and Listing”*

**At your local library or book store:**

*“So You're Thinking About Kidney Transplantation: A Patient and Family's Guide” - By Mark K. Wedel, MD, FACP (ISBN-10: 1625632754 or ISBN-13: 978-1625632753)*