

Kidney Transplantation

A Manual for Patient Education

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EXCEPTIONAL CARE. WITHOUT EXCEPTION.

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 or school.

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. Each patient responds differently and each patient is unique.

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, nurse coordinator, dietician, pharmacist, social worker, and financial coordinator.

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 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 tests, 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 all of your evaluation appointments to learn what this role involves and ask questions as they come up. You must have stable, secure housing, transportation to the Transplant Center for follow up care, and insurance to cover the surgery and costs of your medications.

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, why you need to take them, and assess compliance with your medication regimen.
- A **Transplant Financial Coordinator** will meet with you to discuss your insurance coverage and advise if there are additional coverages you may be eligible for.
- 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 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 ensure donors understand the risks and benefits of donor surgery and advocate for the rights of each donor. If all the test 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 approximately 4 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 and 20 years.

Insurance Information

Most insurance companies including Medicare, Medicaid, private companies, and HMOs 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. Our Transplant Financial Coordinator will work with you to determine the best options for you for coverage for your transplant and post-transplant medications. 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 your candidacy will be presented to the Transplant Multidisciplinary Committee for approval to be placed on the BMC Waitlist. Once 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 or any health conditions that change 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.

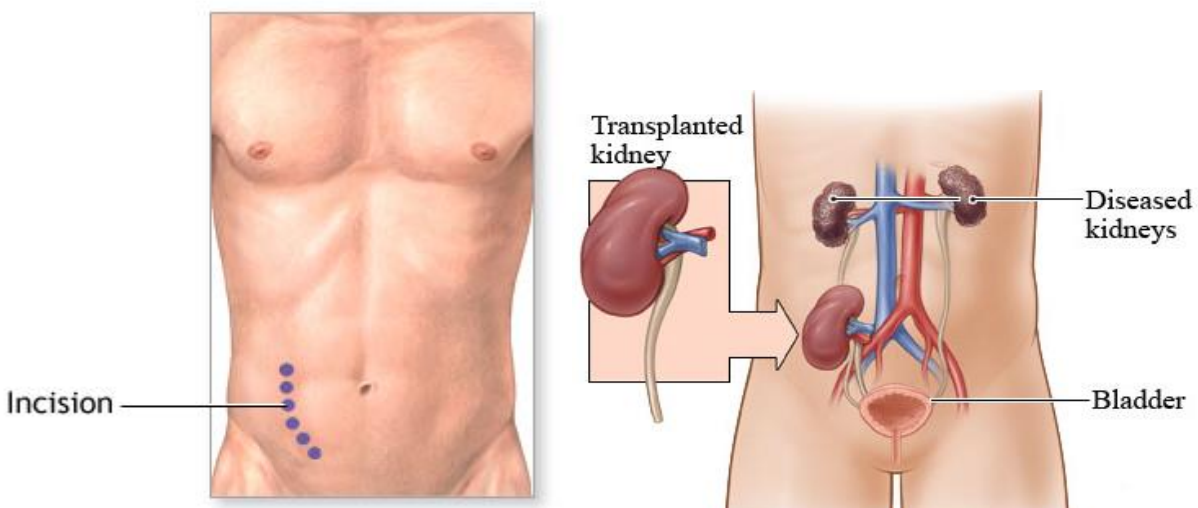
The Transplant Operation

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 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 native kidneys will not be removed. You will be taken to the SICU (Surgical Intensive Care Unit) 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 a few 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- 36 hours after surgery you will be transferred to the Surgical Step Down unit. This is where you will stay until you are discharged from the hospital. The staff on the SICU and Surgical 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.

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 red 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 and our Pharmacy 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 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**, 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.

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 **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.

REMEMBER: DO NOT TO TAKE ANY MEDICATIONS, HERBAL SUPPLMENTS, VITAMINS, OR OVER THE COUNTER PRODUCTS 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: PLEASE DO NOT CHANGE ANY OF YOUR MEDICATIONS UNLESS DISCUSSED WITH A MEMBER OF THE TRANSPLANT TEAM. NEVER SKIP YOUR MEDICINES WITHOUT LETTING THE TRANSPLANT TEAM KNOW.

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 "rejection". 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 time 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

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.

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.

<i>How Much</i>	Your transplant team will tell you how much you need to take (usually 1mg capsules)
<i>How Often</i>	Every 12 hours for immediate release tacrolimus, every 24 hours for extended release tacrolimus
<i>How Long</i>	Lifelong
<i>Side Effects</i>	<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
<i>Special Instructions</i>	<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.

<i>How Much</i>	Your transplant team will tell you how much you need to take (usually 180mg tablets)
<i>How Often</i>	Every 12 hours
<i>How Long</i>	Lifelong
<i>Side Effects</i>	<ul style="list-style-type: none">• Stomach upset (nausea, vomiting, diarrhea)• Low white blood cell count
<i>Special Instructions</i>	<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.

<i>How Much</i>	Your transplant team will tell you how much you need to take (usually 5mg tablets)
<i>How Often</i>	Usually once a day
<i>How Long</i>	Your transplant team will tell you how long you need to take this medicine for
<i>Side Effects</i>	<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

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 (Phospha 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.

Medications to Treat 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 to us 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 doctors 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

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, and peanut butter.

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

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.

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 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 7th 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.

<https://optn.transplant.hrsa.gov/members/member-directory/>



Additional Resources

American Kidney Fund

Website: www.akfinc.org

Phone: 800-638-8299

American Association of Kidney Patients

Website: www.aakp.org

Phone: 800-749-2257

National Kidney Foundation

Website: www.kidney.org

Phone: 800-622-9010

Transplant Living

Website: www.transplantliving.org

Phone: 888-894-6361

United Network for Organ Sharing (UNOS)

Website: 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 seven 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)