

After Your Kidney Transplant



Patient Leadership Committee

The Renal Network, Inc.

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What to Expect After a Kidney Transplant

For patients suffering from end-stage renal disease, there are three treatment options currently available: hemodialysis (including in-center hemodialysis and home hemodialysis), peritoneal dialysis (usually done at home) and kidney transplantation. A kidney transplant is not a cure for your disease, but rather one of the treatment options. When a transplant is successful, it is the preferred treatment among all three; however, a kidney transplant is not the best choice for all ESRD patients. When you are diagnosed with kidney failure, you need to choose the most appropriate treatment for your health and lifestyle. You need to learn as much as possible to help you make an informed decision. This article will provide you with some facts related to kidney transplantation and what to expect after a kidney transplant. You can compare them with facts about dialysis and decide which treatment would be the best for you.

A successful transplant will bring you near normal kidney function. The human kidney will clean your blood much more efficiently than an “artificial kidney” or dialysis machine can. You will feel much better and have more energy. Your life expectancy is longer after a transplant than with staying on dialysis. With a transplant, you will have fewer comorbidities from kidney failure, such as high blood pressure, heart disease, bone disease, neurological disorder, growth retardation for children, and infertility for women. You will have more freedom with a successful transplant than with dialysis. You do not have to be tied to a machine three to four hours, three times a week, as an in-center hemodialysis patient typically does. Home hemodialysis or peritoneal dialysis patients may have more freedom in scheduling the treatment time but they still have to commit three to eight hours a day to the therapy. All dialysis patients are restricted in traveling, while transplant patients can enjoy traveling without any limitations. There are very few dietary restrictions after transplant, and you are encouraged to drink a lot of fluid. Many people believe their quality of life is better with a successful transplant.

We have to keep in mind, however, that there are a few down sides to transplantation. Many of them are caused by the medications used to prevent rejection. There are multiple drugs a patient has to take for life after the transplant. These drugs all have some side effects, the major side effect being a weakened immune system, which lowers a person’s ability to fight against infection and cancer.

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As a consequence, transplant patients are at higher risk for all sorts of infection and cancer. Scientists are working to find better methods to control rejection without compromising the immune system. Staff members closely monitor patients to prevent infection/cancer or detect them early so that treatment can be initiated quickly. Other side-effects include stomach discomfort, diarrhea, poor appetite, joint pain, tremor, and burning sensation of the feet. These symptoms usually subside after the body adjusts to the medication, or they can be treated with medication and dose adjustment. For patients on steroids as part of the anti-rejection regimen, drug-induced osteoporosis may develop over the years. If indicated, it should be monitored and treated.

Post-transplant follow-up with the transplant center can be very time-consuming during the first year. It may interrupt your daily routine, especially if you are still working. During the first year after transplantation, the risk for rejection is much higher. You are required to have frequent lab tests, office visits, and radiological tests, sometimes as often as three times a week. You may need to be readmitted to the hospital for observation, procedures, or operations. If your work needs a letter of documentation for absences from work, ask your doctor to write one for you.

Financial burden is another challenge transplant recipients have to face. Anti-rejection medications are very costly, ranging from \$2,000 to \$4,000 a month. Medicare covers 80% of the cost and your secondary insurance may or may not cover the remaining 20%. Three years after the transplant, you will lose Medicare unless you are 65 years or older or you have another disability. Some insurance plans cover the medication, but require high co-pays from you. The best thing to do is to work with the social worker at the transplant center where you are listed to determine the exact amount you may need to pay out-of-pocket each month. There are many patient assistance programs which can help with the payment. Talk to the transplant social worker to see if you will qualify. Planning ahead can help you to avoid facing an unexpected large pharmacy bill immediately after the surgery.

In summary, kidney transplantation is not a cure for your disease. For some patients, it may be the best treatment option. In most cases, a patient's health, life expectancy and quality of life improve significantly after a successful transplant; however, there are many facts that need to be taken into consideration when you are planning to pursue a transplant. Talk to your nephrologist, social worker at the unit and at the transplant center, and look online (www.kidneypatientnews.org) for as much information as you can find about kidney transplants.

Commonly Prescribed Medications for Kidney Transplant Patients

Part I – Immunosuppressive Drugs

After kidney transplantation, you are prescribed a few new medications in addition to the medications you were taking before the transplant. What do you need to know about these medications, why are you taking them, how do you take them in order to be most effective, and what are the side effects? We will discuss these questions in two short articles. The first article is about anti-rejection medicines and the second one is about the other routinely prescribed post-transplant medications.

Anti-rejection medications are also called immunosuppressants. You will need to take these medications as long as you have the transplanted kidney. In the United States, the most commonly prescribed immunosuppressants are: Tacrolimus (prograf), Cyclosporine (Neoral, Gengraf), Mycophenolate mofetil (Cellcept) or Mycophenolate acid (Myfortic), Sirolimus (Rapamune) and Steroid (Prednisone). You may be prescribed a combination of two or three of the above drugs depending on your transplant center's protocol.

As suggested by their group name, "Immunosuppressants" or "Anti-rejection medications," suppress your body's immune system, preventing the transplanted organ from being rejected. Since the transplanted kidney is foreign to your body, your immune system tries to protect you from the intruder by destroying it, just like destroying a bacteria or virus during an infection. The immunosuppressive drugs weaken the body's defenses, making it incapable of getting rid of the new kidney. This is why you have to take these medicines as long as you have this kidney. Any time you stop taking them, your immune system will kill the transplanted organ. You may still have rejection of your kidney while taking these medications, but it is rare (about 10% chance) and usually reversible with treatment. Now you know why your transplant team always emphasizes the importance of taking anti-rejection medicines and strictly following the directions given by the team. Never skip or stop taking them without checking with the team. Interruption of the medication regimen can cause severe rejection of the transplanted organ. Your transplant team orders laboratory tests for you on a regular basis to monitor your kidney function and the level of the immunosuppressive drugs. The medication doses are adjusted to keep the level therapeutic. Too much or too little drug in your system is harmful.

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Another important aspect to keep in mind regarding immunosuppressive drugs is the drug-drug and/or food-drug interaction. There is a list of medications known to have interactions with immunosuppressants. It is very important to only take the medications prescribed by your transplant team. If you need to take something over-the-counter or a medication prescribed by a physician outside of your transplant team, check with your team member before taking it.

Never use any herbal medications. Although the herbs may offer certain health benefits, they may interact with the immunosuppressants you are taking and can cause severe side-effects. Since there are so many herbal medications on the market, and most of them have never been studied to determine the interaction, the principle rule is to avoid all herbs. The interaction between food and the immunosuppressive drugs is not completely understood. However, we know that any food containing grapefruit can raise the immunosuppressive drug level. This is why, at the time of the transplant, you were told never to eat grapefruit or drink grapefruit juice. Most commonly consumed foods in the U.S. are safe to eat while you are taking immunosuppressive medications, but some of the exotic or ethnic foods have not been studied. To be safe, if you are not sure about the new food you have added to your diet, call your transplant team and check your immunosuppressive drug level to see whether the dose needs to be adjusted.

Each immunosuppressive drug has its own side effects. Please see the following chart for an overview. The most common side effect of this group of medications is that they make you more susceptible to infections. As described above, this group of medicines “suppresses” your immune system and makes it more difficult for your body to recognize and fight bacteria and viruses. To reduce the risk of infection while taking these medications, you should maintain good hygiene, avoid direct contact with people who have active infection, and follow the recommended vaccination schedule. You will also be given medications to prevent certain infections post-transplant for a period of time.

A “suppressed” immune system also increases the risk of cancer development. We advise all the transplant patients to wear sun screen and to follow a cancer surveillance protocol including ultrasound of the native kidneys, colonoscopy, mammogram, pap smear and PSA at regular intervals. Not all of the side-effects will occur in every patient who is taking these medications. If you experience any of these symptoms, report them to your transplant

team. Most of the symptoms can be reduced or resolved by treating with additional medications, lowering the dose of the immunosuppressant, or switching to a different immunosuppressant.

Name of the drug	Side effects
Cyclosporine	hair growth, tremors, high blood pressure, fluid retention, high cholesterol, high potassium, gum swelling
Tacrolimus	hair loss, tremors, headaches, diarrhea, high blood pressure, nausea, high potassium, diabetes (20% risk)
Sirolimus	rash, acne, joint pain, low potassium, anemia, diarrhea, high cholesterol/triglycerides, high blood pressure, mouth sores, lung infection
Mycophenolate mofetil &/or Mycophenolate acid	diarrhea, nausea, vomiting, decrease in white blood cells, anemia, mouth sores
Steroid	insomnia, acne, moodiness, night sweats, high blood pressure, fluid retention, easy bruising, joint pain, muscle weakness, high blood sugar, high cholesterol, vision changes, osteoporosis, increased sensitivity to the sun

Not all of the side-effects will occur in every patient who is taking these medications. If you experience any of these symptoms, report them to your transplant team. Most of the symptoms can be reduced or resolved by treating with additional medications, lowering the dose of the immunosuppressant, or switching to a different immunosuppressant.

In summary, immunosuppressive medications are a group of drugs used to prevent rejection in organ transplantation. It is important to take them as prescribed to ensure their effectiveness. Follow your transplant team’s recommendations to minimize the side effects of these medications, and enjoy many good years with your new kidney.

Commonly Prescribed Medications for Kidney Transplant Patients -- Part II-Non-Immunosuppressive Medications

In addition to anti-rejection medications, a few other types of medications are prescribed for you after kidney transplantation.

Anti-viral drug: Valcyte (Valganciclovir):

This medication is used for preventing illness caused by a virus called Cytomegalovirus, which is usually referred to as CMV. CMV infection in a person with a normal immune system is very mild and often causes no symptoms or just mild flu-like symptoms. Between 50-80% of adults in the United States are infected with CMV by 40 years of age and have antibodies against the virus. Once CMV is in a person's body, it stays there for life. After transplantation, you are given medications to suppress your immune system to prevent rejection. Your weakened immune system provides a good environment for the virus to multiply, which may cause severe disease. You may be infected for the first time at the time of your transplant if your donor has it and you never developed antibodies against it before your transplant, or you may experience reactivation of the dormant or inactive virus you already harbor in your body from previous infection before your transplant. Either situation can lead to severe or even life-threatening illness if not recognized and treated early. CMV disease can be present in various ways, such as pneumonia, stomach or intestinal infection, or severe flu with fever and chills. It can also result in worsening kidney function. It is a common practice now in the U.S. for post-transplant patients to receive Valcyte for three months if there was pre-transplant CMV infection, or six months if the patient never had it before and the donor tested positive for CMV antibody.

Antibiotic: Bactrim (Sulfamethoxazole/Trimethoprim):

This is an antibiotic often used to treat urinary tract infections. After your kidney transplant, you will be placed on this medication for one year to prevent a rare lung infection called Pneumocystis pneumonia, or PCP. It is a pneumonia caused by a yeast-like fungus called Pneumocystis carinii, often seen among immunocompromised patients, such as AIDS patients or transplant patients. In order to prevent this infection in transplant patients, the majority of the transplant centers in the U.S. place patients on this medication for one year after transplantation.

Anti-fungal medication: Nystatin:

This is an oral suspension taken by swishing and swallowing after each meal and at bedtime to prevent fungal infection in the mouth in immunosuppressed patients, usually for three months post-transplant.

Antacids:

There are many drugs in this category such as Zantac, Pepcid, Protonix, Nexium, Prevacid and Aciphex. It is the transplant center's preference to choose one of these drugs to prevent or treat acid reflux among post-transplant patients, typically for the first few months after the transplant, when they are on higher doses of Prednisone, which can cause stomach irritation and ulcers. Later in the course, antacids can be used as needed to treat acid reflux.

Most of these medications you only need to take for a short period of time. In most cases, three months after the transplant, your medication list becomes much shorter. There are other medications you may need for control of high blood pressure, high cholesterol or high blood sugar, for a heart condition, or for other medical problems you may have. These are individualized for each patient.

Living Healthy After Kidney Transplantation

Many factors can affect your health after you receive your kidney transplant, including chronic medical conditions, such as high blood pressure, high cholesterol, or diabetes, and side-effects of medications you are taking to prevent rejection of your kidney. Some of these medications can actually cause high blood pressure, elevated fat levels in the blood (hyperlipidemia), diabetes, weakening of the bones, and weight gain. In this section we will focus on ways you can optimize your health and help control or prevent some of the medication side-effects through diet and exercise. You can help control your blood pressure, blood sugar, fat or lipid levels, weight, and bone health with a good diet and exercise.

EATING HEALTHY

Before your transplant, you most likely adhered to many dietary restrictions. Fortunately, with a functioning kidney transplant, the majority of these restrictions are lifted and you are free to eat a wide variety of foods once again. Choose your foods carefully to receive many health benefits. The following general recommendations should be followed when planning meals after your transplant:

Low-Sodium: For most patients with high blood pressure, a 2-gram per day sodium diet is advised. This can be achieved by reading food labels carefully, using certain herbs and lemon juice rather than salt to add flavor to foods, avoiding processed, canned, or packaged foods, which are often high in sodium, and not adding salt to foods at the table. Many of the foods you enjoy can be found in “low sodium” versions at your grocery store.

Whole Grains: Avoiding refined carbohydrates or “white starch” can help stabilize your blood sugar, prevent hunger and the need for “binging,” lower fats in the blood, and prevent constipation by adding dietary fiber. Whole grains also contain many more nutrients than most white starch products and also have more flavor. Some examples are 100 percent whole wheat, rye, corn, brown rice, millet, quinoa, amaranth, and oats, to name a few. You can find breads, pasta, cereals, and crackers made with these products. If you are diabetic and are counting carbohydrates, you may substitute whole grains with white starch products.

You can help control your blood pressure, blood sugar, fat or lipid levels, weight, and bone health with a good diet and exercise.

Healthy Fats: Eating healthy does not mean eliminating fats from your diet. Your body needs healthy fats in order to function properly. The types of fats you eat are important for healthy arteries and preventing heart disease. There are three types of fats found in foods: saturated (butter, animal and dairy fats, hydrogenated oils),

polyunsaturated (vegetable and corn oils), and monounsaturated (olive oil, canola oil, most nut oils such as peanut oil, avocado, dry-roasted, unsalted nuts). There are also fats found in certain fish, such as salmon and tuna which are beneficial and contain omega-3 fatty acids. These are known to lower triglycerides (a type of bad fat in the blood), maintain a healthy immune system, and even prevent some cancers. The monounsaturated fats confer the greatest health benefits and prevent clogged arteries. Polyunsaturated fats are acceptable in limited amounts. Saturated fats should be avoided. All fats, when fried or eaten after being heated to very high temperatures, change in structure and can be harmful. Therefore, try to limit your intake of fried foods and use baking, grilling, or broiling with minimal amounts of fat or oil as your primary cooking method. It is also important to read labels when buying processed foods and to avoid foods containing hydrogenated or partially hydrogenated oils. In addition, use nonfat dairy products such as milk and yogurt, and substitute red meat with fish or skinless chicken to reduce your saturated fat intake.

Drinking Healthy: Not only what you eat, but what you drink, can also help prevent weight gain and improve blood sugar control. Now that your fluid restrictions have been lifted, you can drink freely, as much as eight to ten glasses of fluid a day. Pure water is an excellent beverage choice. Tea and coffee in moderation, without adding sugar or high fat cream or milk, are also acceptable choices. Certain herbal teas should be avoided due to potential interactions with your transplant medications. Check with your transplant team before drinking any herbal teas. Soft drinks should generally be avoided or limited to sugar-free versions. Juices made from concentrate are very high in sugar and calories and should also be limited. A glass or two of freshly-squeezed juice daily can be used in place of concentrated juice. Substituting nonfat milk or soy milk for regular milk can also help reduce calories while offering the benefits of calcium and vitamin D for strong bones.

Fruits and Veggies: Now that you have a working kidney, your potassium restrictions most likely have been removed. This means you can begin eating a wide variety of fruits and vegetables. Fruits and vegetables are packed with vitamins, minerals, antioxidants, and fiber. Some reports recommend up to nine servings a day of these foods. Substitute sweets and high-fat desserts with fresh fruits and nonfat yogurt. There may be times when your potassium level is elevated, even after your transplant, and you may need to limit certain fruits and vegetables that are high in potassium. However, there are still many that you can continue to eat. Always discuss these concerns with your transplant team.

Vitamins and Supplements: Most transplant centers recommend that you take a multiple vitamin daily to ensure that you are getting the recommended daily amount (RDA) of all of the vitamins and minerals even if you are not receiving them all in the foods you eat. Herbal supplements should be avoided, however, due to potential interactions with your transplant medications.

Always check with your doctor before initiating any exercise program.

EXERCISE

The part of this section focuses on exercise. Most of you have heard about the health benefits of exercise which include lowering blood pressure, controlling blood sugar, weight loss, strengthening bones and muscles, and improving lipid (blood fat) levels. Exercise has also been

linked to reversing depression because activity can release endorphins (happy chemicals in the brain.) Always check with your doctor before initiating any exercise program. If you are not accustomed to exercising, start slowly and gradually build up your endurance and stamina. If you are anemic, this should be treated prior to initiating an exercise regimen. Once you are cleared by your healthcare team, you may start to exercise with a goal of 30 minutes daily or more if tolerated. Weight-bearing exercise (walking, jogging, lifting weights) is the best for preventing osteoporosis or bone loss.

(This section was written by Anita Pakarasi, RN, Transplant Coordinator at Loyola University Medical Center)

Infection Prevention for Kidney Transplant Patients

What a Patient Should Know

As we discussed in the section regarding transplant medications, one of the major side-effects of these medications is weakening of the body's immune system. Infection is common among post-transplant patients as a consequence of immunosuppressive medications. Prevention of infection becomes a major challenge for both the transplant team and you, the patient. Medications to prevent infection are given to you during the first few months after transplantation when the immunosuppressive medications are at their highest doses. With time, the immunosuppressive drug doses will be reduced, and the body's immune system will gradually improve. However, it is important to remember that you should never completely discontinue the immunosuppressive drugs, as long as the transplanted organ is still functioning. You may need to make some lifestyle modifications to protect yourself from bacteria, fungi, and viruses.

Maintain good personal hygiene everyday. Do not share your personal items such as towels, hair brushes, razors, eating utensils, etc. with others and be aware of your physical environment as well. Do not stay in an area that you suspect may be growing mold, such as a recently flooded basement or a poorly ventilated attic. If you breathe air with mold, the fungus can cause severe lung infections. Frequent hand washing (for three minutes each time) and avoiding touching your eyes, nose, and mouth before washing your hands can prevent many infectious diseases.

When you prepare food, do not use the same cutting board for slicing raw animal products such as fish, poultry, and meat as for other food items. Avoid eating raw or undercooked poultry, meat, or fish. Cook meat thoroughly until the center of the meat reaches the required temperature and the juices are golden brown, not pink. Put all unfinished food in the refrigerator immediately. Use 1% bleach to soak fruits you will eat with the skin on for five minutes and then rinse. When traveling in a country with a poor sanitation system, do not drink tap water or eat vegetables and fruits washed with tap water. Cook the vegetables and peel the fruits before eating them.

Infection is common among post-transplant patients as a consequence of immunosuppressive medications.

Prevention of infection becomes a major challenge for both the transplant team and you, the patient.

If you own a pet, dogs and cats are safe to keep in the house as long as someone else is handling the cat litter. Birds and reptiles are not recommended. If you have a fish tank, ask someone else to clean it. Birds, fish, and reptiles can carry many bacteria and viruses.

If you have to undergo any invasive procedure, such as teeth cleaning or a ureteral stent removal, for instance, you need to take an antibiotic prior to the procedure. The doctor may even prescribe an antibiotic for you that will continue for a few days after the procedure. Make sure to

let the doctor who is to perform the procedure know that you are a transplant patient on immunosuppressive drugs.

If you accidentally cut yourself, rinse the area well with running water and clean the adjacent area with soap and water. If the cut is shallow, keep the wound open to air after it stops bleeding. If the wound becomes red and warm to touch, call your transplant team. If the cut is deep, go to the emergency room immediately.

Keeping a good immunization record is important for transplant recipients. You need a flu vaccine every year; a pneumonia vaccine (pneumovax) every five years, and tetanus shot every ten years. A Hepatitis B vaccine booster should be administered whenever the titer becomes too low. A Hepatitis A vaccination is recommended when planning to travel abroad. Keep in mind that you may not use any vaccine made of a live bacteria or virus, such as a small pox vaccine, yellow fever vaccine, or flu vaccine given as nasal inhaler. Before taking a trip outside of the U.S., see a nurse or doctor in the travel clinic in your area to receive the vaccination recommended for that area. You can also check the U.S. Center for Disease Control and Prevention (www.cdc.gov) to see the recommendations for the country you are planning to visit. Always check with your transplant team before receiving any vaccine to ensure that it is safe for you. These are just a few suggestions to help you stay healthy and avoid infections. There are many good practices in daily living for preventing infections which are not included here. Keep in mind the weakened body defense mechanism due to immunosuppressant and make an educated judgment to protect yourself from the invisible enemies around us: bacteria, viruses and fungi. Remember to always talk to your transplant team if you have a question.



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