

Kidney Transplant

PATIENT EDUCATION



SERIOUS MEDICINE. EXTRAORDINARY CARE.®



TABLE OF CONTENTS

1		Transplant Office Information / When to Call	<hr/>
5		Rejection	<hr/>
7		Medications	<hr/>
29		Infections	<hr/>
37		Nutrition/Dehydration	<hr/>
45		Testing	<hr/>
49		Activity	<hr/>
51		Living with Your Transplant	<hr/>
61		Glossary	<hr/>

THROUGH OUR DEDICATED EFFORTS IN EDUCATION, RESEARCH AND CLINICAL MEDICINE, WE HAVE BECOME WORLD-RENOWNED FOR TRANSPLANTATION CARE.

Congratulations!

You have successfully come through surgery. Now the recovery process and life with your new kidney begins. This book is meant to help you and your care partners understand the process. It will help teach you what you need to know about taking care of yourself, and serve as a reference guide for common questions.

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

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

As one patient commented, “You are not trading your situation for one that is medical free; but, in fact, you are changing from having to cope with a chronic illness to chronic management.” The good news is that you will

hopefully be able to have a quality-filled life and resume some of the activities that you enjoyed before you became so ill. This will take time and patience.

After your transplant, it may be helpful for you and your family to speak with another post transplant patient and his/her family, attend a transplant support group, and talk about your concerns with a transplant team member. Our transplant nurse coordinators, social workers, psychologist and chaplain are all available to you. Please ask your nurse or transplant team if you feel you need any of these services. You may be surprised to hear how normal your feelings are, but it is important to have your feelings and concerns addressed. It is important to receive acknowledgement that this is another change in your life and that it will take time to get comfortable with all the changes.

A transplant nurse will review this booklet with you before you go home. Please keep this booklet within reach and refer to it when you have questions.

Transplant Office Information

Mailing Address

Kidney Transplant Department
Nebraska Medicine
987424 Nebraska Medical Center
Omaha, NE 68198-7424

Telephone: 402.559.5000

Toll-free: 800.401.4444

Fax Number: 402.552.3030

Office Hours

Monday to Friday, 8 a.m. to 4 p.m. CST

Weekends and holidays: Closed

Transplant coordinators accept calls:

8 a.m. to 3 p.m. CST

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

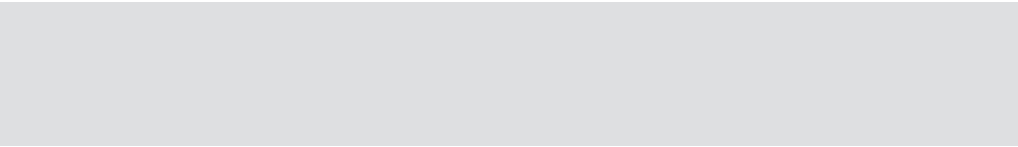
For Emergencies Only

After hours: Ask for the kidney transplant coordinator on call.

In case of an emergency, please proceed to the nearest emergency room. Please remember to tell them that you are a transplant patient and that they must call the transplant physician on call. Call your transplant coordinator after your visit to the emergency room. You are welcome to call with emergent questions, but if possible please wait until office hours. Our access to your health information is limited after hours. We will not be able to order antibiotics or offer treatment over the phone. Our policy for medicine refills after business hours is to call in only enough medicine to get you to the next business day. Please make sure you pay attention to when you will need refills so you don't run out of medicine.

For blood sugars that are too high or too low, call the doctor who follows you for blood sugars. This usually is your primary doctor or an endocrinologist, a doctor who focuses on diabetes conditions.

Use this booklet as a guide or resource for questions that come up after kidney transplantation. Do not be afraid to ask questions about anything. No question is silly. All questions are important. Our goal is to help you go home with the confidence and knowledge that you need to manage your life as a transplant patient.



Notes: _____

When to Call the Doctor

It is Important to:

- Make an appointment with your referring nephrologist (kidney doctor) to be seen six months post-transplant to re-establish care. Having a new kidney and not needing dialysis does not mean your care stops. You need to follow-up with a doctor who specializes in kidney disease and high blood pressure. Regular appointments with your kidney doctor will improve your overall health and will help manage medical problems related to your kidney disease and transplant. The transplant team makes every attempt to communicate with your kidney doctor and/or primary care doctor. It is important to let us know if you change doctors at any time after transplant.
- See your local primary care doctor within the first few weeks after transplant as this is the doctor who is most likely close to where you live and best able to manage your overall health and preventative health maintenance screenings. This is the doctor you most likely will need to see if you develop an illness unrelated to your transplant.

Be aware: Your immunosuppressive medicines can mask the usual signs of infection, so make sure you call right away. Your biggest risk is within the first few months after transplant or after treatment for rejection. You must monitor yourself and recognize the symptoms of infection and get treatment as soon as any of the following symptoms occur. Keep in mind you may not experience any of these signs but you may just not feel “normal.”

When to Call the Doctor, continued

Call your transplant team if:

- Your temperature is higher than 100.5°F
- You have sweats or chills
- You “feel lousy” or have flu-like symptoms, chills, aches, headaches, dizziness, nausea or vomiting
- You have a skin rash
- You have an area of pain, redness, tenderness or swelling at incision site or otherwise
- You have a wound or cut that will not heal
- You have red, warm or draining sores
- You are or have been around someone who is actively ill
- You have a sore, scratchy throat or pain when swallowing
- You have sinus drainage color that is not clear
- You have an ongoing or moist cough
- You have nausea, vomiting and/or diarrhea
- You have white patches in your mouth or on your tongue
- You have trouble urinating, pain or burning, constant urge or frequent urination
- You have bloody, cloudy or foul-smelling urine
- You are short of breath
- You have eye pain you have not had before
- If your doctor has put you on ANY NEW medicines
- You have gained weight or swelling
- You have a wound or cut that will not heal
- Someone you came in contact with was diagnosed with a serious infectious sickness
- You are unable to keep your medicines down or drink enough fluids
- You feel tired and are not able to exercise
- You have an unexplainable poor appetite or weight loss
- You have a skin rash
- You experience problems related to a recent procedure, appointment or admission to the transplant center

Go to the Emergency Department if you experience the following symptoms and cannot see your doctor right away:

- You have shortness of breath
- You have difficulty breathing while lying on your back
- You have a fast or irregular heart beat (feelings of palpitations)
- You have a fast breathing rate
- Severe, uncontrolled pain

Rejection

A problem you can have after your transplant is rejection of the organ. This is also referred to as a complication of organ transplant surgery. It is natural to be anxious about organ rejection. You and your family will be constantly on guard for the signs of rejection.

Rejection is not a disease. It is a normal reaction of the body to a foreign object. The part of the body that causes rejection is the immune system. The immune system is always trying to protect you from any foreign invaders. It quickly tries to destroy anything it doesn't recognize as part of you. When a new kidney is placed in your body, the immune system sees the transplanted organ as a threat and tries to attack it.

Acute and Chronic Rejection

Acute Rejection

Acute rejection happens in the first weeks to months after transplant. Acute rejection can develop at any time and can be treated in several ways:

- IV (intravenous) medicines
- Plasmapheresis. This is a method of removing blood plasma from the body by withdrawing blood, separating it into plasma and cells, and transfusing the cells back into the bloodstream
- Anti-rejection medicines

Chronic Rejection

Chronic rejection happens later, after the transplant. It is common, develops more gradually, and can continue for months or years. Preventing and treating acute rejection may reduce the possibility of chronic rejection.

Rejection is treatable with anti-rejection medicines. The best way to prevent rejection is to take medicines as ordered by your doctor.

Recognize Rejection as Soon as Possible

Episodes of rejection can happen at random times following surgery and are most frequent within the first few weeks or months after surgery. A kidney biopsy is the only reliable method to find out if rejection is developing or decreasing.

Do not miss lab appointments or checkups. We want to make sure you are on the right dose of your medicines. Medicine levels will be checked by blood sample. This is key to prevent organ rejection.

Rejection, continued

Know and Report Symptoms of Rejection

The following are the most common symptoms of rejection. Remember, each person may have different symptoms. It is important to recognize symptoms and report them immediately.

Symptoms may include any or all of the following:

- Temperature of 100.5°F or higher
- Elevated BUN and creatinine (lab test results of your kidney function)
- Swelling, tenderness at transplant site
- Blood in urine
- Decreased urine output
- Increased weight or swelling
- Flu-like symptoms: chills, aches, headache, dizziness, nausea or vomiting
- No symptoms at all

You may notice that many of these symptoms are the same as those you had before your kidney transplant. It does not mean your new kidney will fail. It just means you need medical attention immediately.

Also remember that other minor illnesses may lead to rejection, so don't ignore these. It is always best to call the transplant office and get advice from the transplant coordinator if you have any change in your health.

Treatment Works Best When You Start Early

The best way to prevent rejection is to take all medicines as ordered. Each rejection episode can hurt your transplanted kidney. You may have less chance of damage to your kidney, the sooner the treatment is started. You may need to stay in the hospital to treat the rejection. Treating the rejection may include:

- Steroids
- More powerful anti-rejection drugs
- Plasmapheresis
- A follow-up biopsy of the organ is sometimes done to make sure treatment is working

You should think of rejection as treatable. Catching rejection early, and good medical care, will likely bring rejection under control. Put all this information to use and you will be ready to handle this complication.

Summary

- Rejection is common and is usually treatable
- The best way to prevent rejection is to take medicines as prescribed. If medicine is regularly missed, rejection is sure to happen — it is just a matter of when
- You play the most important part in your health care. Stay calm, stay healthy and stay in close touch with your transplant team

Medications

Medication After Transplant

Medications play an important role after transplant. Some of them will be taken for the rest of your life to prevent your body from rejecting your new kidney. They will be used to treat other medical conditions you may also have. Always take your medication as directed. **Never** stop or start a medication or change a dose without approval from the transplant team. If you miss a dose, always let the transplant team know as soon as possible.

This section covers medications that are commonly used after transplant. This information is a learning tool or guide only. It does not replace advice from your transplant doctor. The following is an overview and does not include every detail about each medication. Make sure to follow the "Dos and Don'ts" that are listed on the next page. These important reminders will help you to use medication effectively and keep you and your new kidney healthy.

Before Leaving the Hospital You Should Know:

- The names of all your medication
- What each pill looks like
- The dose of each medication
- When to take each medication
- What each medication is used for
- Possible side effects

Medications, continued

Dos and Don'ts

1. Always take your medication as directed; never stop, start or change your dose without approval from the transplant team.
2. If a doctor other than your transplant doctor prescribes a medication for you, check with your transplant team before taking it.
3. Always maintain an up to date list of your medication. Bring the current list with you to each doctor appointment.
4. Any time a medication change is made, be sure to update your list and your pillbox.
5. If you miss a dose, do not double the next dose. Contact the transplant team for instructions. Remember, it is best to stay on schedule with all your medication.
6. Store all medicine away from extreme temperatures, direct light and moisture. Make sure that they are always kept away from children and pets.
7. When you travel, keep your medication with you in your carry-on bag and always keep an updated medication list with phone numbers of your transplant coordinator and pharmacy with you at all times.
8. Contact your transplant team if you are feeling too ill to take your medication because of nausea, vomiting or diarrhea. Do not take an extra dose without contacting the transplant team for instructions.
9. **Do not run out of your medication.** It is important to contact your pharmacy ahead of the time for refills in case the medication needs to be ordered.
10. Call the transplant team if you have any side effects, or if you are ever uncertain about a medication or its dose.
11. Do not take any over-the-counter medicine or herbal supplements without the approval of the transplant team. Some of these products interact with your transplant medication or cause side effects, which may be harmful to you and your new kidney.
12. Do not stop taking your medication because of a lack of money. Notify the transplant office during business hours just as soon as you anticipate that you may have a problem. Our social workers, pharmacy counselors and financial counselors will work with you. They can find out if there are other options to help you get your medication. Be prepared to provide financial information as well as income tax paperwork. Remember, if you lose your job, file federal taxes. Without federal tax paperwork, it is hard to file for assistance. **Please do not wait until Friday afternoon to notify us that you may have a problem. Please do not wait until you are out of medication.** There are possible solutions available for patients, but it takes time to sort them out and make the necessary contacts to check qualifications. Please let us know immediately if you know of any possible change in your insurance or finances.

Medications, continued

13. If your medication looks different when you receive a refill, check with the pharmacist to make sure it is the same medication.
14. If your dose of medication has changed without your knowledge when you receive your refill, confirm the dose with your transplant team. Any dose changes will be communicated to you by your transplant team.
15. Always check with the transplant team before planning a pregnancy.

Medication to Prevent Rejection (Also Called Immunosuppression or Anti-Rejection Medication)

Anti-rejection medication helps keep your new kidney from being rejected as a foreign object by your body's immune system. They are important to keep your new kidney alive. Most patients take a combination of three medications to prevent rejection.

Medication to Prevent Infection

Anti-infection medication is a group of medication that helps prevent infections in your body. They are given because your body's immune system will not be able to fight infection as well since you are taking anti-rejection medication. You will take three

medications to prevent infection — one to prevent bacterial infections, one to prevent viral infections and one to prevent fungal or yeast infections (also covered in the following pages).

Injectable Medication to Prevent Rejection

Initially, you will be given injectable intravenous or subcutaneous medication to prevent acute rejection. These are called induction medications. These medications will protect you and your new kidney until oral medications are started and are at levels to prevent rejection.

The two most commonly used induction medications are basiliximab (Simulect)[®] and alemtuzumab (Campath)[®] and one of these will be given at the time of your transplant. Both medications prevent your immune system from attacking your new kidney as a foreign object. Alemtuzumab (Campath) is given on the day of the transplant and basiliximab (Simulect) will be given on the day of your transplant and again as prescribed by the transplant surgeon. The steroid, methylprednisolone (Solu-medrol)[®] is also given to all patients at the time of transplant for induction.

Medications, continued

Tacrolimus (Prograf®, also called “Fk” or “Fk-506”)

Uses

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

Schedule

Tacrolimus is taken every 12 hours. For example, if you take your morning dose at 9 a.m., your evening dose is at 9 p.m.

Dose Changes and Lab Monitoring

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

Possible Side Effects of Tacrolimus

- Headaches
- Tremors
- Numb or tingling hands/feet
- Hair loss
- Trouble sleeping
- Increased risk of infection
- High blood pressure
- High blood sugar
- Increase in cholesterol levels
- Decrease in magnesium levels
- Increase in potassium levels
- Abnormal kidney function
- Stomach discomfort and/or diarrhea

Special Notes

Do not drink grapefruit juice or pomegranate juice because it can interfere with your tacrolimus level.

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



Prograf®
0.5 mg



Prograf®
1 mg



Prograf®
5 mg

Medications, continued

Cyclosporine, Modified (Neoral[®], Gengraf[®]), Cyclosporine (Sandimmune[®]) *Not Used With Prograf[®]

Uses

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

Schedule

Cyclosporine is taken every 12 hours. For example, if you take your morning dose at 9 a.m., your evening dose is at 9 p.m.

Dose Changes and Lab Monitoring

- Cyclosporine doses will be changed based on a blood level drawn by the lab, called a cyclosporine level
- Do not take your cyclosporine dose before your blood is drawn. The transplant team wants to see the "trough" or "valley" level, which occurs about 30 minutes before you take your next dose. Take the prescribed dose after your blood is drawn. The transplant doctor will evaluate the result of the cyclosporine level
- The transplant team occasionally changes your dose based on other factors, such as other lab tests or any of the following possible side effects. The transplant coordinator will call you if you should change your dose

Possible Side Effects of Cyclosporine

- Headaches
- Tremors
- Numb or tingling hands/feet
- Excessive hair growth
- Swelling or overgrowth of gums
- Trouble sleeping
- Increased risk of infection
- High blood pressure
- High blood sugar
- Increase in cholesterol levels
- Decrease in magnesium levels
- Abnormal kidney function
- Stomach discomfort

Special Notes

Do not drink grapefruit or pomegranate juice because it can interfere with your cyclosporine level.

Do not interchange different formulations of cyclosporine. For example, if you start taking Neoral[®], do not switch to Sandimmune[®] unless your transplant doctor decides you should do so. If you have to switch from Neoral[®] to a generic formulation, make sure it is Cyclosporine, Modified.

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



Sandimmune[®]
25 mg



Neoral[®]
25 mg



Neoral[®]
100 mg

Medications, continued

Prednisone

Uses

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

Schedule

Prednisone is usually taken once a day and should be taken with food. For example, you should take your morning dose with breakfast.

Dose Changes and Biopsies

Initially after transplant, your Prednisone dose will be gradually tapered down to a maintenance dose. Your Prednisone dose may be changed in the future based on biopsies of your organ. If your biopsy shows no rejection, the transplant team may lower your Prednisone dose. Likewise, if your biopsy shows rejection, your Prednisone dose may be increased.

Possible Side Effects of Prednisone

- Increase in appetite
- Weight gain
- Water retention (swelling in ankles/feet)
- Round face or "chubby cheeks"
- Mood changes or anxiety
- Trouble sleeping
- Night sweats
- Pimples
- Purple or red bruising
- Vision changes or cataracts
- Osteoporosis
- Increased risk of infection
- Increase in cholesterol levels
- High blood sugar
- Stomach irritation/ulcers

Special Notes

It is dangerous to stop taking Prednisone all at once. Doses should be reduced with a doctor's instruction.

Be alert for infections and report any black tarry stools or abdominal pain.

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



Prednisone®
5 mg

Medications, continued

Mycophenolate Mofetil (Cellcept®, Also Called "MMF") Mycophenolate Sodium (Myfortic®, Mycophenolic acid)

Uses

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

Schedule

Mycophenolate is taken twice a day. Schedule doses 12 hours apart. For example if you take your dose at 8 a.m., you should take your evening dose at 8 p.m.

Dose Changes

Your mycophenolate dose will generally not change unless you are having intolerable side effects.

Possible Side Effects of Mycophenolate

- Stomach discomfort
- Diarrhea
- Nausea/vomiting
- Decrease in platelets
- Increase or decrease in white blood cells
- Decrease in red blood cells
- Increase risk of infection
- Increase in cholesterol levels
- Increase in blood sugar
- Electrolyte abnormalities — a decrease in magnesium or calcium levels

Special Notes

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

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

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



Medications, continued

Sirolimus (Rapamune®)

Uses

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

Schedule

Sirolimus is usually taken once a day.

Dose Changes and Lab Monitoring

- Your dose of sirolimus will change based on a blood level drawn by the lab, called a sirolimus level. If you have an appointment scheduled for a lab draw, do not take your dose before your blood is drawn. The transplant team wants to see the "trough" level, which occurs about 30 minutes before you would take your next dose. You may take your prescribed dose after your blood is drawn.
- When your transplant doctor evaluates the result of the sirolimus level, he/she will let you know if you should change your dose. The transplant team may also change your dose based on other factors, such as other lab tests or possible side effects.

Possible Side Effects of Sirolimus

- Impaired wound healing
- Stomach discomfort or heartburn
- Nausea
- Diarrhea
- Headaches
- Tremors
- High blood pressure
- Water retention (swelling in ankles/feet)
- Abnormal kidney function
- Increased risk of infection
- Increased cholesterol and triglyceride levels
- Mouth sores

Special Notes

Do not drink grapefruit juice or pomegranate juice while taking sirolimus because it can interfere with your sirolimus level.

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



Rapamune®
Liquid medication



Rapamune®
0.5 mg



Rapamune®
1 mg



Rapamune®
2 mg

Medications, continued

Azathioprine (Imuran®)

Uses

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

Schedule

Azathioprine is usually taken once a day.

Dose Changes

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

Possible Side Effects of Azathioprine

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

Special Notes

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

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

Medications, continued

Sulfamethoxazole/Trimethoprim SS (Bactrim[®], Septra[®], "Smz-Tmp")

Uses

Bactrim is used to prevent bacterial infections, including pneumocystis carinii (jirovecii) pneumonia (PCP); the transplant team will determine a different medication for you if you are allergic to sulfa medication.

Schedule

Bactrim SS daily for one year.

Possible Side Effects of Bactrim

- Nausea
- Rash/itching
- Increase in sensitivity to sunlight

Special Notes

- Do not take Bactrim if you are allergic to sulfa medication
- Always take Bactrim with a full glass of water to protect your kidneys
- Wear sunscreen to protect your skin from sunburn

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

Medications, continued

Valganciclovir (Valcyte®)

Uses

Valganciclovir (Valcyte®) is used to prevent viral infections, including a virus called cytomegalovirus (CMV). Transplant patients are more susceptible to developing this infection if they or their donors have had CMV in the past. Valganciclovir is also used to prevent and/or treat herpes simplex viruses and shingles.

Schedule

Valganciclovir is usually taken once a day with food. However, the dose or schedule may be adjusted for patients with abnormal kidney function.

Dose Changes

Your valganciclovir dose may change during the course of therapy based on your kidney function.

Possible Side Effects of Valganciclovir

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

Special Notes

- Your transplant team will monitor your blood cell counts while you take this medication
- Report any unusual bleeding or bruising
- Do not crush, chew or cut tablets before swallowing. Avoid direct contact of broken or crushed tablets with the skin or mucous membranes because valganciclovir is a potential carcinogen
- Valganciclovir may cause birth defects and impaired fertility; men and women of childbearing age should use birth control during treatment with valganciclovir. Women must keep using birth control for 30 days following treatment with valganciclovir. Men must keep using birth control for 90 days following valganciclovir treatment

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



Valcyte®

450 mg

Medications, continued

Valacyclovir (Valtrex®)

Uses

Valacyclovir (Valtrex®) is used to prevent viral infections, including a virus called cytomegalovirus (CMV).

Transplant patients are more susceptible to developing this infection if they or their donors have had CMV in the past. Valacyclovir is also used to prevent and/or treat herpes simplex viruses, shingles, and chickenpox.

Schedule

Valacyclovir is usually taken three times per day with food. However, the dose or schedule may be adjusted for patients with abnormal kidney function.

Dose Changes

Your valacyclovir dose may change during the course of therapy based on your kidney function.

Possible Side Effects of Valacyclovir

- Nausea
- Headache
- Diarrhea
- Vomiting
- Rash
- Dizziness
- Decrease in white blood cell count
- Decrease in red blood cell count
- Decrease in platelets

Special Notes

- Your transplant team will monitor your blood cell counts while you take this medication
- Report any unusual bleeding or bruising
- Valacyclovir tablets are large. You may cut them in half to aid in swallowing if necessary

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



Valtrex®
1,000 mg

Medications, continued

Everolimus (Zortress)

Uses

Everolimus is used to prevent or treat rejection. It lowers the body's immune response to the transplanted kidney and/or pancreas.

Schedule

Everolimus is taken twice a day. Schedule doses 12 hours apart. For example, if you take your morning dose at 8 a.m., you should take your evening dose at 8 p.m.

Dose Changes and Lab Monitoring

- Your dose of everolimus may change based on a blood level drawn by the lab, called an everolimus level. Do not take your everolimus dose before your blood is drawn. The transplant team wants to see the "trough" or "valley" level, which occurs about 30 minutes before you take your next dose. Take the prescribed dose after your blood is drawn
- The transplant doctor will evaluate the result of the everolimus level. The transplant team occasionally changes your dose based on other factors, such as other lab tests or any of the following possible side effects. The transplant coordinator will call you if you should change your dose

Possible Side Effects of Everolimus

- Mouth sores
- Acne
- Diarrhea
- High blood pressure
- Headache
- Muscle cramps
- Fatigue
- Bloating or swelling of the face, arms, hands, lower legs or feet)
- Abnormal kidney function
- Increased risk of infection
- Impaired wound healing
- Increase in glucose and cholesterol levels

Special Notes

Do not drink grapefruit or pomegranite juice because it can interfere with your everolimus level.

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



Zortress®
0.25 mg



Zortress®
0.5 mg



Zortress®
0.75 mg

Medications, continued

Acyclovir (Zovirax®)

Uses

Acyclovir is used to prevent or treat viral infections, including herpes simplex viruses and shingles.

Schedule

Acyclovir is usually taken with food and should be taken with plenty of water. Your dose and schedule will be determined by the transplant team, and there may be adjustments for patients with abnormal kidney function.

Dose Changes

Your acyclovir dose will generally not change during the course of therapy unless you are having intolerable side effects or your kidney function changes.

Possible Side Effects of Acyclovir

- Headaches
- Nausea/vomiting
- Diarrhea
- Dizziness/fatigue
- Confusion or mood changes

Special Notes

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

Medications, continued

Nystatin Liquid

Uses

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

Schedule

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

Dose Changes

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

Possible Side Effects of Nystatin Liquid

- Unpleasant taste
- Nausea/vomiting
- Diarrhea

Special Notes

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

Medications, continued

Tacrolimus Extended Release (Astagraf XL[®], Envarsus XR[™])

Uses

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

Schedule

Tacrolimus extended release is taken every 24 hours. You should take it at the same time every day.

Dose Changes

- Tacrolimus doses will be changed based on a blood level drawn by the lab, called a tacrolimus level
- Do not take your tacrolimus dose before your blood is drawn. The transplant team wants to see the "trough" or "valley" level, which occurs about 30 minutes before you take your next dose. Take the prescribed dose after your blood is drawn. The transplant doctor will evaluate the result of the tacrolimus level
- The transplant team occasionally changes your dose based on other factors, such as other lab tests or any of the following possible side effects. The transplant coordinator will call you if you should change your dose

Possible Side Effects of Tacrolimus Extended Release

- Headaches
- Tremors
- Numb or tingling hands/feet
- Hair loss
- Trouble sleeping

- Increased risk of infection
- High blood pressure
- High blood sugar
- Increase in cholesterol levels
- Decrease in magnesium levels
- Increase in potassium levels
- Abnormal kidney function
- Stomach discomfort and/or diarrhea

Special Notes

- Do not drink grapefruit juice or pomegranate juice because it can interfere with your tacrolimus level
- Do not take Envarsus XR[®] or Astagraf XL[®] with an alcoholic beverage
- Astagraf XL[®] capsules must be swallowed whole. Do not open, break, crush, chew, or dissolve capsules before administration
- Envarsus XR[®] tablets must be swallowed whole. Do not chew, divide or crush tablets
- Envarsus XR[®] and Astagraf XL[®] are not interchangeable



Astagraf XL[®]
0.5 mg



Astagraf XL[®]
1 mg



Astagraf XL[®]
5 mg



Envarsus XR[®]
0.75 mg



Envarsus XR[®]
1 mg



Envarsus XR[®]
4 mg

Medications, continued

Pentamidine Oral Inhalation (Nebupent®)

Uses

It is used to prevent *Pneumocystis jirovecii* pneumonia.

Schedule

Pentamidine is given as an oral inhalation via nebulizer once monthly after transplant. Your doctor will determine the duration of therapy. Inhalation treatments are typically administered by a respiratory therapist in a clinic setting.

Dose Changes

The transplant team may change your dose based on other factors, such as other lab tests or any of the following possible side effects. The transplant coordinator will call you if you should change your dose.

Possible Side Effects of Pentamidine Inhalation

- Unpleasant taste
- Decreased appetite
- Respiratory effects
 - Bronchospasm
 - Cough
 - Wheezing
 - Dyspnea (difficult or labored breathing)
 - › If respiratory side effects are severe, another medication can be given as a pre-treatment to lessen these side effects
- Cardiac arrhythmia

Special Notes

Pentamidine, given by inhalation is only effective at preventing *Pneumocystis jirovecii* pneumonia. It is not an effective treatment if you have an active *Pneumocystis jirovecii* infection.

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

Medications, continued

Belatacept (Nulojix®)

Uses

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

Schedule

Belatacept is given as an infusion over approximately 30 minutes every 28 days. Belatacept may be given more frequently for several weeks when starting therapy.

Dose Changes

- Doses of belatacept are based on your weight. If you have significant changes in your weight, your dose may change
- The transplant team may change your dose based on other factors, such as other lab tests or any of the following possible side effects. The transplant coordinator will call you if you should change your dose

Possible Side Effects of Belatacept

- Diarrhea
- Constipation
- Nausea/vomiting
- Edema
- Fever
- Cough
- Headaches
- Decreased white blood cell count
- Increased risk of infection
- Increased risk of malignancy
- Abnormal kidney function
- Stomach discomfort and/or diarrhea

- Behavioral changes – any of these symptoms should be reported to your doctor right away:
 - Change in mood
 - Unusual behavior
 - Confusion
 - Memory impairment
 - Change in walking, talking, or balance
 - Decreased strength or weakness
 - Change in vision

Special Notes

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

Due to the risk of serious side effects associated with belatacept, you will be asked several questions regarding your current state of health prior to each belatacept infusion. You should also receive a medication guide prior to each infusion of belatacept, which gives an overview of uses, serious side effects, and how to proceed if you experience belatacept side effects.

Belatacept is used in place of tacrolimus or cyclosporine. You should not be taking either of these medications long term when receiving belatacept on a scheduled basis. You may be instructed to slowly decrease your dose of tacrolimus or cyclosporine when starting belatacept. Your doctor will give you specific instructions.

You must continue to take your other anti-rejection medication as instructed by your doctor. Belatacept is typically given as part of a regimen in conjunction with mycophenolate and prednisone.

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

Medications, continued

Other Routine Medications

High Blood Pressure Medication

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

High Blood Sugar Medication

The medication that you take to prevent rejection can also cause high blood sugar levels. Even if you had diabetes that was controlled with oral medication before transplant you may need insulin injection after treatment.

Antiacids/Anti-ulcer Medication

These medications are important because you are taking many medications that can cause stomach irritation. You will usually be prescribed one of the following medication to protect your stomach: esomeprazole (Nexium), lansoprazole (Prevacid), rabeprazole (Aciphex) or omeprazole (Prilosec), pantoprazole (Protonix), deslansoprazole (Dexilant). Other medication that could be used are ranitidine (Zantac) or famotidine (Pepcid).

Vitamins

Vitamins are used to supplement the diet so you receive the recommended daily nutrition requirement. Please avoid multi-vitamins with “extra” ingredients such as energy boosters, weight loss, etc. These “extras” can interfere with the absorption of your transplant medication. We will have you take a multi-vitamin daily.

Aspirin

Most transplant patients will need to take a baby or regular strength aspirin each day to promote a healthy heart. You will be taking this medication to decrease your chance of blood clots after your transplant. The specific action of this medication is to keep platelets from sticking together, which helps prevent blood clots from forming. Aspirin also decreases pain and lowers temperature.

Special Notes

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

Medications, continued

Over-the-counter Medications

Headache or Muscle Aches or Pains

You may take Tylenol (acetaminophen) or a pain medication that is prescribed by the transplant team. Do not take more than 4,000 mg of Tylenol per 24 hours, which is no more than eight double-strength (500 mg) tablets or 12 regular-strength (325 mg) tablets.

Do not take:

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

These medications can interact with your transplant medication or harm your kidneys.

Constipation

You may take docusate (Colace), Fiber-Con, Miralax or Senkot for constipation. Exercising, drinking plenty of water and increasing fiber in your diet are other medications to help relieve constipation. Contact the transplant team if constipation persists.

Diarrhea

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

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

Allergy/Cold Symptoms

You may take dextromethorphan for cough or guaifenesin to loosen thick secretions. You may take the following antihistamines for runny or stuffy nose and itchy or watery eyes: loratidine (Claritin or Alavert) or diphenhydramine (Benadryl). You may also use a saline nasal spray for nasal congestion. Do not use Afrin nasal spray. If you take a decongestant such as pseudoephedrine (Sudafed), phenylephrine, Coricidin HP or products that have D attached to the name, such as Claritin-D, you must monitor your blood pressure as the decongestant medication can cause your blood pressure to be elevated. Call your primary care doctor at once if you have persistent cold symptoms, including cough, fever, increased shortness of breath or yellow/green drainage because you may have an infection that requires antibiotics. Notify the transplant team of any medication your primary care doctor prescribes.

Indigestion and Heartburn

You may take ranitidine (Zantac), famotidine (Pepcid or Pepcid AC), nizatidine (Axid) or Tums for heartburn or indigestion. Do not take cimetidine (Tagamet).

Other Ailments

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

Medications, continued

Herbal Medications/ Supplements

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

Pregnancy and Transplant Medications

Most medication used after transplant can pose a risk to an unborn baby developing in the mother's womb. Some of the medication can even affect the fertility of a male transplant patient. Always check with your transplant doctor before planning a pregnancy; contact your transplant doctor immediately if you think you are pregnant. See the section on "Activity" for further information about sexual activity.

Infections

To protect your new kidney and prevent your immune system from rejecting it, you are taking “immunosuppressive medicines.” These anti-rejection medicines try and stop or limit your immune system (the white blood cells that fight infection) so that the new kidney is not seen as a foreign object by your body. But, these same important medicines increase your risk for infection. The types of infections that can happen include:

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

Preventing Infections

Protect Yourself

- Wash your hands carefully and frequently. This is the best way to stop the spread of germs and to prevent infection
- We recommend you or your care partner keep a bottle of hand sanitizer with you all the time
- Keep your hands away from your face and mouth
- Wash your hands after coughing or sneezing, and throw tissues in the trash immediately
- Take good care of your skin. No matter how small, clean cuts and scrapes with soap and water. If you are taking prednisone, your skin will not heal as quickly as before your transplant and may bruise more easily
- Shower daily
- Practice good dental hygiene
- Eat a healthy, well-balanced diet and follow safe food preparation guidelines
- Do not eat unpasteurized foods (farm-fresh eggs/milk/cheeses)
- Limit your visitors for the first several weeks
- If your visitors have cold or flu symptoms, ask them to return when they are well
- If someone in your family becomes ill with a cold or flu, have that person follow normal precautions (using separate drinking glasses, separate towels, covering mouth when coughing, frequent hand washing, etc.)
- Keep your house clean and free of excess dust
- Do not work in or visit any form of construction site. Dust can cause fungal infections which may be harmful. If visiting this type of area becomes necessary you need to talk with your transplant team and see if you should wear a mask
- If you enjoy fishing, be very careful with fish hooks, fish fins and fillet knives. Protective gloves should be worn when handling these items

Infections, continued

- You may keep your pets, but you should not handle animal waste. Do not clean bird cages, fish or turtle tanks or cat litter boxes. The feces of some animals contain parasites and can cause infections. Fish tanks can develop fungus and can be infectious. If you cannot avoid pet waste, use excellent hand washing afterwards. Also, wash hands after petting animals. Keep pets' vaccinations up to date
- Wear gloves and wash hands after gardening and wear a mask if moving mulch (better yet, have someone else move mulch for you)

Caring For Your Incision

- Check your incision every day until it is healed for signs of infection such as redness, drainage, odor or increased pain. Call the transplant center if you notice any of these changes
- You may shower daily. Wash the incision with soap and water, gently, do not scrub incision site. Pat dry with a clean towel
- Do not soak in the tub or swim until your skin incision is completely healed. This usually takes about one month
- You may put a dry gauze dressing over the incision to absorb any drainage
- Always wash your hands before and after treating your incision

Viral Infections

During the pre-transplant workup, you were tested for past exposure to:

- Cytomegalovirus (CMV)
- Herpes simplex virus (HSV)
- Hepatitis viruses
- Human immunodeficiency virus (HIV/AIDS virus)

A history of infection with CMV or HSV is common. You may have been exposed to these viruses in childhood. They can stay dormant in the body for a lifetime. They can reactivate after a transplant when you are on immunosuppressive medicine and cause illness.

Cytomegalovirus (sahy-toh-meg-uh-loh-vahy-ruh s) (CMV)

CMV, is a common infection following kidney transplant. You are at greatest risk in the first three months after transplant because of the high doses of immunosuppressive medicines. More than half of all Americans have had exposure to CMV, which usually causes a mild illness, with flu-like symptoms in the general population. Reactivation of the dormant or new infection with CMV can cause serious infection after transplant. You will be placed on valgancyclovir, valacyclovir or acyclovir for the first three to six months in order to prevent serious illness from this virus.

Infections, continued

Signs of CMV infection:

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

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

BK Virus

BK virus, also called polyomavirus, is a virus that most people get in childhood. Once you get a BK virus infection, the virus stays in your system forever. This is called latent, or like being “asleep” in your body. But it does not cause a problem in most people.

Sometimes, when your immune system is not working well, the virus “wakes up.” Then it can cause symptoms of infection. The BK virus can become active in the transplant patient as a result of the anti-rejection medicines and can affect the transplanted kidney. The BK virus can harm the kidney and slow the functioning of the kidney. It can even cause the kidney to fail. In order to detect and treat the virus before any changes in kidney function are seen, the transplant team screens your blood for the BK virus.

Treatment for BK virus usually includes decreasing the anti-rejection medicines and possibly giving an oral medicine called leflunomide or an IV medicine called Cidofovir®. Early diagnosis and treatment are important—so get your labs drawn.

Herpes Simplex Virus (HSV)

These viruses most often infect the skin, but they can also appear in other areas like the eyes and lungs. HSV type 1 causes cold sores and blisters around the mouth. HSV type 2 causes genital sores. HSV is transmitted by direct contact of secretions from an infected person to one who is not infected. Most infections are mild, but sometimes they can be severe. Although there is no cure for HSV, it can be treated.

Symptoms of herpes include:

- Tingling sensation before an outbreak
- Painful, fluid-filled sores in your mouth or genital area. If you have sores or lesions, contact your transplant team right away
- Fever

Report any pain with swallowing. Women should also watch for any unusual vaginal discharge. Contact your transplant team right away if you think you may have HSV around your mouth or genitals.

Infections, continued

What You Can Do

- Keep the areas around the sore as clean and dry as possible
- Wash your hands with soap and water after touching the sore
- Wear loose-fitting clothing to avoid irritating the genital sores and spreading the virus
- Avoid kissing or having oral sex with someone who has a cold sore
- Avoid having oral sex or intercourse with someone who has genital sores

Varicella-Zoster (Chickenpox)–(VZV)

Chickenpox used to be a common childhood illness in the United States. It's much rarer now, thanks to the varicella vaccine. Most people that have had chickenpox are immune from having it again. However, the VZV virus continues to live in the body for life and can come back as shingles. Stay away from anyone with active chickenpox. It can cause a more severe infection in transplant patients who were never exposed to the virus. Or, it may cause shingles in those who have previously had chickenpox. Call your transplant coordinator immediately if you have been exposed. Do not wait to see if you are going to get sick. Do not get the chickenpox (varicella) vaccine.

Herpes Zoster (Shingles)–(VZV)

Shingles is also called herpes zoster. It is a painful skin rash caused by the herpes zoster virus. This is the same virus that causes chickenpox. After a person has chickenpox, the virus remains inactive in the nerve cells. Years later, the virus can become active again and travel to the skin. It appears as a rash or small water blisters, usually very painful and most commonly on the chest, back or face. They run along the nerve pathways on the surface of the skin. Call your transplant coordinator immediately if you have this kind of rash. Do not get the shingles vaccine.

Bacterial Infections

Bacterial infections can happen after organ transplant surgery. Right after surgery your wound may get infected. This is due to the anti-rejection medicine you are taking. Also, the incision site must be watched closely for any signs of redness, swelling, tenderness or drainage. You may or may not have a fever. You should call your transplant team if you have symptoms of infection. They can happen at any place in the body, including:

- Lungs
- Bloodstream
- Urinary tract
- Incision area

Infections, continued

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

Pneumocystis Carinii

Pneumocystis jirovecii [noo-muh-sis-tis] is caused by a fungus. This fungus is common in the environment and rarely causes illness in healthy people. However, it can cause a lung infection in people with a weakened immune systems like patients on anti-rejection medicine.

Symptoms include:

- Cough
- Fever
- Shortness of breath

For the first year after transplant, you will take Bactrim every day to prevent infection. If you are allergic to sulfa, you may be given a different medicine.

Fungal Infections

Candida (Yeast)

Yeast infection occurs when yeast that grows in moist areas of the body such as the mouth, groin, armpits or genital areas. When it is growing in the mouth, it is called thrush and appears as white, patchy fuzzy areas on the roof of the mouth, tongue, throat or food pipe (called the esophagus). It can cause pain and tenderness and make swallowing difficult. It is treated and prevented with nystatin "swish and swallow liquid." You will start this medicine after your transplant and continue for one month.

When yeast occurs on the skin, it can be treated with creams or lotions. Vaginal infections usually cause a discharge that may be yellow or white, lumpy, foul-smelling and often itchy. These infections will be treated with vaginal cream, suppositories or oral medicines. If yeast spreads inside the body, it can become a more severe infection and may require intravenous (IV) treatment with a variety of oral and/or IV medications.

Infections, continued

Aspergillosis

Aspergillus (as-pergillo-sis) is a common dust. It is mold found in decaying vegetation and airborne dust. Aspergillosis enters the body by breathing infected air found in damp or dusty places such as old barns, construction sites, basements, attics, etc. The spores are present in mulch and cow or horse manure. Even mowing grass will put you at risk for aspergillosis. Wearing a face mask and gloves is recommended.

Histoplasmosis

Histoplasmosis (his-toh-plaz-moh-sis) is a disease that travels through the air. It is found in bird and bat droppings. You can also come in contact with it when contaminated soil is disrupted by construction or renovation activities. You should avoid exposure to bird and bat droppings and construction sites which may be contaminated.

Other Types of Infection

Toxoplasmosis

Toxoplasmosis (tok-soh-plaz-moh-sis) is an infection caused by a parasite that is often found in cat feces. Because it can cause severe symptoms in someone with a weakened immune system, you should not change litter boxes. Notify your transplant team if you are bitten or scratched by cat.

Tuberculosis (TB)

Tuberculosis (too-bur-kyuh-loh-sis) is an infection caused by mycobacterium tuberculosis. It is contracted by breathing infected airborne droplets. TB is mainly an infection of the lungs. Tell the transplant team right away if you have contact with a person suspected of having or has been diagnosed with TB.

Symptoms include:

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

Immunizations

Ask your transplant team when you may continue your vaccination schedule. Usually we recommend you wait at least three months.

We recommend:

- Pneumonia vaccine every five years
- Flu shot yearly (not flu mist)
- Tetanus booster every 10 years

Infections, continued

Live Vaccines

Live vaccines should be avoided. Live vaccines include varicella (shingles), oral polio; measles, mumps and rubella (MMR); yellow fever; smallpox; and chickenpox. Ask your transplant team before you or your family member needs to receive any vaccinations. You should avoid contact for 2 weeks with anyone who has received a live vaccine.

Dental Exams

We recommend routine dental care. Daily teeth and mouth care are important because your mouth can also be a source of infection. Wait 3 months after your transplant before scheduling a dental appointment, except in cases of emergency. Taking antibiotics before a dental exam or a dental procedure is not necessary. However, there are many other medical conditions that do require antibiotics before seeing the dentist. Please contact your primary care doctor or other specialty doctor before your dentist appointment to find out if you will need antibiotics before your appointment.

Urinary Tract Infections

Symptoms include:

- Increased pressure and/or urgency to urinate
- Increased frequency to urinate
- Burning upon urination
- Low back or belly pain
- Blood in urine
- Fever

Prevent a urinary tract Infection

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

Nutrition/Dehydration

Your Guide to Eating Healthy After Your Kidney Transplant

You have recently had a kidney transplant and may be wondering if your diet will be different from before your transplant. These diet guidelines describe changes you may need to make in order to feel your best. This includes:

- Food safety
- Calorie and protein needs to help in healing, while preventing weight gain
- How to monitor carbohydrate intake (while preventing high blood sugars)
- Your overall heart-healthy diet that includes electrolytes in your diet

Food Safety

Because of your recent transplant and medicines you are on to prevent organ rejection, this can cause an increase your risk for food-borne illness. To lower the risk:

- Do not eat:
 - Raw and undercooked meat
 - Raw and undercooked seafood
 - Raw and undercooked eggs
 - Dairy items or juice and cider that are not pasteurized
- Avoid cross contamination of raw meat by dirty knives, cutting boards, or dirty work surfaces with other foods
- Always wash fresh fruits and vegetables
- Clean work surfaces
- Change dish cloths daily
- Always wash your hands before eating

- Keep cold foods cold and hot foods hot. Avoid eating room temperature foods and meats thawed on the counter
- Do not eat leftovers that are more than 2 to 3 days old
- Calorie and protein needs
- Short-term goals: Your recovery
- Your calorie and protein needs will increase right after your transplant. This is because surgery has put more stress on your body and because your wounds need to heal

You must eat and drink to provide your body the building blocks for healing and to help prevent infection and muscle loss. You will be given a diet based on the transplanted kidney's function. Usually this is a well-balanced general diet. If the new kidney isn't working as well as expected, you may need to cut back on sodium, potassium and other fluids for a while. Your transplant team will talk to you about this.

During the first few weeks of recovery, be sure to eat nutritious foods. For example: lean beef and pork, chicken, turkey, fish, low-fat milk, cheese, yogurt, eggs, nuts, whole-grain breads and cereal, and fruits and vegetables will give you the protein, vitamins and minerals you need.

If you have a poor appetite or unintended weight loss, tell the transplant dietitian.

Maintain blood glucose control after transplant if you are diabetic. Anti-rejection medication can cause elevated blood sugars and increase your

Nutrition/Dehydration, continued

risk for diabetes. If this occurs after transplant it will be addressed by your transplant team.

Long-term Goals

Maintain a desirable weight. Weight gain after a transplant can be a problem and is common due to improved appetite and fewer diet restrictions. Weight gain also can occur from side effects of anti-rejection medications. Weight gain after transplant increases your risk for high blood pressure, diabetes, heart disease, joint or bone disease and may shorten the life of your new organ. We want you to be as healthy as possible to enjoy the life of your new organ for as long as possible.

To control your weight, pay attention to the number of calories you are getting in food and in drinks. Fat adds the most calories to your diet, so try low-fat ways to prepare your meals and trim added fats from your diet to save calories. Do not eat fast food. Have low-calorie snacks on hand for snacking — fruits, vegetables and low-fat dairy products. Read labels and pay attention to portion sizes. To keep your mind off of food, try to stay busy with your favorite hobbies and activities (reading, gardening or yard work, housework, dancing, crafts, etc.). Keep moving daily with exercise and activities you enjoy to burn more calories. Make a plan and stick with it. If you struggle to control your weight, contact the transplant dietitian — what do you have to lose besides weight?

Bone health is important. Anti-rejection medicines may affect bone strength. In addition, any poor bone health before transplant may make bone disease even more likely after transplant. Eat calcium-rich foods (low-fat dairy and cheese). Take calcium supplements and medicines as prescribed. Exercise to keep your bones strong. Don't smoke.

Heart-healthy Eating

A heart healthy diet is meant to help lower cholesterol levels and blood pressure. It may also help to decrease the risk of heart disease. It includes eating a variety of foods that are low in fat, especially saturated fat and trans fats. The diet is also low in cholesterol and low in sodium. Adding fiber and Omega-3 fatty acids to your diet are recommended.

What Do These Terms Mean?

Saturated Fats: These fats are usually solid at room temperature. They are the “bad” fats that raise cholesterol. Some sources are: high-fat dairy products, high-fat meat products, butter, lard, palm and tropical oils.

- *A low saturated fat item will have only 1 gram/serving*
- *A saturated fat-free item will have less than 0.5 gram/serving*
- *Aim for <5-6 percent of total calories from saturated fat*

Nutrition/Dehydration, continued

Trans Fats: A process called hydrogenation turns liquid (unsaturated) fats (or oils) into solid fats. This type of fat, like saturated fat, can raise your cholesterol levels. You should avoid this type of fat. Some sources of trans fat include: some margarines, vegetable shortenings, peanut butter, crackers, cookies, etc. Recommended <1 percent of total calories from trans fat.

Omega-3 Fatty Acids: This is a type of polyunsaturated fat that may help to prevent blood clots and help your blood vessels dilate (or get bigger). This can make your blood flow more smoothly. They are the “good” types of fat. Adding this type of fat to your diet is recommended.

- *Sources include: Fatty fish (salmon, mackerel, tuna, halibut, lake trout, sardines, etc.), canola oil, flaxseed and nuts (1 1/2 oz/day)*
- *Consumption of fish two to three times a week is recommended*

Sodium: Sodium is in most foods naturally. Processed foods are usually high in sodium. Many food items have low-sodium varieties. Sodium can cause you to retain fluid and/or increase your blood pressure. No more than 1,500 mg of sodium (new guidelines) a day is recommended.

- *Try to use other herbs/seasonings instead of salt (use salt substitutes only with a doctor's permission)*
- *A low sodium item will have 140 mg of sodium or less/serving*
- *A very low sodium item will have 35 mg of sodium or less/serving*

How much fat can I have in a day?

The American Heart Association (AHA) recommends no more than **30 percent** of your total calories to come from fat. The recommendation is different for each person. It is based on how many calories you need everyday. You can visit www.mypyramid.gov to find a meal plan for you.

Nutrition/Dehydration, continued

Hydration

It is important to drink approximately two liters of fluid (eight full 8-ounce glasses of fluid, 68 ounces) per day. Make sure you understand what your fluid needs are. It is best to avoid fluids that have caffeine or limit your caffeine drinks to one per day.

It is important for you to know the symptoms of dehydration. Dehydration can be the cause for an increase in BUN and creatinine levels. Dehydration (and low blood pressure) can also cause acute tubular necrosis (ATN) in which the kidney can temporarily shut down, causing a rise in creatinine and BUN.

Signs of Dehydration

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

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

It is best to talk to a registered dietitian with all of your nutrition-related questions. A registered dietitian has specific training and can provide you with the best information regarding the foods you eat and any diet restrictions you may need. A transplant registered dietitian can be reached at 402.552.3648.

Nutrition/Dehydration, continued

Potassium Content of Foods

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

High Potassium Foods

Avocado	French fried potatoes	Pumpkin, canned
Apricots, canned or dried	Honey dew melons, 1/8 small	Rutabagas
Banana, 1/2	Kiwi	Spaghetti sauce
Beans, canned with pork	Kohlrabi, fresh or cooked	Spinach, cooked
Beef, ground	Lentils	Sweet potatoes/yams
Beef roast	Mango	Tomato, 1 medium
Beets	Milk	Tomato or vegetable juice, low sodium
Beet greens	Nectarines	Tomato sauce/paste
Broccoli	Okra	Winter squash: acorn and butternut
Brussel sprouts	Orange, fresh	Yogurt
Cantaloupe, 1/8 small	Orange juice	Zucchini
Chicken	Peanut butter	
Chinese cabbage	Pears	
Dates, 1/4 cup	Potato, baked, boiled or mashed	
Figs, 2 whole	Prune juice	
Fish: tuna, salmon, haddock or cod	Prunes	

Medium Potassium Foods

Apple	Corn	Peas
Apple juice	Cottage cheese	Pineapple, juice or canned
Apricot nectar	Eggplant	Plums, canned or fresh
Asparagus, fresh or cooked	Figs, canned	Pudding, vanilla
Blackberries	Fruit cocktail	Radishes
Broccoli	Gooseberries	Raisins, 2 tablespoons
Cabbage	Grapes, 15 small	Raspberries
Carrots	Grapefruit, 1/2	Rhubarb
Cauliflower	Lemon juice	Summer squash
Celery	Mushrooms, canned or fresh	Tangerine
Cherries	Onions	Turnips
Collard: mustard or turnip greens	Papaya	Watermelon, 1 cup
	Peach	Spinach, raw

Nutrition/Dehydration, continued

Low Potassium Foods

Applesauce	Green beans	Pears, canned or nectar
Blueberries	Green peppers	Wax beans, canned (low sodium)
Cranberry juice/sauce	Lemon	
Cucumbers	Lettuce	
Grape juice	Peach, canned or nectar	

Magnesium Content of Food

High Magnesium Foods

Avocado	Nuts: almonds, brazil nuts or cashews	Spinach, fresh, frozen or canned
Cereal, all bran or 100 percent bran	Seeds: pumpkin or squash	Swiss chard, cooked
Muffin, oat bran	Soybeans, cooked	Tofu, raw or regular

Medium Magnesium Foods

Acorn squash	Chocolate milk	Peanut butter
Artichoke	Fish: tuna	Potato, baked with skin
Bean: black, lima, navy, white, kidney, pinto or great northern	Nuts: chestnuts, hazelnuts, walnuts, peanuts	Rice: brown
Beet greens	Oatmeal	Soy milk
	Okra, frozen	Spaghetti: whole wheat

Low Magnesium Foods

Banana	Prune juice	Sweet potato, canned
Baked beans	Pumpkin, canned	Tomato sauce
Bread: whole wheat	Sardines	Wild rice
Chickpeas	Seeds: sunflower	Yogurt
Lentils	Spinach, raw	
Milk: all types	Summer squash	

Nutrition/Dehydration, continued

Phosphorus Content of Food

High Phosphorus Foods

Almonds	Milk: all kinds	Sardines
Biscuit	Nuts	Seeds
Beef	Oatmeal	Soybeans and soy milk
Bran cereal	Organ meats	Tofu
Cheese and yogurt	Pancake and waffle	Tortillas
Chicken	Peanut butter	Turkey
Cottage cheese	Pork loin	Dark colas
Fish: tuna	Potato, baked with skin	
Granola	Pudding	

Medium Phosphorus Foods

Asparagus	English muffins	Rice: brown or wild
Bagel	Granola bars	Spaghetti: whole wheat
Baked beans	Muffins	Sweet potato, baked with skin
Bread: whole wheat	Mushrooms	
Corn	Noodles: egg	
Eggs	Peas	

Low Phosphorus Foods

Beans: green or yellow	Cream of wheat and grits	Pretzels and popcorn
Bread: white, pumpernickel or rye	Coffee and tea	Spinach
Brussel sprouts	Fruit juices	Soda: lemon lime or clear
Cereals: rice and corn	Fruits	Tomato
Cream cheese	Gelatin	White rice and pasta
	Greens	Sausage: pork

Testing and Procedures

The transplant office has made plans for you to have your labs drawn at a hospital or local lab convenient for you. Please have your lab drawn before clinic visits. The lab results are also faxed to the transplant office for the transplant team to review.

We will not be calling you with lab results or reviewing them over the phone unless they are abnormal. You may review your own lab results. Any labs drawn at Nebraska Medicine can be reviewed by using in the portal, One Chart Patient. For labs drawn at your local lab, we gave them permission to give the results to you, if you ask for them.

Below is a list of the lab values that we will be watching. Your lab results can fall outside of the “normal” range but still be “normal” for you. It is important for you to know what your expected lab range/baseline is. However, it may be several weeks after transplant before we will know what your “normal” lab values are.

It is very important that you have nothing to eat or drink after midnight before your lab draw. You may have a little water. We call this a “fasting lab.” Fasting labs help us monitor your blood

sugar (glucose) levels. The blood sugar levels can be elevated and/or more difficult to control after transplant. If you have received a pancreas transplant, the blood sugar results help us know that your transplanted pancreas is working.

If you live outside of the local area, tubes and mailers will be supplied to you at the time of discharge. These are used by your lab to draw blood to be sent to the transplant center. These lab tests will measure your immunosuppression levels. The tubes and mailers are automatically replaced by our lab to yours, as they are used. However, in the early weeks after transplant you may be having frequent labs drawn and your supply of tubes and mailers may get low. Please feel free to call the transplant office if you or your lab need more. Also, if you have home health care after transplant, you will need to take your tubes and mailers to your local lab the first time that you go (after discharge from home health care). You may leave your supply there and then we will send the next supply to your local lab.

Testing, continued

Things to Keep in Mind

- We will not call unless there are issues
- Use My Chart | Patient as an online tool to review lab values at Nebraska Medicine
- Contact your local lab for results
- Labs are drawn about 30 minutes prior to your morning medication dose

Test	Normal Range
Hemoglobin (Hgb)	10–16 gms/dl
Hematocrit (HCT)	30–46%
White Blood Count (WBC)	4,000–10,000/ul (Usually reported out as 4.0-10.0)
Platelet Count (Plat)	150,000–400,000/ul (Usually reported out as 150-400)
Blood Urea Nitrogen (BUN)	6–20 mg/dl
Serum Creatinine (Scr)	0.64–1.27 mg/dl – male 0.44–1.03 mg/dl – female
Sodium (NA)	135–145 mmol/L
Potassium (K)	3.6–5.0 mmol/L

Test	Normal Range
Bicarbonate	20.0–31.0 mmol/L
Magnesium Level	1.8–2.5 mg/dl
Phosphorus Level	2.4–4.7 mg/dl
Glucose	65–110 mg/dl
Cyclosporine Level	Varies
Tacrdimus Level	Varies
Sirolimus Level	Varies
Everolimus Level	Varies

Testing, continued

Ultrasound

Ultrasounds are done frequently after transplant. This test is done in the Radiology Department and utilizes sound waves to look for abnormalities of your transplanted kidney.

Kidney Biopsy

It is common that a kidney biopsy is needed. A biopsy of the transplanted kidney may be needed to find out the cause of abnormal labs and help us give you proper treatment. Light sedation is typically used. A needle is passed through the skin into the transplanted kidney. A small piece of kidney tissue is taken out and examined under a microscope for signs of rejection. You will remain on bed rest for six hours after this procedure. There may be blood in your urine for up to 24 hours after the biopsy. Drinking more fluids will help with this. Because sedation is used you will need a ride home.

Tell the transplant team if you are taking medicines to thin your blood.

Stent Removal

At the time of the kidney transplant, a small tube (stent) may be placed inside the ureter (the tube that connects your new kidney to your bladder). The tube is left in place for about 4 to 6 weeks. The tube is removed by inserting a lighted instrument into the urethra (tube from the bladder to the outside of your body) and removing the stent. A local anesthetic is

used to reduce the discomfort. Though this procedure sounds uncomfortable, it does not require special medicine or any sedation. It can be safely and comfortably done in a urology office and takes just a few minutes. A general anesthetic to remove this tube is not needed; exception is made with pediatric patients.

Talk to your coordinator if you are not sure if a stent was placed.

Cancer Screening

As a transplant patient, you will need to take anti-rejection medicine for the rest of your life, as long as you have a functioning organ transplant. These medicines place transplant patients at a higher risk for getting cancer. Because of this, it will be necessary to do routine yearly screening tests such as: mammograms (for women), a prostate cancer blood test (for men), and stool specimens for blood. Women will be encouraged to have a yearly Pap test and pelvic exam. We recommend annual follow up with your local primary care doctor for a cancer screening based on age and risk factors. It is also important to schedule complete comprehensive skin exams yearly.

Activity

You have just had major surgery. You will have low energy and a lower level of strength. After you are out of the hospital, you should be able to take care of yourself dressing, bathing, eating, as well as walking every day.

It is very important to walk as much as you can to help rebuild your energy levels, control weight, prevent constipation, prevent joint and muscle weakness (especially if you are on prednisone) and contribute to your overall sense of physical well-being. Plan to rest frequently and listen to your body's cues. If you are tired, take a nap.

Lifting, Sports and Driving

Do not do strenuous activity such as heavy lifting for at least 6 weeks after transplant. Do not lift anything greater than 10 pounds (about one gallon of milk) for at least 6 weeks, or as directed by your doctor. After 6 weeks, you may return to non-contact sports such as golfing, swimming and bowling. However, keep in mind that the transplanted kidney is placed close to the body surface, and that means it could be more easily injured during contact sports. We recommend that you check with the transplant office before you participate in any contact

sports. Avoid jarring activities such as speed boating, snowmobiling or horseback riding for at least 3 months.

Driving is usually allowed after 2 weeks or after you stop your pain medicine. You should be off pain medicine for 24 hours before attempting to drive. You will need a driver if you are having a procedure.

Do not drive if:

- You have blurred vision
- You are still in pain and/or needing pain medicine. You must be "pain free" before attempting to drive

Returning to Work

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

Activity, continued

Exercise

When you are allowed to begin an exercise program, you will need to work up to where you are exercising four to six times a week for at least 30 minutes. This is over a period of 6 months. The rule of thumb is start slowly, be consistent and stop if you experience chest pain, shortness of breath, nausea, rapid heart rate or faintness.

Physical Benefits of Exercise

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

Psychological Benefits of Exercise

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

Sexual Activity

You may resume sexual activity 4 weeks after your transplant surgery. How quickly you return to your usual patterns will depend mostly on your recovery progress. Your sexual functioning may be affected by your transplantation and/or certain medicines. Some people avoid sexual activity because they are afraid of rejection or infection. If you have any of these fears, you may want to check with your transplant team. If you are sexually active and do not have a steady sexual partner, you must use condoms to reduce the risk of sexually transmitted diseases such as AIDS, HIV, syphilis, herpes, hepatitis or gonorrhea.

You must use contraception to prevent unplanned pregnancy also. Don't be afraid to ask your doctor, nurse or transplant coordinator questions about this while you are hospitalized or during your clinic visits.

Living with Your Transplant

Your Daily Routine

- Take your vital signs (blood pressure, temperature, heart rate) at the same time every day. Take them in the morning and at night, as directed by your transplant team. Write them every day in your home care flow sheet. Bring the book with you to your clinic visits
- Weigh yourself every day, first thing in the morning after going to the bathroom and before eating. Use the same scale and wear the same amount of clothing. The scale should be on a hard level surface to get an accurate reading. Record your weight in your home care flow sheet
- Record blood sugars as directed. Follow up with your diabetes doctor if you have any concerns
- Take your medicines as directed by your transplant team. NEVER skip a dose of immunosuppressive medicine. Call your transplant coordinator if you miss a dose
- Shower daily using a mild soap and water
- Good hand washing is important. Wash your hands with soap and warm water. Lather well, rubbing your hands together and cleaning all surfaces including under the fingernail beds. Always wash hands before preparing food or eating food. Wash hands after using the bathroom or after touching soiled linens or clothes

Sun Exposure

Transplant patients are more at risk of developing skin and lip cancers. Since the risk increases over time, you must always protect yourself from ultraviolet rays of the sun that cause skin cancer.

Use sunscreen every day that has a skin protective factor (SPF) rated 15 or greater. Remember to put sunscreen on your face, neck and hands, and re-apply as needed. Stay away from the mid-day sun (10 a.m. to 3 p.m.) when ultraviolet rays are strongest. Wear a hat, long sleeves and slacks when outdoors, unless you are wearing sunscreen.

Alcoholic Beverages

Alcoholic beverages are allowed. We recommend strict moderation for several reasons:

- Drinking beer, wine, and liquor may damage your liver
- Medicines such as tacrolimus, cyclosporine, mycophenolate and trimethoprim-sulfamethoxazole are broken down by the liver and, if combined with alcohol, could harm your liver
- Alcohol has the potential to change the way your liver breaks down the anti-rejection medicines and this could put you at risk to rejection

Living with Your Transplant, continued

- Alcoholic beverages also contain a large amount of calories
- Liquors and wines contain concentrated sweets

Tobacco Use

DO NOT SMOKE OR CHEW TOBACCO. The Surgeon General of the United States has determined that both active and passive smoking can be harmful to your health. Smoking is a risk factor for many diseases. It will increase your risk for developing coronary artery disease and add to your already increased risk for osteoporosis, development of cancers and lung disease. Smoking marijuana can cause serious fungal lung infections. Ask your family and friends not to smoke when you are around. If you need further assistance to quit smoking, call the transplant team. There are many options available to help you stop smoking.

Pregnancy

If you are thinking about getting pregnant after transplant, it is very important to talk to the transplant team, obstetrician and transplant coordinator. It is possible for women to become pregnant within a few months after transplant; however, it is best to wait at least one to two years. This allows time to make sure that the transplanted organ is functioning well and that anti-rejection medicine doses are

at maintenance level and stable. Some of the medicines to control rejection may cause birth defects. Contact your doctor before becoming pregnant.

If it has been one to two years since your transplant and you are thinking about having a baby, you should have:

- Stable levels of anti-rejection medicines
- Stable function of the transplanted organ
- Good kidney function
- Normal blood pressure or well-controlled high blood pressure
- Normal blood sugar levels or well-controlled diabetes
- Overall good health

Vacation and Travel

If you are planning extended travel, are leaving the country, or will miss getting labs done, please notify the transplant team.

When taking public transportation, remember there will be many people traveling with you, sometimes in close areas such as on buses, trains and planes. Air is recirculated in these places, which means you may be breathing air containing viruses and bacteria from other people. Good handwashing is very important at all times but especially when you travel.

Living with Your Transplant, continued

It is wise for you to be extra careful when traveling. It is best to contact your transplant team to discuss the area you plan to visit while traveling outside the U.S. They can also tell you on how to get information on current health risks for the area where you plan to travel. It is recommended that you schedule a traveler's health appointment at least 4 to 6 weeks before your trip. Nebraska Medicine Vaccine & Safe Travel Clinic has two locations in Omaha: Village Pointe, 110 N. 175th St., 402.596.4411, and at Midtown Clinic, 139 S. 40th St., 402.595.3939.

Contact your transplant coordinator or doctor to help determine if you will need any medicines or vaccinations before leaving on your trip.

Health Maintenance Following Transplant

Appropriate and timely health care screening is important for everyone, but it is even more important if you have received an organ transplant. Anti-rejection medicines can increase your cancer risk. To make sure you have continued good health, we ask that you have the following screenings with the appropriate health care provider at the recommended intervals.

Primary Care - Health Maintenance

Set appointments again with your referring kidney doctor. Primary care providers are health care professionals who provide general care. They may be family medicine or internal medicine doctors, nurse practitioners or doctor's assistants. You should see them for:

- Medical history and physical examination yearly based on your risk factor
- Blood pressure check yearly or more frequently as needed
- Diabetes screening
- Skin exam
- Lipid monitoring (cholesterol check) yearly
- Yearly stool screen for blood
- Colonoscopy every 5 years after the age of 50, unless previously abnormal or you have a family history of colon cancer
- Bone health monitoring (Dexascan) every 2 to 4 years based on previous results and/or bone therapy

Women

- Mammogram
- Breast exam
- Pelvic exam
- Pap test

Discuss your plan of care with your primary care provider.

Living with Your Transplant, continued

Men

- Prostate/testicular exam every 1 to 2 years if over the age of 40, then yearly after the age of 50
- Prostate Specific Antigen (PSA) lab test yearly after the age of 40

Other Health Care

It is important to take care of your teeth and eyes as well. Follow the recommendations below:

- Dentist (at least) yearly
- Eye exam every 2 to 4 years after age 40 and every 2 years after age 60

Your health history may cause you to have more frequent testing. Please ask your primary care provider to fax any abnormal results or results that concern you to the transplant office at **402.552.3030** or call **402.559.5000**.

Home Records

When you are discharged, a transplant nurse, nurse practitioner or doctor's assistant will instruct you on your schedule for follow-up lab tests. A letter will be sent to your local lab with instructions as well. If you are getting lab work done at a lab that is not part of Nebraska Medicine, we will provide you with tubes and mailers to take with you to your lab the first time you go. The tubes and mailers will be replaced by our lab as they are used.

Lab results may be recorded on your home care flow sheet. Make sure that you are fasting when your lab work is drawn so we can monitor your blood sugar results each time you have labs done. Also, do not take your transplant anti-rejection medicine until your lab work is done.

Weigh yourself daily. It is important to use the same scale and to weigh yourself at the same time each day. Record your weights.

Check your temperature every day and record it on the home care flow sheet. Report any temperature over 100.5°F or any persistent (over several days), low-grade temperature greater than 100°F.

Check your blood pressure every morning and at bedtime, and record it. Always check your blood pressure in the same position (lying, standing, sitting). If your blood pressure is higher than 160/95 for two days in a row, or lower than 110/65, please call the transplant office.

Blood pressure ranges for pediatric patients will vary depending on the age of the child. Please contact the pediatric nephrology team to provide the ranges for your child and write the information in the space below.

Living with Your Transplant, continued

Writing Your Donor Family Letter Guidelines

Anonymity

Donor families are offered the opportunity to save a life through organ donation, while their identity remains anonymous. Each family's loss is personal. How family members cope with their loss may determine their receptiveness to correspond with recipient families. Our intention in encouraging donor and recipient correspondence is to provide support to families experiencing the grieving process and to provide the opportunity for recipients to express their gratitude to the donor families. We are encouraged by the potential emotionally healing benefits of correspondence, but we are careful to protect the confidentiality of those who do not wish to participate. Therefore, we initially limit correspondence to an anonymous format.

Letter Content

The decision to write your donor family is a very personal one. Sometimes, transplant recipients choose to write to donor families to express their gratitude. If you find that it is too difficult to write a letter, a simple card can also be uplifting to the family. We have made suggestions for the content that might be included in your letter. These suggestions are only meant to be a guideline and are not meant to dictate what you should include in your letter. You may also call Donate Life Services for

additional information, 402.559.9566. However, to keep the correspondence confidential, do NOT include your last name, address, city, state, phone number, email address and any reference to Nebraska Medicine. Please include any information that might help the donor family "picture" you.

This letter will more than likely be read and shared with many donor family members. Be careful not to include negative information. Even though the outcomes of some transplants are not as successful as others, this does not diminish the gift. We are still indebted to these gracious donor families whose intentions were to save a life.

Examples include:

- Address the letter "Dear Donor Family"
- Recognize the donor family's gift and include thanks for this gift
- If you wish, express your condolences for their loss
- Use your first name or nickname only; do not include your last name
- If you choose to omit your first name, simply sign: a grateful recipient, kidney recipient, friend, etc.
- Your age and gender
- Your family situation such as marital status, children or grandchildren
- Your hobbies or interests

Living with Your Transplant, continued

- Your job or occupation. Do not mention your employer's name or recognizable status or position
- Explain what has happened in your life since your transplant. Did you return to school, accept a new job, have children, travel
- Your current physical condition
- If you would be open to future communication from the donor family
- Since the religion of the donor family is unknown, please consider this if you include religious comments
- Other family members may include their own letters to the donor family
- Be sensitive to communication around holidays, anniversary of donor's death, etc.

Mailing Your Letter

Allow extra mailing time. Your letter is first reviewed by a Donate Life Services coordinator at Nebraska Medicine to make sure confidentiality guidelines have been met. Next, it is mailed to the organ procurement organization (OPO) that worked with your donor's family. The OPO will then forward the letter to the donor family.

Although most families are happy to receive a letter from the recipient, every donor family is given the option of not reading the recipient's letter. Some donor families move and cannot be contacted. If your letter is unable to be forwarded, you will be notified.

How Do I Send My Letter?

1. Place your card or letter in an unsealed envelope.
2. **DO NOT** place a stamp, write your return address or your full name on this envelope.
3. Place a separate piece of paper with your full name and the date of your transplant in this unsealed envelope.
4. Place the unsealed envelope into another envelope addressed to:

**Donate Life Services
Nebraska Medicine
3860 Leavenworth St.
Omaha, NE 68105-8136**

Will I Hear From the Donor's Family?

You may or may not hear from the donor's family. Some donor families have said that writing about their loved one and their decision to donate helps them in their grieving process. Even though they are comfortable with their decision to donate, other families prefer privacy and choose not to write the recipients. Many donor families will wait until they have heard from a recipient before writing to that person.

The communication should be family driven. Communication may be a one-direction, one-time letter of thanks, or it could grow into a series of mutual letters between donor family and recipient. Each relationship will be unique. It

Living with Your Transplant, continued

is important to respect the comfort level of the donor family in regard to timing and frequency of sending letters.

We have included a few sample letters from grateful recipients. If you have any further questions regarding donor family correspondence, or you would like further assistance in writing your donor family, please feel free to contact us at 800.956.7426 or 402.559.9566.

Living with Your Transplant, continued

Sample Letter

Dear Donor Family,

We are writing to thank you for making the unselfish decision to donate life in order that our daughter, Allison, could live. She received a liver, small bowel and pancreas from your loved one. The transplant surgery went well and she had a good recovery. She was hospitalized for about three weeks as an inpatient and then another five weeks in outpatient care.

Allison received the transplant just three weeks before her 23rd birthday. She had a condition called short bowel syndrome and since birth has received the majority of her nutrition through a central intravenous catheter. Over the years, this IV nutrition caused liver damage, and more recently it led to life-threatening central IV line infections.

Despite her medical issues, Allison has always been a very optimistic and involved person. While in high school, she was very active in school activities and 4-H and also played piano and organ at our church and area churches. She has been attending college with a major in early childhood education. She was supposed to graduate in December 2006, but she had to postpone college commitments due to a lengthy hospital stay last fall. In January, she was scheduled to start a practicum as a child-life specialist at a hospital pediatric unit. Since her recovery has progressed so well, she was given permission to complete that during the month of April. She plans to graduate in May. Her career goal is to become a certified child life specialist and work in a hospital pediatric unit.

Allison has an older brother, Curtis; younger brother, Ryan; and younger sister, Andrea. We live on a farm and our children attended a small town school. They've been very involved in school, community, church and 4-H activities. Family times are very important to us all.

You are a very special family for sharing your loved one's life in order that Allison could live. It is our hope that we can continue to write and share our lives with you, as we hope you will write and share about yourselves and your loved one. We, and many others in our extended family and community, have prayed for your family during this time of loss.

Our sincere thanks and love,

Living with Your Transplant, continued

Sample Letter

Dear Donor Family,

We can't imagine the pain and sorrow you have experienced since the death of your loved one. My husband and I extend our sincere sympathy to you and your entire family. It is also our hope that the following letter is of some comfort.

Twenty seven years ago, about this time of year, I was diagnosed with Type I diabetes. Since the age of 4 I endured daily injections, constant blood monitoring, timely meals and complications related to this disease. Living with diabetes became a way of life for me and those around me.

With a lot of determination, plus the love and support of family and friends, my childhood was much like all of my friends. I was active in sports and loved babysitting. As long as I can remember, my dream was to become a teacher. I worked hard in college, graduated magna cum laude with a Bachelor of Science degree in elementary education with an endorsement in coaching. The day I received the phone call offering me the third-grade position and assistant volleyball coach position at a public school nearby was one of the happiest in my life.

Eight years later, I am still at the same school doing what I love. During that time, I also met and married the man of my dreams. Chris is a journeyman lineman with a local power company and is also an active fireman and EMT in our community. He is an avid hunter who loves the outdoors. When we have time, we enjoy being with our nieces and nephews and working in our yard and flower gardens.

During 2002, I began experiencing complications related to the diabetes, and I was devastated to learn my kidney function was decreasing. In May 2005, it became evident that a transplant was inevitable and the process was begun. As a result of the required evaluation, coronary artery disease was discovered and it was determined that I would need a heart stent. We were also warned that the heart catheter, required for the procedure, may further reduce the function of my kidneys. To make a long story short, I spent the summer recovering from heart surgery and learning to do peritoneal dialysis at home. Without the love and support of my husband and our families, I would not have been able to return to my next class of third graders that fall, which by the grace of God I was able to do!

Fast forward two years and another very special phone call; this one bittersweet. I spent another summer recovering from the life-giving surgery. It has been a little over five months since I have been insulin free. No daily injections, no finger pricks to test blood sugar. No hooking up to a machine each night to cleanse my body of toxins. No calling in sick at least once a week. I can eat whatever and whenever I want. I can walk stairs and not be out of breath. My feet don't hurt. My ankles and face aren't swollen. I have energy at the end of the day. It is hard to believe that a phone call can make such a difference in someone's life, but it did!

I have been given a second chance and enjoy a quality of life that I haven't had in a long time... I am forever grateful! There was a time when I didn't know if I would be able to continue teaching. I plan to begin my Master's degree in education this next spring. My husband and I have begun to think about the possibility of adopting a child. There is once again "hope" in our lives... all because of someone very special. It is said that time heals all things... and it is our wish that each new day brings you peace and renewed strength.

Very sincerely,

Living with Your Transplant, continued

Sample Letter

Dear Donor Family,

My name is Maddy and I'm 9 years old. I got a liver from your loved one. I needed a liver transplant because I had Wilson's disease. Thank you for my new liver. I would have died without a new liver. I didn't want to die because I wanted to be with my family.

I'm sorry that you are feeling sad right now. I know you miss your loved one. I think about you a lot.

I have a little sister, Olivia. She is 7 years old and she's very funny. I like soccer and my favorite holidays are Christmas and Thanksgiving. I have short blonde hair and blue eyes.

I never felt better before and I will take care of my liver.

Love,

Glossary

A

Absolute Granulocyte/Neutrophil Count - the number of white blood cells mature enough to fight infections.

Acute - usually rapid onset, brief, not prolonged.

Afebrile - without fever.

Anemia - a condition in which there is a decreased amount of hemoglobin due to a decreased number of red blood cells.

Anesthesia - a process using medicines to put a patient into a sleep-like state, thereby eliminating the sensation of pain.

Anesthetic - medication that dulls the pain sensation in the area it is injected into or puts the patient in a sleep state.

Antacid - a drug that relieves heartburn or acid indigestion.

Antibiotic - a drug used to fight bacterial infections.

Antibodies - a protein that is part of the body's immune system. Antibodies are produced in response to foreign tissues. Some antibodies are harmful to transplant patients and can cause them to reject organs they are "sensitized" to or incompatible with.

Antifungal - a drug used to fight fungal infections.

Antiviral - a drug used to fight viral infections.

Arterial Blood Gases (ABGs) - reports how much oxygen and carbon dioxide is carried by the arterial blood.

Arterial Line (art line) - an IV-type catheter placed into an artery to monitor blood pressure and sample arterial blood.

Aspergillosis - a fungal infection found in decaying vegetation and airborne dust.

B

Bands - a form of less mature granulocyte that fights infection.

Bacteria - small organisms that can cause an infection, germs.

Biopsy - the removal of a small piece of tissue for microscopic examination.

Glossary, continued

Blood Urea Nitrogen (BUN) - a waste product in the blood; used as a measurement of kidney function.

Bronchoscopy - an examination of the large air passages in the lungs.

C

CAT or CT Scan - computerized axial tomography; a three dimensional X-ray.

Central Line - (see Central Venous Catheter).

Central Venous Catheter - a small hollow tube inserted into blood vessels and used to painlessly draw blood and give medicines and fluids.

Chest X-ray - examination of lungs using low-dose radiation to produce a picture.

Chronic - prolonged, long-term, lasting a long time.

CMV (cytomegalovirus) - a virus that can cause infection in immunosuppressed people; it can affect the lungs or other organs.

Coagulation - process where blood clots form.

Corticosteroid - steroid hormones that are produced in the adrenal cortex.

Creatinine - a waste product in the blood; used as a measure of kidney function.

Culture - a process for identification of bacteria and other organisms in blood, sputum and other bodily fluids.

Crossmatch - the mixing of blood between donor and recipient to detect harmful antibodies.

Cyclosporin (CSA) - a drug used to prevent rejection.

D

Dehydraton - lack of water.

Detoxify - removal of toxic substances from the body.

Diabetes - persistent high blood glucose levels.

Dialysis - a process that filters impurities and excess fluids from the blood when the kidneys are not working well.

E

Echocardiogram (echo) - a measurement of heart function and blood flow through the use of sound waves.

Glossary, continued

Edema - swelling caused by too much fluid.

Electrocardiogram (EKG) - a recording of the heart's electrical activity.

Electrolytes - minerals in the blood such as potassium, sodium, etc., that must be maintained within a certain range to keep the body functioning well.

Endotracheal (ET) - a tube placed through the mouth or nose into the windpipe or airway.

Erythrocytes - another name for red blood cells.

F

Febrile - with a fever.

G

Granulocyte - a sub-type of white blood cells named because of the presence of granules in the cell. These cells protect the body against bacterial infection.

Gut - stomach and intestines.

H

Hematocrit - part of the blood occupied by red blood cells.

Hemoglobin - the part of red blood cells that carries oxygen to tissues.

Hematology - the medical specialty involved in the study and treatment of diseases related to the blood and blood-forming tissue.

HEPA Filter - high efficiency particulate air filter used to provide clean air in transplant rooms.

Herpes Virus - a group of viruses, one of which is herpes simplex virus.

Histoplasmosis - fungal infection usually acquired by inhaling spores of fungus in soil dust and found in bird droppings.

Human Leukocyte Antigen (HLA) - marker found on white blood cells and most body cells which is used for typing tissues of donor and recipient for compatibility.

Hyperalimentation or "Hyperal" - an IV solution with a high nutritional content given in place of oral food intake when someone is unable to eat; also called total parenteral nutrition (TPN).

Hypertension - high blood pressure.

Glossary, continued

I – K

Immune System - a network of cells and organs that work to defend the body against infection.

Immunity - biological defenses to avoid infection or disease.

Immunization - administration of a vaccine to protect against communicable diseases.

Immune Globulin - an intravenous medication that helps protect the body from disease and prevents harmful antibodies from returning.

Immunosuppressive Medications - medications used to suppress the recipient's immune system and prevent rejection of the transplant.

Incentive Spirometer - a device or piece of equipment to aid the function of the lungs by having a person/patient breathe in deeply.

Intake - volume of fluids going into the body.

IV, or Intravenous - directly into the vein.

Irradiated Blood Products - treated with radiation to kill white cells that could attack other cells in the body.

Intrathecal (IT) - an injection into the fluid of the spinal column.

Intubated - having an endotracheal tube placed into the windpipe to assist a patient who has difficulty breathing.

Kidney Biopsy - a procedure in which a needle is used to obtain small pieces of tissue from the kidney for examination under a microscope.

L

Lumbar Puncture (LP) - a needle is placed into the spinal column to obtain samples of spinal fluid; also called a spinal tap.

Lymphoid Cells - blood cells that mature in the lymph tissue.

Lytes - abbreviated version of electrolytes; see Electrolytes.

Glossary, continued

M – N

Megakaryocytes - another word for platelets.

Modified Protective Isolation (MPI) - a type of isolation where increased precautions are taken to protect a patient from infection.

Muga Scan/Heart Scan - test that determines how the heart is functioning.

Myeloid Cells - blood cells that mature in the bone marrow.

O

Output - volume of fluid going out of the body.

Oximeter - a device that clips to the finger or ear lobe and measures how much oxygen is being carried by the blood circulating in the body.

P – Q

Perineal Care - special care of the skin and tissue in the genital and rectal areas.

PET Scan - also called Position Emission Tomography, a medical imaging technique that monitors metabolic, or biochemical, activity in the brain and other organs by tracking the movement and concentration of a radioactive tracer injected in the bloodstream.

Petechiae - small dark purple or red spots under the skin caused by blood leaking out of the vessels; may indicate a low platelet count.

Plasmapheresis - a procedure in which the plasma portion of the blood is removed along with harmful antibodies and replaced with a plasma-like substance.

Platelets - blood cells that help prevent bleeding and help the blood to clot when vessels are broken.

Pneumocystis Pneumonia (PCP) - a type of lung infection that may cause severe pneumonia in people with low resistance to infection.

Potassium - mineral element in the body important for heart and muscle activity.

PRA (panel reactive antibodies) - a gauge to measure the amount of antibodies in the recipient. The higher the PRA, the more difficult it is to find a compatible organ for transplant.

Protocol - a plan of care or treatment.

Pulmonary Function Test (PFT) - a study of how well the lungs are working, i.e. the amount of air a person/patient is breathing in and out.

Glossary, continued

R

Red Blood Cells - cells in blood that carry oxygen to blood and tissues.

Rejection - the body's response to foreign tissue such as a transplanted organ.

Renal - pertaining to the kidney.

Respirator - a machine that pushes air and extra oxygen into the lungs.

S

Segs - a form of granulocyte mature enough to fight infection.

Sepsis - the presence of organisms or infection in the blood.

Septic Shock - the body's reaction to infection in the blood characterized by a dangerous drop in blood pressure and altered function of other organs.

Shingles - painful lesions caused by a virus.

Sodium - an electrolyte important for fluid balance.

Spinal Tap - (see Lumbar Puncture).

Stent - a small tube placed in the tube that connects the new kidney to the bladder.

Steroid - a drug used in combination with other drugs to prevent and/or control graft versus host disease.

Swan Ganz - a catheter (or thin tube) used to measure pressures within the heart and lungs.

T

Thrush - yeast infection in the mouth and throat causing white patches.

Titer - a special measurement of substance in blood or urine.

Toxoplasmosis - an infection caused by a parasite often found in cats that eat other small animals.

TPN or Total Parenteral Nutrition - (see Hyperalimentation (hyperal)).

Glossary, continued

U – Z

Ureter - a small tube placed in the tube that connects the new kidney to the bladder.

Urinalysis - microscopic examination of a urine specimen done in the lab.

Urinary Tract Infection - infection involving bladder, kidneys or urethra.

Ventilator - a machine that pushes air and extra oxygen into the lungs.

Virus - a type of organism that invades cells and causes them to produce more virus, leading to an infection.

White Blood Cell - a type of blood cell that helps fight infection.



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