A GUIDE TO
YOUR HEALTH CARE
AFTER KIDNEY
TRANSPLANTATION
Acknowledgements

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Congratulations on your recovery following kidney transplantation! This manual provides important information about your care as you and your family prepare for discharge from the hospital. As you are learning by now, kidney transplantation is far more than the operation you recently experienced. It is important for you to learn about your care so that you will have the best possible outcome with your healthy kidney. You are the most important member of the transplant team and active participation in your care will lead to a successful recovery.

Purpose

This handbook is designed as a general reference for care after kidney transplantation. Transplant centers often have different care routines, monitoring guidelines, and immunosuppressive routines following kidney transplant. It is always very important to check with your transplant coordinator when you have a question or concern about any aspect of your care. Review this handbook with your nurse, transplant coordinator, or clinical nurse specialist and know your center’s specific guidelines.

Your transplant center’s specific guidelines should always be followed.

Your Responsibilities

You are the most important caretaker of your transplanted kidney. To have the best outcome as a transplant recipient you should:

✓ Know all your medications: doses, times and why you are taking them.

✓ Follow your medication schedule daily and make changes only as ordered by your transplant physician.

✓ Maintain routine contact with your transplant team through your transplant coordinator.
  • My transplant coordinator is:
    ________________________________
  • Phone number: __________________
  • Fax number: ____________________
  • Email address: __________________

✓ Attend follow-up appointments and/or transplant clinic as instructed.

✓ Have blood tests drawn routinely as required.

✓ Monitor your weight, blood pressure, and temperature as required.

✓ Maintain a healthy lifestyle that includes a balanced diet, regular exercise, and routine check-ups.
Your Transplant Team

Maintaining regular contact with your transplant team is important. Team members will continue to provide medical care, advice, and support for you and your family throughout the transplant process. Team members vary in each transplant center, but usually include:

You!
You are the most important member of the transplant team. You should have a good understanding of your medical care and be actively involved in your care through clinic appointments and communicating with members of the team.

Transplant Surgeon
Transplant surgeons are medical doctors who specialize in kidney surgery and transplantation. The surgeons perform the operation and will be involved in your care and medical management as you recover from surgery.

My transplant surgeon(s): _______________________________________________________

Transplant Office number: _____________________________________________________

Nephrologist
A nephrologist is a medical doctor who specializes in medical problems of the kidney. Most patients with kidney disease have a nephrologist who manages their medical care before transplant. Some patients continue care with a nephrologist after transplant.

My nephrologist: _______________________________________________________________

Nephrology office number: ____________________________________________________

Management varies by transplant center, so you may have follow-up care with a transplant physician, transplant surgeon, or nephrologist. They will be responsible for the management of anti-rejection medications and any medical issues directly related to the transplant. For health problems not related to your kidney transplant, you should continue to contact your local physician or general practitioner. Your transplant coordinator will work with you to plan your follow-up care after you leave the transplant center.
Nurse Practitioner (NP) or Physician Assistant (PA-C)
A nurse practitioner is a registered nurse who has completed advanced education, usually a master's degree, and training in the diagnosis and management of common medical conditions and chronic illnesses. Physician Assistants are non-physician clinicians who are licensed to practice medicine with a physician's supervision. Most PAs also have a master's degree. NPs and PAs provide a broad range of health care services. They provide some of the same care as physicians while working closely with a supervising physician. A nurse practitioner or physician assistant working at a transplant center might manage your daily medical care when you are in the hospital or may follow your progress in the outpatient clinic.

My NP or PA: ___________________________  Phone: _________________________

Transplant Coordinator (RN, CCTC)
Transplant Coordinators are usually licensed registered nurses (RN). They have extensive experience in the care and management of transplant recipients, both before and after transplant. Your coordinator will be involved in preparing you for discharge and will also follow your care after you return home. Your coordinator may refer you to other team members for services that you need and will be available to discuss any questions or concerns you may have as you begin to adapt to life following your transplant. The initials CCTC after your coordinator's name mean that your coordinator has passed a transplant certification examination as a Certified Clinical Transplant Coordinator.

My coordinator: ___________________________  Phone: _________________________

Medical Social Worker (MSW)
A medical social worker in transplantation specializes in helping patients and families cope with the stresses and challenges of the transplant process. Your social worker may help you by identifying community supports, assisting you with housing while staying in the hospital community, helping with financial difficulties, providing emotional support, and providing information and referrals for support groups or counseling.

My social worker: ___________________________  Phone: _________________________

Clinical Nurse Specialist (CNS)
A clinical nurse specialist is a registered nurse with an advanced practice degree in a nursing specialty. The transplant clinical nurse specialist is usually involved in the transplant evaluation as well as post-transplant care and will provide information on all facets of the transplant process, assess any potential problems, provide supportive care, and will help in preparing you for discharge. This advanced practice nurse may be involved with your care while you are in the hospital and after discharge.

My CNS: ___________________________  Phone: _________________________
Pharmacist
A pharmacist is a licensed medical professional who dispenses prescription medications. As part of the transplant team, the transplant pharmacist may help monitor your medications while you are in the hospital and during clinic visits. The pharmacist may also be involved in your discharge teaching and will provide information about your medications and instructions on how to take them.

My pharmacist: __________________________  Phone: _________________________
My pharmacy: ___________________________  Phone: _________________________

Dietician
A dietician specializes in helping patients maintain good nutrition. Your dietician will help manage your nutrition before and after transplant. The dietician may also work with you on any special dietary instructions or diets for medical complications such as diabetes, high blood pressure, high potassium levels, or high cholesterol.

My dietician: ____________________________  Phone: _________________________

Other members of my Transplant Team:

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MEDICATIONS

One of the most important responsibilities you will have after transplant is taking your medications as they are prescribed. You will learn a lot about your medications before you leave the hospital.

What you should know about your medications:

• The brand name and generic name
  Medications are known by two different names. The brand name is the name given to the medication by the pharmaceutical company that produces it. The generic name is the common, non-branded name of that medication. There can be several brand names for a generic medication. For example, tacrolimus and Prograf® are the same medication. Tacrolimus is the generic name and Prograf® is the brand name.

• The purpose or reason for taking each medication
  A medication often has more than one use and may be prescribed for different reasons. You should always know why you are taking each medication. For example, fluconazole is a medication used to treat fungus infections, but it can also be used to increase tacrolimus levels.

• What each medication looks like
  You must be able to recognize each medication by color, shape, and size. Many medications have a similar appearance with only slight differences. They must be looked at closely to be sure the correct medication is being taken. Magnesium oxide, sodium bicarbonate, and some generic forms of Bactrim® are all large, round, white pills. If you look closely, though, you will see some differences.

• When to take each medication
  Some medications, such as the anti-rejection medications tacrolimus and cyclosporine, must be taken on time daily so that the appropriate level of that medication is maintained. It is important to know what time you need to take each medication. Work with your coordinator or nurse to arrange a medication schedule that is easy to follow with your daily routine.

• How to take each medication
  You probably take most of your medications by swallowing a pill or capsule. Occasionally, particularly for children, a pill may be divided or crushed and mixed with food or liquids. Discuss how to take each of your medications with your nurse or coordinator. Some pills should not be crushed because breaking up the pill will decrease its effectiveness.
• How long each medication is prescribed
Some medications may be prescribed for only 7 to 14 days, such as antibiotics. Others, like your anti-rejection medications, are usually prescribed for your lifetime. Some medications can be discontinued after a complication or side effect has resolved.

• The most common side effects
Every medication has side effects, but these are not experienced by everyone. You should know the most common side effects that each medication may cause and what can be done to relieve or lessen any side effects.

• Any special instructions
Some medications must be taken with food or on an empty stomach or separated from certain meds. Discuss any special instructions for your medications with your nurse, pharmacist, or coordinator.

• What to do if you are late, miss a dose, or forget to take a dose
If you are very late taking a medication or have skipped a dose, either because you forgot or you have been vomiting, call your transplant coordinator. After asking you a few questions and considering your current health status, your coordinator will advise you on what to do.

• How to order your medications
Your transplant coordinator, nurse, or social worker will help you find the most convenient way to order your medications. As you are preparing for discharge, have your caregiver get your medications at the hospital’s outpatient pharmacy or at a retail pharmacy in the area. Be sure that you have at least a 30-day supply of all your medications before you leave the hospital.

• When to order your refills/repeat prescriptions
The number of refills you have for each medication depends on how long you will be taking the medication. Your insurer may also specify how many refills can be ordered. After the prescription has been submitted to your pharmacy, you may call for refills/repeat prescriptions. However, all new prescriptions and any changes in the medications you are already taking must be called in or sent to your pharmacy by your physician. It is very important to monitor the number of pills you have so you can order your refills in time or call your coordinator to do this so that you avoid missing any doses. You should always have at least a one week supply of medications.

• What is the cost for your medications?
It is important to know your financial responsibility for your medications so you can plan ahead. In the United States, some medications may be completely covered by insurance, while others have co-payments. Often, insurance companies have a deductible you must meet before your medication coverage begins. It may be helpful for you or a family member to call your insurance case manager or approved pharmacy provider before your medications are ordered. A toll-free number for “prescriptive authorization” is usually on the back of insurance cards. This contact person should be able to tell you what your cost is for each prescribed medication. Internationally, medication costs vary by country. You should discuss the possible cost of your prescriptions with your transplant coordinator, social worker and/or transplant financial counselor.
Medication Guidelines

Call your transplant coordinator if you:
• are unable to take your medications because you are nauseated, feeling sick, or vomiting
• have diarrhea and are worried that you are not absorbing your medications
• have forgotten to take your medication or missed any doses due to illness
• notice that the directions on the medication label from the pharmacy are different than what you were told
• feel you are having an unusual reaction or side effects to a medication
• would like to take Tylenol® (acetaminophen) for fever
• would like to take an over-the-counter cold remedy, cough suppressant, diet aid, herbal medicine, or medications that you have not previously discussed with your doctor
• are instructed to take any new medications by your local doctor or if any changes are made to your current medications by another doctor.

Organize a medication schedule that fits well with your daily routine.
• Work with your transplant coordinator, nurse, or pharmacist to arrange a schedule that fits into your daily routine so that taking your medications is convenient. A convenient schedule will improve your success for taking all your medications at the right time every day.
• Some people find it helpful to follow a written schedule or a check-off list.
• Pill reminder containers and medication alarms may also be helpful. Pill containers can be stocked with a week's supply of medications. Medication alarms can be set to remind you to take your medications on time.

• Always keep a copy of your medication schedule with you. If you are being seen in clinic, your doctor’s office, or in an emergency room, it will help to have a current list of your medications.
• Some people find it difficult to take medicines that are prescribed more than one or two times a day. If this is a problem for you, ask your doctor if the medicine can be taken less frequently. In some cases, the amount of medication can be changed and the dosage times decreased. For example, instead of taking two tablets of magnesium three times a day, your doctor may adjust the dose to three tablets two times a day.
Medications

Storing your medications:

- Keep medications in the original containers with the caps closed. If you use a pill reminder container, keep the container sealed. It is important that you can recognize different medications when they are together in a pill container in case a dose has changed.
- Store your medications in a cool, dry place away from sunlight. Do not store them in the bathroom because moisture may interfere with the effectiveness of some medications.
- Do not store medications in a refrigerator unless instructed to do so by your pharmacist.
- Keep all medications in a safe place, out of reach of children and pets.
- It may be helpful to keep a few doses of your medications in another place, aside from your household. Sometimes transplant recipients will store extra doses of anti-rejection medications at a family member’s house, in their office, or with the school nurse in case of an emergency.
- It is helpful to bring your medications, filled medication container and/or medication list with you for clinic visits or if you are admitted to the hospital. This will insure that you will not miss any doses.
Medications to Treat or Prevent Rejection

This section contains information about commonly prescribed medications following kidney transplantation. It includes the purpose of each medication, the usual dosage and dosage forms, the most common side effects, and other significant information. This information is presented as a general guide for the kidney transplant recipient and is not all-inclusive. Always contact your transplant coordinator or your transplant team to be aware of your center’s recommendations and specific medication protocols.

If you are pregnant or planning to become pregnant, your transplant physician and obstetrician/gynecologist should be consulted to review and discuss your current medication routine and your medication history. Some medications may be harmful to the fetus, so adjustments may need to be made.

Anti-Rejection Medications

Tacrolimus (Prograf®)

Purpose: Tacrolimus is used to prevent or treat rejection after kidney transplant. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Tacrolimus may be used by itself or in combination with other anti-rejection medications to prevent rejection.

Dosage: Tacrolimus is available in 0.5 mg (yellow), 1 mg (white), and 5 mg (pink) capsules. It is usually dosed twice daily. Doses should be taken 12 hours apart. It is important to take tacrolimus on time every day to insure a stable level of immunosuppression. Most transplant centers advise that patients not be more than one hour early or one hour late in taking their doses of tacrolimus.

Side effects: The side effects of tacrolimus vary and are usually related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects include:

Nervous system side effects (neurotoxicities): These side effects are more commonly seen with a high tacrolimus level (>15). They usually resolve as the level is decreased. High tacrolimus levels may cause headache, insomnia (trouble sleeping), numbness and tingling of the hands and feet, hand tremors, or an increased sensitivity to bright or blinking
Kidney dysfunction (nephrotoxicity): Tacrolimus can affect the kidneys by causing the arterioles, small branches of the arteries, to constrict or get smaller. When the arterioles are constricted, kidney function is affected causing high blood pressure and/or high levels of potassium and low levels of magnesium in the blood. The blood urea nitrogen (BUN) level and creatinine may also increase. Long term kidney dysfunction may occur.

Infection: If you are taking tacrolimus, your immune system is suppressed. Because your body’s natural ability to fight infections is decreased, you may be more likely to develop infections. You are at greatest risk for developing infections when your tacrolimus level is high, usually during the first three months after transplant. You are also at risk for infection if you are being treated for rejection with higher doses of tacrolimus and other anti-rejection medications.

Other side effects that may be experienced with tacrolimus are nausea, diarrhea, high blood sugar, and hair loss.

Additional information:
• Do not change the dose of tacrolimus or take it more or less often than prescribed for you by your transplant physician.
• Tacrolimus levels are monitored through blood tests. Levels are monitored daily in the early postoperative period, then less frequently over time. Most patients have a tacrolimus level checked monthly by the time they are several months post-transplant. Although management of immunosuppression varies by transplant center, levels usually range from 15 to 18 ng/ml in the early post-operative period or during treatment for rejection. Levels may be decreased to 5 to 10 ng/ml after one to two years if the patient has had no recent rejection episodes and has stable kidney function.
• Tacrolimus levels should be drawn one to two hours before taking a dose or about 10 to 12 hours after the previous dose. This is called a trough level and is the lowest level of tacrolimus that is present in the blood. For example, if you take tacrolimus at 8:00 AM and 8:00 PM, your trough level should be drawn between 6:00 and 8:00 AM or 6:00 and 8:00 PM. On days when you are having blood work, be sure to have your labs drawn before taking tacrolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
• Your dose of tacrolimus may be increased if you are experiencing kidney rejection. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
• Food can affect the tacrolimus level. Eating a full meal within two hours of taking tacrolimus may lower the level by as much as 30%. Some transplant centers prefer that patients not eat for an hour before or after taking tacrolimus. Please check with your coordinator or transplant pharmacist for your center’s guidelines. A light breakfast or meal appears to have no effect on tacrolimus absorption.
• Take your tacrolimus dose in the same way and at the same time every day to maintain a stable level.
• You should not eat grapefruit or drink grapefruit juice while taking tacrolimus.
Chemicals in grapefruit can interfere with the enzymes that break down tacrolimus. Grapefruit, grapefruit juice, or the herbal products of grapefruit will increase tacrolimus levels. Patients who are taking tacrolimus may develop a very high level of their medication if grapefruit is taken at any time of day. All forms of grapefruit and drinks containing a significant amount of grapefruit juice should be avoided if you are prescribed tacrolimus. An increased tacrolimus level increases your risk of infection and serious side effects.

- Some medications should not be taken with tacrolimus.
  - Two hours from tacrolimus: sucralfate (Carafate®, Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
  - Two to four hours from tacrolimus: sodium bicarbonate (Bicitra®, Polycitra®)
  - Tacrolimus interacts with some other medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with tacrolimus.
  - If you miss a dose of tacrolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose as your levels may need to be monitored more frequently.
  - Store tacrolimus capsules at room temperature and away from the reach of children and pets.
  - If you are planning to become pregnant, discuss the use of tacrolimus with your transplant physician and obstetrician/gynecologist.

**Cyclosporine (Sandimmune®, Neoral®, Gengraf™)**

**Purpose:** Cyclosporine is used to prevent or treat rejection after transplant. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Cyclosporine may be used by itself or in combination with other anti-rejection medications to prevent rejection.

**Dosage:** Cyclosporine is available in two formulations that are not identical. These are cyclosporine (Sandimmune®) and cyclosporine-modified (Neoral® and Gengraf™). Cyclosporine is made by several pharmaceutical companies. Your body absorbs the different cyclosporine formulations in different ways. Because of this difference in absorption, be sure that your pharmacy always gives you the brand of cyclosporine that has been prescribed for you.

Neoral® and Gengraf™ are also available as a liquid. You may find that the liquid form of cyclosporine tastes better if diluted with milk, chocolate milk, or orange juice. Mix cyclosporine and a room-temperature liquid in a glass or cup and stir it with a metal spoon. Do not use styrofoam or soft plastic cups since some cyclosporine could cling to the foam container or plastic. Hard plastic containers are acceptable for safety reasons with small children.

Cyclosporine is usually dosed twice daily and should be taken at the same time each day to insure a stable level of immunosuppression. Most transplant centers advise that patients not be more than one hour early or one hour late in taking their doses of cyclosporine.
**Side effects:** The side effects of cyclosporine vary and are usually related to the blood level of the drug. Side effects are more commonly seen when levels are high, particularly in the early weeks after transplant and during treatment for rejection. The most common side effects are:

**Nervous system side effects** (neurotoxicities): These side effects are more commonly seen with a high level and usually resolve as the level is lowered. High levels of cyclosporine may cause headache, hand tremors, trouble sleeping (insomnia), and numbness and tingling of the hands and feet.

**Kidney dysfunction** (nephrotoxicity): Cyclosporin can affect the kidneys by causing the arterioles, small branches of the arteries, to constrict or get smaller. When the arterioles are constricted, kidney function is affected causing high blood pressure and/or high levels of potassium and low levels of magnesium in the blood. The blood urea nitrogen (BUN) level and creatinine may also increase. Long term kidney dysfunction may occur.

**Infection:** Cyclosporin suppresses the immune system. Because your body’s natural ability to fight infections is decreased, you may be more likely to get infections. You are at greatest risk for developing infections when your cyclosporine level is high, particularly during the first three months after transplant, and if you are being treated for rejection with increased immunosuppression.

**Cosmetic side effects:** Cyclosporine can cause some changes in your appearance. Excessive hair growth (hirsuitism) can occur. Patients may also develop bleeding and tenderness of the gums. The gums can swell and become overgrown (gingival hyperplasia). Acne may develop or worsen in patients taking cyclosporine.

**Additional information:**
- Do not change the dose of cyclosporine or take it more or less often than prescribed for you by your transplant physician.
- Cyclosporine levels are monitored through blood tests. Levels are monitored daily in the early postoperative period, then less frequently over time. Most patients have a cyclosporine level checked monthly by the time they are several months post-transplant. Although management of immunosuppression varies by transplant center, levels usually range from 200-250 ng/ml in the early post-operative period or during treatment for rejection. Levels may be decreased to 100-150 ng/ml after one to two years if the patient has had no recent rejection episodes and has stable kidney function.
- Cyclosporine levels should be drawn one to two hours before taking a dose or about 10 to 12 hours after the previous dose. This is called a trough level and is the lowest level of cyclosporine that is present in the blood. For example, if you take cyclosporine at 8:00 AM and 8:00 PM, your trough level should be drawn between 6:00 and 8:00 AM or 6:00 and 8:00 PM. On days when you are having blood work, be sure to have your labs drawn before taking cyclosporine so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- Your dose of cyclosporine may be increased during an episode of rejection or to prevent rejection if your level is low. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
• Take your cyclosporine dose in the same way and at the same time every day to maintain a stable level.
• You should not eat grapefruit or drink grapefruit juice while taking cyclosporine. Chemicals in grapefruit can interfere with the enzymes that break down cyclosporine. Grapefruit, grapefruit juice, or the herbal product of grapefruit will increase cyclosporine levels. Patients who are taking cyclosporine may develop a very high level of their medication if grapefruit is taken at any time of day. All forms of grapefruit and drinks containing a significant amount of grapefruit juice should be avoided if you are prescribed cyclosporine. An increased cyclosporine level increases your risk of infection and serious side effects.
• Some medications should not be taken with cyclosporine.
  • Two hours from cyclosporine: sucralfate (Carafate®), Mylanta®, Tums®, magnesium oxide, magnesium gluconate (Magonate®)
  • Two to four hours from cyclosporine: sodium bicarbonate (Bicitra®, Polycitra®)
• Cyclosporine interacts with some other medications, causing higher or lower levels. Always check with your transplant coordinator before starting any new medication to be sure that it does not interfere with cyclosporine.
• If you miss a dose of cyclosporine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose. Levels may need to be monitored more frequently until the cyclosporine level is stabilized.
• Cyclosporine capsules and liquid should be stored at room temperature and away from direct sunlight. Cyclosporine capsules are packaged in individual blister packs. Do not open the blister pack until you are ready to take the medication, because air and light will damage the medication. An opened bottle of cyclosporine liquid may be used for up to two months. Be sure to keep cyclosporine and all medications out of the reach of children and pets.
• If you are planning to become pregnant, discuss the use of cyclosporine with your transplant physician and obstetrician/gynecologist.

Prednisone (Deltasone®) or Prednisolone (Orapred®)

Purpose: Prednisone is a steroid used to help prevent or treat rejection in organ transplantation. It prevents rejection by inhibiting the cells in the immune system that cause rejection and is given with tacrolimus or cyclosporine. Although many kidney transplant patients require prednisone for life, some transplant recipients can be weaned from steroids within weeks to a few months after transplant. Some centers do not use steroids unless the medication is needed to treat rejection.

Dosage: Prednisone is available in several strengths including 1 mg, 2.5 mg, 5 mg, 10 mg, and 20 mg tablets. It is also available in a liquid form called prednisolone. Prednisone is usually prescribed once daily and should be taken in the morning. If taken at night, it can affect your sleep. In people with diabetes, prednisone may be taken twice daily, with one dose taken in the morning and the second dose with dinner. This helps even out the effect of prednisone on blood glucose levels.
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**Side effects:** Prednisone can have many side effects, but these vary depending on the dose, frequency and duration of your treatment. The most common side effects include: an increased appetite, weight gain, stomach irritation and/or stomach ulcers, mood changes, irritability, anxiety, and acne. You may also retain fluids which may make your face, hands, and ankles “puffy.” Side effects that can occur with higher dosages over a longer period of time include bruising, high blood pressure, high cholesterol levels in the blood, high blood sugar, muscle weakness, night sweats, bone weakening, delayed wound healing, cataracts, glaucoma, and growth retardation in children.

**Additional information:**
- Be sure you know your correct dose of prednisone and that you have the correct strength of the medication. Because prednisone is available in several strengths, it is easy to get confused.
- Do not change the dose of prednisone or take it more or less often than prescribed.
- If prescribed once a day, prednisone should be taken in the morning so that it does not affect your sleep.
- If prednisone is to be stopped, the dose must be decreased slowly over several weeks. If prednisone is stopped completely, serious complications may occur.
- Prednisone should be taken with food because this medication can cause stomach upset.
- If you miss a dose of prednisone, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose. Since your own body’s production of a natural steroid (cortisol) is disturbed when you take prednisone, missing doses could make you sick.
- If you are taking prednisone, examine your skin routinely for bruising. If you have any wounds that are not healing well, notify your transplant coordinator. Maintain good care of your skin. This is especially important if you have diabetes.
- Your physician may advise you to avoid concentrated sweets, like candy bars and soda, while taking prednisone. High blood sugar can develop with higher doses of steroids. Patients who already have diabetes may find it more difficult to control their blood sugar when they are taking prednisone.
- If you are taking prednisone, you will usually be prescribed an antacid and an acid blocker so that you do not get a stomach ulcer. If you develop a stomach ulcer from prednisone, you may have an upset stomach or abdominal pain. Sometimes stomach ulcers can cause bleeding which will make your stools look black and tarry. Call your transplant coordinator with any of these symptoms so medications and treatment can be prescribed promptly.

**Sirolimus (Rapamune®)**

**Purpose:** Sirolimus is used to prevent rejection in organ transplant recipients. It prevents rejection by inhibiting the cells in the immune system that cause rejection. Sirolimus may be the only immunosuppressant that is prescribed for you, or it may be prescribed to be taken with prednisone, tacrolimus or cyclosporine.

**Dosage:** Sirolimus is available in 1 mg (white) and 2 mg (yellow) tablets. It is also available in a liquid. Sirolimus is taken once or twice daily and should be taken on time to insure a stable level of
immunosuppression. The liquid form of sirolimus should be mixed with one to two ounces of water or orange juice in a glass or cup. Do not use a styrofoam or paper cup because sirolimus may cling to the container. The tablet should be swallowed whole and never crushed or broken.

**Side effects:** The side effects of sirolimus vary and are usually related to the level of the drug. The most common side effects are: an increased risk of infection, nausea, diarrhea, a low red blood cell count (anemia), high cholesterol and/or triglyceride levels in the blood, a low white blood cell count, a low platelet count, low potassium levels, headache, acne, mouth sores, arthritis, swelling of hands and feet, and muscle cramping. Side effects usually resolve as the dose is reduced.

**Additional information:**
- Do not change the dose of sirolimus or take it more or less often than prescribed for you by your transplant physician.
- Check with you transplant coordinator or pharmacist about the correct time to take your dose of sirolimus. Since sirolimus works with tacrolimus and cyclosporine, some centers prefer that sirolimus be taken about four hours from these medications. Other centers recommend taking the medications at the same time.
- Sirolimus is usually not started immediately after transplant like other anti-rejection medications because it can affect wound healing. Patients may be prescribed cyclosporine or tacrolimus for the first six to eight weeks after transplant, then changed to sirolimus. In some cases, sirolimus may be added.
- The dosage of sirolimus may be increased during an episode of rejection or to prevent rejection if your level is low. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Sirolimus levels are monitored through blood tests. Levels are monitored one to two times weekly in the early postoperative period, then less frequently over time. Most patients have a sirolimus level checked monthly by the time they are several months post-transplant. The desired sirolimus level depends on whether it is the only immunosuppressant you are taking or if you are taking it with tacrolimus or cyclosporine. Although management of immunosuppression varies by transplant center, levels usually range from 5 to 15 ng/ml if used with tacrolimus or cyclosporine; 12 to 24 ng/ml if used alone.
- Sirolimus levels should be drawn one to four hours before taking a dose or about 20 to 24 hours after the previous dose if it is taken once a day. This is called a trough level and is the lowest level of sirolimus that is present in the blood. On days when you are having blood work, be sure to have your labs drawn before taking sirolimus so that an accurate trough level is obtained. Bring a dose with you to take after your labs have been drawn so you will not be late taking your dose.
- If you miss a dose of sirolimus, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- Sirolimus tablets should be swallowed whole without crushing or breaking. The medication is coated on the outside of the tablet, so breaking or crushing the tablet can result in losing some of the drug.
- If you take the liquid form of sirolimus, mix your dose in one to two ounces of orange juice or water in a glass or cup. Do not use a styrofoam or paper cup because sirolimus may cling to the
Kidney Handbook

container. Rinse the container with another ounce of water or orange juice and swallow that amount as well. It is also advisable to rinse your mouth with more water or orange juice after swallowing the medicine. Some patients have developed mouth ulcers from the liquid form. These ulcers usually resolve over time or with decreased dosing.

• Store sirolimus tablets at room temperature and out of the reach of children. The liquid form of sirolimus must be refrigerated after the bottle is opened. It can be used for one month after opening.

• If you are planning to become pregnant, discuss the use of sirolimus with your transplant physician and obstetrician/gynecologist.

Azathioprine (Imuran®)

Purpose: Azathioprine is used to help prevent or treat rejection in organ transplant recipients. Azathioprine is a “helper” immunosuppressant and is prescribed in addition to tacrolimus, cyclosporine, and/or prednisone.

Dosage: Azathioprine is available as a tablet and a liquid. It is prescribed once daily and should be given at about the same time each day.

Side effects: Azathioprine may lower the number of white blood cells in your body, the cells that fight infection. It may also lower platelets, which are cells that help your blood clot. Other side effects may include nausea, vomiting, and rash. Azathioprine may also be harmful to the liver resulting in an increase in the liver functions tests (LFTs). It can also cause an inflammation of the pancreas (pancreatitis).

Additional information:
• Do not change the dose of azathioprine or give it more or less often than prescribed.
• The dose of azathioprine may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
• If you miss a dose of azathioprine, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
• Azathioprine interacts with a medication called allopurinol, a drug used to treat gout. Call your transplant coordinator if you are diagnosed with gout or if a doctor has prescribed this medication for you. Azathioprine and allopurinol cannot be taken together.
• If you are taking azathioprine and considering becoming pregnant, consult your transplant physician and obstetrician/gynecologist.

Mycophenolate mofetil (Cellcept®)
Mycophenolate sodium (Myfortic®)

Purpose: Mycophenolate is used to help prevent or treat rejection in organ transplant recipients. It is usually given with tacrolimus, cyclosporine and/or prednisone.

Dosage: Mycophenolate is available in two formulations: CellCept® and Myfortic®. Myfortic is enteric-coated to help decrease stomach upset and other gastrointestinal (GI) side effects.
**Side effects:** Mycophenolate may lower the number of white blood cells in your body, the cells that fight infection. It may also lower the number of platelets which help your blood clot. Other side effects include nausea, stomach irritation, vomiting, and diarrhea. Side effects may decrease over time or resolve with a lower dose of mycophenolate. The enteric-coated form of mycophenolate helps decrease GI side effects in some patients.

**Additional information:**
- Do not change the dose of mycophenolate or take it more or less often than prescribed.
- The dose of mycophenolate may be increased during an episode of rejection or to prevent rejection. The dose may be decreased if you have an infection or if you have complaints or complications due to side effects of the medication.
- Mycophenolate capsules should be swallowed whole and should not be opened. The powder inside the capsule may be harmful if inhaled. Mycophenolate tablets should not be broken or crushed.
- If you miss a dose of mycophenolate, take it as soon as you remember. If it is near the time for the next dose, skip the missed dose and resume your regular dosing schedule. Call your transplant coordinator if you have missed a dose.
- If you are a woman of childbearing age and taking mycophenolate, it is important to discuss the use of this medication with your transplant physician and obstetrician/gynecologist. Women of childbearing age should use contraception while on this medication. If mycophenolate is discontinued, contraception should be continued for an additional six weeks to assure that the drug is eliminated from the body before becoming pregnant.

**Antithymocyte globulin:**

**ATG (Thymoglobulin®, Atgam®)**

**Purpose:** Antithymocyte globulin (ATG) is an immunosuppressant given in some transplant centers as a “pre-conditioning” agent immediately before transplant surgery. One dose of ATG is given about four hours before transplant surgery to reduce the body’s immune response and possibly reduce the risk of rejection. Some transplant centers also use ATG to treat rejection if the rejection does not resolve after treatment with steroids.

**Dosage:** ATG is available only as an intravenous (IV) solution and is given in the hospital.

**Side effects:** During the ATG infusion, patients may have fever, chills, rash, low blood pressure, increased heart rate, or difficulty breathing. To minimize this infusion reaction, patients are usually treated with methylprednisolone (Solumedrol®), acetaminophen (Tylenol®)/paracetamol, and diphenhydramine (Benadryl®) before and during the infusion. The infusion may also be slowed down to decrease side effects. Patients are closely monitored during the infusion to watch for any of these side effects.

Later side effects include a low white blood cell count, a low platelet count, pain, headache, fever, abdominal pain, diarrhea, high blood pressure, nausea, swelling of the hands and feet, and an increased level of potassium in the blood.
**OKT3 (Orthoclone®, muromonab-CD3)**

**Purpose:** OKT3 is an immunosuppressant that is used to treat moderate to severe rejection of the kidney.

**Dosage:** OKT3 is available only as an intravenous (IV) solution and is administered in the hospital. It is given through an IV once a day for 7 to 14 days.

**Side effects:** Because some patients have a reaction to the first or second dose of OKT3, they are monitored closely during treatment with OKT3. In some transplant centers, patients are transferred to the Intensive Care Unit (ICU) for 24 to 48 hours after the first dose. Methylprednisolone, an IV steroid, is given before OKT3 to decrease the severity of this reaction.

OKT3 may cause low blood pressure, a high heart rate, fever, chills, and/or flu-like symptoms. Patients may also experience wheezing, difficulty breathing, fluid in the lungs (pulmonary edema), headache, confusion or seizures. Other side effects include high blood pressure, tremor, rash, itching, diarrhea, nausea, vomiting, joint pain, sensitivity to light (photophobia), kidney dysfunction, and an increased risk of infection.

**Medications to Treat or Prevent Infection**

**Trimethoprim/sulfamethoxazole: TMP-SMX (Bactrim®, Septra®)**

**Purpose:** This medication is used to prevent or treat a type of pneumonia called *Pneumocystis jeroveci pneumonia* (PJP). Patients who have a suppressed immune system are at greater risk for this pneumonia.

**Dosage:** To prevent PJP, patients are prescribed one dose of TMP/SMX to be taken three times a week, usually on Monday, Wednesday, and Friday. Some transplant centers prescribe a lower dose that is taken daily. TMP/SMX is available in tablets or liquid.

**Side effects:** Patients who are allergic to sulfa drugs will have an allergic reaction to TMP/SMX. These patients may develop a rash, itching, and/or hives. If you are allergic to sulfa drugs, your transplant physician will prescribe another medication to prevent PJP, usually pentamidine or dapsone.

Other side effects of TMP/SMX include nausea, vomiting, diarrhea, mouth ulcers, a low red blood cell count (anemia), a low white blood cell count, or a low platelet count. TMP/SMX can cause an increase in liver and kidney function tests in some patients.
Ganciclovir (Cytovene®)  
Valganciclovir (Valcyte®)

**Purpose:** Ganciclovir and valganciclovir are used to prevent or treat certain viruses that commonly occur in patients who have a suppressed immune system. Cytomegalovirus (CMV), herpes simplex infections (HSV), and Epstein Barr Virus (EBV) infections are usually treated with ganciclovir or valganciclovir, depending on transplant center routines.

**Dosage:** Ganciclovir is usually given twice daily for 14 days through an IV to treat an active CMV infection. In some cases, it may be given longer until the virus resolves. Some transplant centers give ganciclovir for 14 days after transplant to try to prevent a CMV infection, particularly if the patient is at high risk for developing CMV.

Valganciclovir (Valcyte®) is the oral form of ganciclovir and is available as a tablet or liquid. Valganciclovir may be prescribed for three to six months after transplant to prevent CMV in patients who are at risk for the virus.

**Side effects:** Side effects may include: nausea, vomiting, headache, pancreatitis, irritation from the IV infusion (phlebitis), confusion, and seizures. Ganciclovir can affect the white blood cell count and platelet count, but this usually resolves by decreasing the dose or by stopping the medication. Ganciclovir is eliminated from the body by the kidneys, so patients with kidney dysfunction receive a lower dose. Studies in animals have shown that ganciclovir affects fertility and sperm production. It is recommended that male and female transplant patients of childbearing age use contraception during ganciclovir therapy and for at least 90 days after discontinuing the medication. Breastfeeding should be avoided during treatment with ganciclovir.

**Additional information:**
- If you are diagnosed with CMV, the first few doses of IV ganciclovir are usually given in the hospital. If you are doing well, you will be discharged to complete the IV treatment at home with home care nursing support.
- Since ganciclovir/valganciclovir is eliminated from the body by the kidneys, drink plenty of fluids while you are receiving this medication. Patients are encouraged to drink two to three liters of fluid daily (unless fluid restricted) while taking valganciclovir.
- Valganciclovir tablets should be swallowed whole and taken with food.
- Avoid handling crushed or broken valganciclovir tablets. Wash the affected area thoroughly if your skin comes in contact with the powder.
- There is an increased risk of infection while on ganciclovir and valganciclovir therapy. Call your transplant coordinator if you have fever, chills, unhealed sores, or white plaques in your mouth.
Acyclovir (Zovirax®)  
Valacyclovir (Valtrex®)  
Famciclovir (Famvir®)  

**Purpose:** Acyclovir is a medication used in the treatment of certain viruses, particularly herpes simplex infections (HSV-1, HSV-2) and varicella-zoster infections (chickenpox, shingles). Valacyclovir and famciclovir are similar medications that can also be used to treat these infections. These medications help decrease the pain caused by the herpes lesions (sores) and also help them heal.

**Dosage:** The dose of acyclovir depends on the type of herpes infection being treated and if the herpes infection is active or being prevented. Patients with open herpes lesions (sores) are usually treated with intravenous (IV) acyclovir. When the lesions are crusted and healing, the oral form of acyclovir is prescribed to complete treatment.

**Side effects:** The most common side effects of acyclovir are headache, tiredness, dizziness, seizures, insomnia, fever, rash, nausea, vomiting, diarrhea, elevated liver function tests, muscle aches, and kidney dysfunction.

**Additional information:** If you have herpes, acyclovir will not prevent you from spreading herpes to others. Intercourse should be avoided when symptoms of genital herpes are present or when there are active lesions (sores) in the genital area. Condoms can help prevent the spread of genital herpes.

Cytomegalovirus Immune Globulin (Cytogam®)  

**Purpose:** Cytogam® is a medication used to prevent and treat cytomegalovirus (CMV) and Epstein Barr Virus (EBV) infections in patients who are immunosuppressed.

**Dosage:** Cytogam® is given through an IV infusion in the hospital or clinic. The dose and frequency vary depending on transplant center routines. Cytogam® can be given to treat an active infection or to help prevent infection.

**Side effects:** Side effects are uncommon, but when they do occur include flushing, sweating, muscle cramps, back pain, nausea, vomiting, wheezing, chills, and fever.
Antifungal Agents

Nystatin (Mycostatin®) and Clotrimazole (Lotrimin®, Mycelex®)

Purpose: When you are taking anti-rejection medications, particularly prednisone, there is a greater risk for getting an infection from fungus. This infection usually develops in the mouth and throat (thrush), the vaginal area, or on the skin.

Dosage: An antifungal medication is prescribed to treat fungus at the site of the infection. Nystatin, a liquid antifungal, is prescribed if a patient has fungus or thrush in the mouth. The liquid should be swished in the mouth for several seconds, then swallowed. Sometimes a lozenge (Mycelex troche®) is prescribed to be dissolved in the mouth. Vaginal creams, suppositories, and ointments are also available for vaginal or skin infections.

Side effects: Side effects are uncommon, but may include nausea, vomiting, and diarrhea. Side effects of clotrimazole also include mouth irritation, a stinging sensation, and increased liver function tests.

Additional information:
• Nystatin oral solution should be swished and held in the mouth for as long as possible (at least 30 seconds), then swallowed.
• Clotrimazole lozenges should be dissolved slowly in the mouth.
• Patients should not eat or drink for about 15 to 20 minutes after taking the liquid or lozenge so that the medication can be absorbed into the tissue of the mouth and esophagus. These capsules should be swallowed whole because they contain time-released granules that are slowly released over 12 to 24 hours. The capsules should not be chewed or opened. Esomeprazole (Nexium®) capsules, however, can be opened for patients who have difficulty swallowing capsules. This medication can be taken by mixing the granules with water.
Gastrointestinal (GI) Agents, Antacids and Acid Inhibitors

GI Agents and Antacids:
- Sucralfate (Carafate®)
- Antacids: Mylanta®, Tums®, Rolaids®, Maalox®, Di-Gel®

H2-Blockers:
- Famotidine (Pepcid®)
- Cimetidine (Tagamet®)
- Ranitidine (Zantac®)

Proton-Pump Inhibitors (PPIs)
- Omeprazole (Prilosec®)
- Esomeprazole (Nexium®)
- Lansoprazole (Prevacid®)
- Pantoprazole (Protonix®)
- Rabeprazole (Aciphex®)

Purpose: Following transplantation, patients are at risk for developing stomach irritation and ulcers. This can be caused by steroids and also stress which may increase the amount of acid in your stomach. You may be prescribed one or two GI agents and/or antacids after transplant. Sucralfate works by coating existing ulcers and the lining of the stomach. This coating protects the tissue from irritation by stomach acid. Acid blockers (the H2 blockers and PPIs) work by blocking the mechanism that produces acid so you have a decreased amount of acid in your stomach.

Dosage: Each antacid is dosed differently. Your risks for developing stomach ulcers and the length of time after transplant will determine what GI agents, antacids, and/or acid blockers are prescribed for you.

Side Effects: Most patients are able to take these medications without any problems. Side effects are rare but can include headache, diarrhea, nausea, vomiting, and abdominal pain.

Additional Information:
- Antacids may increase or decrease the absorption of many medications. Antacids (Carafate®, Mylanta®, Tums®, Rolaids®, Maalox®, Di-Gel®) should be taken two hours away from other medications, particularly mycophenolate, tacrolimus, cyclosporine, and sirolimus.
- Antacids should be taken on an empty stomach or before meals to be most effective. Antacids should be taken on an empty stomach so that the stomach is coated with the medication. These medications should be taken before meals so that the antacid does not bind with phosphorus in the foods you eat which can lower phosphorus levels in your blood.
- The proton pump inhibitors (PPIs) listed above are available in capsules. These capsules should be swallowed whole, not chewed because the capsules contain time-released granules that are slowly released over 12 to 24 hours. Esomeprazole (Nexium®) capsules can be opened and the granules mixed with water before taking.
- Lansoprazole (Prevacid®) is also available as a tablet that dissolves in the mouth (solutab) and as granules that are mixed with water before taking.
**Medications to Treat Electrolyte Imbalances**

**Purpose:** Sometimes medications can cause imbalances in the body's electrolytes. Electrolytes are substances your body needs to maintain fluid balance and to help with other functions of your body. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body.

Medications to treat or prevent electrolyte imbalances may be needed for several reasons. Sometimes these imbalances are due to side effects of other medications. For example, a high level of tacrolimus or cyclosporine can cause magnesium levels in your blood to be lower than normal. Sometimes imbalances can occur if your kidneys are not working well. If you have a lot of diarrhea because of an infection or as a side effect of a medication, the bicarbonate level in your blood may be low.

When electrolytes are higher or lower than the normal range, medications such as the ones listed below are used to treat or prevent imbalances.

Before kidney transplantation, patients with kidney failure often develop problems with calcium and phosphorus balance. High calcium levels may result from hyperparathyroidism. This condition occurs when the parathyroid glands, located in the neck by the thyroid gland, secrete too much parathyroid hormone. High phosphorus levels occur because the diseased kidneys cannot get rid of extra phosphorus. After kidney transplant, the opposite problem occurs. The overactive parathyroid glands may cause the kidney to excrete too much phosphorus, so blood levels of phosphorus are low. Kidney transplant patients are encouraged to eat foods that are high in phosphorus. Phosphorus supplements (K-Phos®, NeutraPhos®) may also be prescribed.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Use</th>
<th>Possible Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Magnesium oxide</td>
<td>to treat or prevent low magnesium levels</td>
<td>diarrhea, abdominal cramping, muscle weakness, high magnesium levels, low blood pressure</td>
</tr>
<tr>
<td>Magnesium gluconate (Magonate®)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fludrocortisone (Florinef®)</td>
<td>to treat or prevent high potassium levels to treat low blood pressure</td>
<td>high blood pressure, edema, headache, rash, low potassium levels</td>
</tr>
<tr>
<td>Sodium bicarbonate, sodium citrate, citric acid (Bicitra®)</td>
<td>to treat or prevent low bicarbonate levels</td>
<td>edema, increased gas, abdominal distention, low levels of potassium and/or calcium, high levels of sodium</td>
</tr>
<tr>
<td>Phosphorus replacement (Neutra-Phos®, Neutra-Phos-K®)</td>
<td>to treat or prevent low phosphorus levels</td>
<td>low blood pressure, high phosphorus levels, nausea, vomiting, high potassium levels, diarrhea</td>
</tr>
<tr>
<td>Potassium chloride (K-Dur®)</td>
<td>to treat or prevent low potassium levels</td>
<td>high potassium levels, nausea, vomiting, diarrhea, abdominal pain, muscle weakness, heart problems</td>
</tr>
</tbody>
</table>
Blood Pressure Medications

Purpose: High blood pressure (hypertension) is a common condition that is seen in the general population. After transplant, patients who have had high blood pressure may need to continue to be treated for this condition. Sometimes, high blood pressure occurs in patients who had normal blood pressure before the transplant. Hypertension after transplant can be a side effect of medications, particularly some of the anti-rejections medications. High blood pressure also occurs if the kidneys are not working well.

There are many medications that can be used to treat high blood pressure. They work in different ways to control hypertension. Sometimes patients are prescribed more than one blood pressure medication because the medications work together to control hypertension. Sometimes a diuretic ("water pill") is needed to work with these medications. Your doctor will prescribe the blood pressure medications that are right for you to control high blood pressure and any complications you may have. The table below includes some common medications used to treat high blood pressure.

<table>
<thead>
<tr>
<th>Medication</th>
<th>Possible Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACE inhibitors</td>
<td>headache, low blood pressure, dizziness, faint feeling, fatigue, vertigo, insomnia, high potassium, increased creatinine levels</td>
</tr>
<tr>
<td>Enalapril (Vasotec®)</td>
<td></td>
</tr>
<tr>
<td>Lisinopril (Prinivil®)</td>
<td></td>
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<tr>
<td>Ramipril</td>
<td></td>
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<tr>
<td>Calcium Channel Blockers</td>
<td>swelling, headache, flushing, palpitations, affects levels of some immunosuppressant medications</td>
</tr>
<tr>
<td>Amlodipine (Norvasc®)</td>
<td></td>
</tr>
<tr>
<td>Nifedipine (Procardia®)</td>
<td></td>
</tr>
<tr>
<td>Isradapine (DynaCirc®)</td>
<td></td>
</tr>
<tr>
<td>Diltiazem (Cardizem®)</td>
<td></td>
</tr>
<tr>
<td>Verapamil (Isoptin®)</td>
<td></td>
</tr>
<tr>
<td>Beta Blockers</td>
<td>low heart rate, low blood pressure, fatigue, dizziness, chest pain, swelling</td>
</tr>
<tr>
<td>Atenolol (Tenormin®)</td>
<td></td>
</tr>
<tr>
<td>Metoprolol (Lopressor®)</td>
<td></td>
</tr>
<tr>
<td>Toprol XL®</td>
<td></td>
</tr>
<tr>
<td>Diuretics</td>
<td>dry mouth, thirst (dehydration), low potassium levels, high blood glucose levels, weakness, palpitations, tinnitus (ringing in ears), rash</td>
</tr>
<tr>
<td>Furosemide (Lasix®)</td>
<td></td>
</tr>
<tr>
<td>Hydrochlorothiazide (Diuril®)</td>
<td></td>
</tr>
<tr>
<td>Alpha Blockers</td>
<td>dizziness (especially when standing suddenly), allergic reaction, chest pain, palpitations, rash</td>
</tr>
<tr>
<td>Doxazosin (Cardura®)</td>
<td></td>
</tr>
<tr>
<td>Prazosin (Minipress®)</td>
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</tbody>
</table>
Over-the-Counter (OTC) Medications

After transplant, patients may have complaints about common every day illnesses, just like the general population. People often take over-the-counter (OTC) medications to treat common illnesses such as the flu, colds, and diarrhea. If you want to take an OTC medication for cold or flu symptoms, be sure to contact your doctor or transplant coordinator before taking these remedies. Some OTC medications could interact with your transplant medications. It is also important that your doctor knows when you are ill because your illness could be related to your transplant, rather than being a routine community-acquired illness.

Always contact your transplant center before starting any new medications.

- OTCs for Diarrhea
  Diarrhea may occur after transplant as a side effect of some commonly prescribed medications. Magnesium often causes diarrhea. You may have diarrhea if you eat foods that are spoiled or that you do not tolerate well. Food allergies cause diarrhea in some people. Diarrhea can also be a symptom of an infection by a fungus or bacteria in your gastrointestinal (GI) tract, or the result of a common virus. If you have diarrhea for more than 24 hours or if you develop fever with diarrhea, contact your transplant coordinator or physician. If you have diarrhea, your transplant medications may not be absorbed well in your intestine. This could result in lower levels of immunosuppression. If your immunosuppression level is lower than desired, you may be at risk for rejection.

Your doctor will prescribe the appropriate medication if you have diarrhea. If you have a bacterial infection in your GI tract, an antibiotic may be prescribed. Do not take an OTC medication for diarrhea unless told to do so by your doctor.

- OTCs for Constipation
  If you are constipated, you may get some relief by increasing fiber in your diet. Eat plenty of bran, whole grains, fresh fruits, and vegetables. Drinking plenty of fluids can also help. Talk to your doctor about this if you are fluid-restricted. Activity also helps. Gradually increase your activity level and try to exercise daily.

Contact your doctor and/or transplant coordinator if constipation continues to be a problem. Do not take any OTC medications for constipation unless told to do so by your doctor. The most commonly used OTC medications for constipation include Metamucil®, Fiber-Con®, Senokot®, Milk of Magnesia, and Miralax®. Colace® (docusate) is a stool softener. It may be prescribed immediately after surgery to prevent constipation and straining to have a bowel movement. Enemas to lubricate the intestine can also be helpful in some patients who are constipated.
OTC Medications

• OTCs for Headache and Muscle Aches
If you have a headache or muscle aches that do not occur with fever, most transplant centers recommend taking acetaminophen (Tylenol®)/paracetamol. Check with your doctor or transplant coordinator for the recommended dose of acetaminophen/paracetamol and the frequency of dosing. Be sure you know your center’s guidelines about using acetaminophen/paracetamol. If your headaches worsen or become more frequent, or if your headache presents with fever or vomiting, contact your doctor or transplant coordinator.

Ibuprofen products (Motrin®, Advil®, Nuprin®, Midol®) and naproxen products (Naprosyn® or Aleve®) are common OTC medications used to treat headaches, muscle aches, and joint pain. Ibuprofen and naproxen products are not recommended by most transplant centers, particularly in the first few months after transplant. These medications can affect the kidneys and the liver. They can also cause stomach ulcers and bleeding in the stomach and GI tract. Although ibuprofen or naproxen may be appropriate medications to take for pain, be sure to talk to your doctor before using these medications.

• OTCs for Colds, Coughs, and the Flu
If you have cold or flu symptoms, particularly with fever, call your doctor or transplant coordinator. Be sure you know your center’s guidelines for what to do if you have a cold or the flu. If your doctor thinks your symptoms might be related to a transplant illness, you may be asked to have a check-up and/or have labs drawn. If you are thought to have a common community-acquired cold or flu, ask what OTC remedy you can take to relieve your symptoms. Most OTC cold and flu medications contain a combination of medications such as an antihistamine to dry your secretions and help you sleep, acetaminophen for aches and fever, and/or a cough suppressant. Avoid taking more than one OTC cold medication because many have the same ingredients and you could accidentally take too much medication.

• OTCs for Seasonal or Environmental Allergies
Over-the-counter allergy medications can help relieve the symptoms of seasonal allergies such as hay fever or allergies to pollen, dust, animal dander, or certain foods. There are several OTC medications that can be used to relieve the symptoms of allergies. If you have an allergy, contact your transplant coordinator for your center’s recommendations.
• **Nutritional Supplements**
  After transplant, some patients may be advised to take a daily multivitamin, vitamin supplements, and/or mineral supplements. This is usually because they had poor nutrition before transplant due to chronic kidney disease or if they had a difficult recovery after transplant. Your dietician will give you guidelines for eating healthy after transplant and will discuss your specific dietary needs. Always check with your doctor or transplant coordinator before taking any nutritional supplement that has not been prescribed for you.

• **Herbal Products**
  Herbal products, herbal remedies, and some herbal teas should be avoided after transplant. Most transplant centers strongly recommend that transplant recipients avoid all herbal products. In the United States, herbal products are classified as dietary supplements by the Food and Drug Administration (FDA), so these products have not been tested for effectiveness, side effects, and drug interactions. Product safety and doses are not regulated. Herbal remedies may interact with your transplant medications or affect your transplanted kidney.

St. John’s Wort is an example of an herbal remedy that can cause complications in transplant recipients. St. John’s Wort is a well-known herbal supplement used to treat depression. This herb increases the metabolism, or breakdown of medications. In transplant patients, this increase in metabolism causes a decrease in cyclosporine, tacrolimus or sirolimus levels. Lower levels of cyclosporine, tacrolimus or sirolimus will increase your risk of rejection.

Herbal supplements should be avoided. If you are interested in taking any herbal products, discuss your center’s guidelines with your transplant coordinator. Never take an herbal supplement without telling your physician or transplant coordinator. These products can interact with your medications and lead to significant problems with your transplanted kidney.
Complications Following Kidney Transplantation

Although kidney transplantation is a successful treatment for end stage kidney disease, complications can occur. Knowing the common symptoms of these complications, reporting the symptoms to your physician or coordinator, and getting early treatment will lead to a good outcome. The transplant team will watch you closely for complications and will prescribe medications and/or treatments to prevent and control any potential problems.

Risks that can occur with any surgery include bleeding, pneumonia, breathing problems, stroke, or wound infections. Surgical complications that can occur following kidney transplantation include:

### Bleeding
Bleeding can occur with any surgery because the body tissues and blood vessels are cut. If bleeding occurs after kidney transplant surgery, it is usually detected within the first 12 to 24 hours following the operation. The patient is returned to the operating room to repair the bleeding blood vessel. Transplant recipients are monitored very closely for any symptoms of bleeding during the early post-operative time.

### Vascular Thrombosis
Vascular thrombosis is a rare but very serious complication after transplant. This occurs when blood clots form in the small blood vessels of the kidney, causing a blockage of blood flow to or from the kidney. People who have a history of blood clots or certain types of autoimmune diseases, are at higher risk for developing blood clots in the kidney. If you have a risk for developing blood clots, your physicians and surgeons will prescribe medications to keep your blood “thinner” and will follow you closely for any symptoms.

### Renal Artery Stenosis
The renal artery, the main blood vessel that enters the kidney, may become stenosed (scarred) as it heals. If the artery becomes scarred, this blood vessel becomes very narrow and constricted. If the artery is narrowed, blood flow to the kidney decreases. The renal artery carries blood that contains oxygen, so this blood is very important to maintain good kidney function. A decreased amount of blood from the renal artery may affect kidney function and cause high blood pressure.

### Ureteral Stenosis and Urine Leak
The ureter is the tube that drains urine from the kidney to the bladder. During kidney transplant surgery, the ureter is attached to the recipient’s bladder. Sometimes the ureter may not heal properly where it is attached.
to the bladder. If this occurs, an area of narrowing develops that can cause the flow of urine to be blocked. This is called ureteral stenosis.

If the attachment does not heal completely, the connection may come apart. If this occurs, urine will leak into the abdomen. To avoid this complication, a ureteral stent is usually placed during surgery. A ureteral stent is a long spaghetti-sized plastic tube that supports the ureter as it heals and helps drain urine from the kidney to the bladder. The stent is removed several weeks after transplant through a procedure called a cystoscopy.

Some patients are not aware that a stent is in place, while others have complaints of voiding more frequently, having an urgency to void, or having discomfort or burning with voiding. If you have any of these symptoms, sometimes medications can help. If you have greater discomfort, or if mild discomfort changes to sudden pain, contact your doctor. There could be a problem with the stent.

A ureteral stent can cause some people to have blood in their urine (hematuria). The urine will have a light pink appearance. Although you may be worried about this, you are not losing a lot of blood. Some centers encourage patients to drink a lot of fluids to minimize the amount of blood in the urine. If your urine becomes redder and thicker, call your doctor immediately.

Fever after transplant can be a symptom of several complications. If you develop a fever, your doctor will determine the source of the fever so that the appropriate treatment is begun. Fever in a patient with a ureteral stent could be a symptom of an infection related to the stent.

Lymphocele
The lymphatic system is a network of vessels that carry lymph throughout the body. Lymph is a clear fluid that carries white blood cells to fight infection and is involved in the immune system. During surgery, some of the lymph vessels in the abdomen are cut. There is a possibility that the cut lymphatic vessels will leak fluid and this fluid may collect around the new kidney. This fluid collection is called a lymphocele and occurs in about 10% of patients who have a kidney transplant. The lymphocele will usually go away on its own but sometimes this fluid collection will block the flow of blood or urine. If this happens, the lymphocele must be drained or the lymphatic vessel repaired through surgery.

Delayed Graft Function
Sometimes the transplanted kidney may not clean the blood or make urine immediately after transplant. This condition is called delayed graft function or acute tubular necrosis (ATN). Delayed graft function is a common complication following kidney transplant, particularly in deceased donor transplantation, and is usually reversible.

There are several reasons why the kidney may not work well in the early period after surgery. Delayed graft function can occur in deceased donor transplants when there is a prolonged “cold time.” Cold time starts when the kidney is removed from the donor and cooled with a solution to preserve the organ. It ends when the blood vessels of the donor kidney are connected to the recipient’s blood supply. Another reason for delayed graft function may be the effect of some transplant medications on the transplanted kidney. These medications will be adjusted to help the kidney heal. The quality of the donor kidney may also lead to delayed graft function.

As the kidney heals, kidney function will gradually improve. It can take a few hours to a few weeks for the transplanted kidney to begin to work well. Patients sometimes need dialysis during this time.
FEVER

What is fever?
Fever is an increase in body temperature that is above the normal body temperature of 98.6°F (F) or 37°C (C). Fever is not an illness, but is a symptom of an illness. Fever can be caused by a minor illness as well as a serious infection. Fever is usually defined as a body temperature greater than or equal to 101°F or 38.5°C.

If you are taking prednisone, your body may not be able to show a high fever, so even a low-grade fever, greater than 100°F or 38°C can be important. Discuss the fever temperature range with your doctor or transplant coordinator. Be sure you know what temperature is considered to be a fever for you.

Why would I get a fever?
In the general population, fever could be a symptom of a cold, the flu, or another type of infection. Now that you have had a kidney transplant, your immune system is suppressed so that your transplanted kidney will not be rejected. If you get a fever after kidney transplant, it could be from a community-acquired cold or flu. But fever after transplant can also be a symptom of rejection or a specific infection related to having a suppressed immune system. A fever in the early post-operative period can be an infection related to the surgery or procedures.

What should I do if I have a fever?
It is very important to call your doctor and/or transplant coordinator if you have a fever of 101°F/38.5°C or higher. Check with your transplant coordinator about your center’s guidelines on calling when you have fever. Be sure that you have a thermometer when you leave the hospital and that you are able to read it. Digital thermometers are available if you have trouble reading a glass thermometer.

If you have a fever, most transplant centers recommend that you:
• call your transplant coordinator or physician immediately if your fever is 101°F/38.4°C or greater.
• do not take any medications to treat your fever until told to do so

Depending on how high of a fever you have and other symptoms of your illness, you may be told to take acetaminophen (Tylenol®) or paracetamol. Be sure to take the recommended dose at the appropriate time interval, usually every 4 to 6 hours. You may also be instructed to have blood tests drawn or to go to your Transplant Clinic, physician’s office, or local Emergency Room for an examination.

Ibuprofen products (Motrin®, Advil®) are sometimes used to treat fever. These products should not be taken by kidney transplant recipients unless advised to do so by your doctor. Although ibuprofen can treat high fevers effectively, it can affect liver and kidney function. Ibuprofen can also cause stomach irritation, ulcers, and GI bleeding.
**Fever**

Kidney Handbook

**My responsibilities in monitoring for fever:**

- I must have a working thermometer that my caregiver or I can read before I leave the hospital.

- I should have a supply of acetaminophen (Tylenol®) or paracetamol to take for fever if I am instructed to do so.

- After I am discharged from the hospital, I should take my temperature every ________________

- I should call my transplant coordinator or primary doctor if my temperature is greater than or equal to _____° F or _____° C.

- If I am told to take acetaminophen (Tylenol®) or paracetamol my dose is:

  ___________mg or _____ tablets

  every ________ hours as needed

  for fever greater than or equal to __________.

  I should not take more than ______ doses in a 24 hour period.

- I should not take any ibuprofen products, such as Motrin® or Advil® unless instructed to do so by my doctor.
REJECTION

What is rejection?
Your body’s immune system is designed to seek and destroy any foreign object that it finds in your body, such as a cold virus, a flu virus, or a transplanted organ. The process of destroying the foreign object, the transplanted organ, is called rejection. Rejection occurs as your body’s immune system responds to the presence of the transplanted kidney. Rejection actually shows that your immune system is working. However, in transplant recipients, this immune response needs to be suppressed to protect the transplanted kidney.

There are several types of kidney rejection. These types are described by the kind of cells causing the rejection, when the rejection occurs, and by the severity of the rejection.

Hyperacute rejection occurs within minutes of the kidney transplant. It occurs when the recipient’s antibodies immediately recognize the kidney as foreign and attack it. An antibody is a protein produced by the immune system. Antibodies help the body fight organisms that are recognized as foreign, or not belonging to that body. Hyperacute rejection can not usually be treated and results in the loss of the kidney. A special test called a crossmatch is completed before kidney transplant to identify antibodies that could cause hyperacute rejection.

Accelerated acute rejection occurs within the first three to seven days after kidney transplant. It is caused by antibodies that may have been inactive at the time of transplant but get reactivated soon afterwards. This form of rejection is difficult to treat, but there have been recent improvements in treatments for this type of rejection. Patients with high antibody levels (high PRA) are at higher risk for developing accelerated acute rejection. Some transplant centers have special treatment protocols for patients with high antibody levels that are used before they receive a transplant.

The most common form of rejection is acute cellular rejection. In this type of rejection, the body’s blood cells identify the kidney as foreign and begin mounting an army of cells to attack the kidney. Although acute rejection can happen at any time, about 15 to 25% of kidney transplant recipients have at least one mild to moderate episode of acute rejection within the first three months after transplant. Acute rejection can be treated. Having acute rejection does not mean that you will lose your transplanted kidney, but it is very important that rejection is diagnosed and treated as soon as possible. To help detect rejection, you should have your blood tests completed routinely as requested by your transplant center, have routine follow-up visits with your doctor, and report any symptoms you are having to your transplant center.

If the rejection process does not completely resolve, or if it continues slowly over time, it is called chronic rejection. Chronic rejection is more difficult to treat because of more permanent changes in the kidney tissue.
How do I know I am rejecting my kidney?
An injury to the kidney could be caused by rejection, infection, or side effects of medications. Measuring the renal (kidney) function tests regularly and watching the pattern of the results can help your doctor decide what is happening to your kidney.

Your transplant doctor or nephrologist may suspect that you have rejection if any of these numbers are increased from the normal range.

Measurement ranges of blood tests vary by center. Adjust the normal ranges in the table below to your center’s guidelines. If your blood test results are out of the normal range, your transplant physician or transplant coordinator will discuss the results with you. Some abnormal lab values may be acceptable as you recover from transplant or a related complication and should improve over time.

(Lab values are US and UK measurements.)

<table>
<thead>
<tr>
<th>Test</th>
<th>Normal Adult Range (US)</th>
<th>Normal Adult Range (UK)</th>
<th>Indicates</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood urea nitrogen (BUN)</td>
<td>8-25 mg/dl</td>
<td>3.4-8 mmol/L</td>
<td>↑ rejection, kidney dysfunction, dehydration, high protein diet, side effect of prednisone or other medications ↓ liver disease; over-hydration, malnutrition</td>
</tr>
<tr>
<td>Creatinine (Cr)</td>
<td>Males: 0.6-1.3 mg/dl</td>
<td>134-146 mmol/L</td>
<td>↑ rejection, kidney dysfunction, side effect of some medications, dehydration ↓ muscle wasting</td>
</tr>
<tr>
<td></td>
<td>Females: 0.5-1.2 mg/dl</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What are the symptoms of rejection?
After you leave the hospital, your blood tests will be monitored less frequently. If rejection occurs, you may experience some mild symptoms, although some patients may continue to feel fine for a while. The most common early symptoms include:

- fever greater than 100° F or 38° C
- increased kidney function tests (BUN and creatinine)
- decreased urine output
- tenderness over the graft
- swelling of hands, eyelids, or lower extremities
- weight gain of 2-4 lbs (1-2 kgs) in 24 hours

Additionally, your doctor may want you to have a kidney biopsy to confirm that your symptoms are caused by rejection.

How is rejection treated?
Rejection does not mean that you will lose your kidney, but early diagnosis and treatment are very important to avoid complications.

Mild to moderate rejection is treated by increasing immunosuppression. The amount and/or frequency of your anti-rejection medications are usually increased. If you are taking prednisone, the dose may be increased. If you are not taking prednisone, it may be prescribed for a few
weeks to treat the rejection. Sometimes the IV form of prednisone is given for several days to treat rejection that does not resolve with oral prednisone. Another way to treat rejection is by adding or combining other anti-rejection medicines, such as mycophenolate mofetil, sirolimus, or azathioprine.

Severe rejection is treated as described above, but other agents that more strongly affect the immune system are used. The most common medications used for severe rejection of the kidney are OKT3 and antithymocyte globulin (ATG, Thymoglobulin®, Atgam®). These medications are given by IV in the hospital and patients are monitored closely to be sure that the rejection is resolving.

As rejection resolves and your kidney recovers, the doses of these additional anti-rejection medications may be decreased or stopped. The level of your primary anti-rejection medication, usually tacrolimus or cyclosporine, may be reduced. Your transplant team’s goal is to have you on the lowest amount of immunosuppression possible so that you do not reject your kidney and have good kidney function. Lower immunosuppression also contributes to a decreased risk of infection and other side effects from high levels of immunosuppressive medications.

Rejection of the kidney can usually be treated successfully if it is detected early. It is important to take all your medications exactly as prescribed to help avoid rejection.

What is a kidney biopsy?
Although your symptoms and kidney function test results help diagnose rejection, a kidney biopsy confirms that the kidney is being rejected. A small piece of kidney tissue is examined under a microscope for signs of rejection.

The biopsy procedure is usually done as an outpatient or short-stay hospital procedure. To prepare for the biopsy, the area where your kidney was placed will be cleaned with an antiseptic solution. You will be given an injection of a local anesthetic, or numbing medicine, into the area where the biopsy will be done. An ultrasound is usually done to determine the best place to insert the biopsy needle. After the area is numb, the doctor will advance a special needle into the kidney to take out a small piece of tissue. It may look like a short piece of string. The actual biopsy only takes a few seconds. The tissue is placed into a special solution and taken to the pathology lab to be processed and viewed under the microscope. Your biopsy results may be
ready later that day or within one to two days. You may be called or asked to return to clinic to discuss your biopsy results and any treatment that may be necessary.

Following a kidney biopsy, you will be required to rest in bed for two to four hours. Your nurse will monitor you for complications related to the biopsy through your vitals signs, physical assessment, blood tests, and/or any physical complaints. Your urine will be checked for the presence of blood (hematuria).

Most patients feel fine after a kidney biopsy. Sometimes the biopsy site may be a little tender, like a bruise, for a day or two. After biopsy, a small amount of blood in the urine is common, but it should not be extremely bloody or have any clots. Call your transplant center immediately if your urine becomes bloody or if you pass any clots in your urine.

Will I always have to be concerned about rejecting my kidney?
The risk of rejection decreases over time but rejection can occur at any time. Your doctor and transplant coordinator will discuss your biopsy results, medication changes, and/or treatment plan with you over the phone or in clinic. Good communication with your transplant team and following your care routine are key factors for a successful outcome after kidney transplant.

To decrease my risk for rejection and to monitor symptoms of rejection, I should:
- know and understand the signs and symptoms of kidney rejection
- take all my medications as prescribed
- make sure I always have a supply of my medications
- stay in regular contact with my transplant coordinator or transplant team for any changes in my immunosuppression
- have my blood testing done as instructed
- follow-up on my blood test results with my transplant coordinator
- call my transplant coordinator or physician if I think I am experiencing any symptoms of rejection
- avoid excessive alcohol, recreational/illegal drugs, and any herbal remedies or supplements
Infection

Why am I at risk for getting infections?
Kidney transplant recipients require anti-rejection medications to suppress their immune system so that the transplanted kidney is not rejected. Because the immune system is suppressed by these medications, transplant recipients are always at risk for infection. This risk is highest in the first three to six months after transplant. Infections can also occur when higher levels of immunosuppression are needed to treat rejection.

If you are doing well, have good kidney function, and have not had any episodes of rejection, your transplant doctor may slowly lower your level of immunosuppression after a few months. Using less immunosuppression, when possible, will help decrease your risk of infection.

How can I decrease my risk of infection?
There are many ways to stay healthy after transplant and avoid infections. The following guidelines are commonly recommended for transplant recipients. Discuss how you can prevent the risk of infection with your transplant team. Know your center’s specific guidelines.

Hand washing:
- Practice good hand washing techniques. Use warm water and soap, and scrub vigorously for 1 minute. Be sure to scrub between your fingers and under your nails as well.
- Wash your hands well before eating and preparing food, after going to the bathroom, after changing diapers, and after playing with pets.
- Encourage any family and friends who are in contact with you to practice good hand washing techniques.

Contacts:
- Wash your hands well before caring for any wounds or doing any dressing changes. Report any changes in the wound (increased redness, swelling, or drainage) to your transplant coordinator.
- Avoid putting your fingers or hands in or near your mouth, particularly if you have not washed your hands recently.
- Avoid close contact with people who have obvious illnesses such as colds and flu.
- Avoid crowds, particularly when in a closed area, during cold and flu season or when you are highly immunosuppressed.
- Do not share eating utensils, cups, and glasses with others since many viral illnesses are spread through saliva and mucous. Do not share razors or toothbrushes.
Pets:
• If you have pets, be sure that they are healthy and have had all recommended vaccines.
• Do not handle animal waste. Do not clean bird cages, fish or turtle tanks, or change cat litter.
• Some types of pets should be avoided such as reptiles, turtles, amphibians (frogs), hamsters, and guinea pigs. These animals can carry infections that could cause you to become ill. Some transplant centers also recommend that transplant recipients avoid having caged pet birds in their homes, such as parrots or parakeets.

Gardening:
• Wear gloves when working in the garden and in soil.
• Wash your hands frequently when gardening.
• Some transplant centers request that gardening be avoided for about three to six months after transplant until the immunosuppression level is lower.
• Avoid compost piles, wet leaves, and rotting organic matter. These materials can carry mold which can cause significant respiratory infections in immunosuppressed patients.

Swimming
• Kidney transplant recipients may swim in chlorinated pools after their incision and wounds are healed and all drainage tubes are removed.
• Small standing bodies of water such as ponds or small lakes that may contain infectious organisms should be avoided.
• Swimming in oceans or large lakes may be permitted at three to six months after transplant if the water is tested to be safe for the general population by the local health department.
• Public hot tubs should be avoided.

Sexual Activity
• Practice safe sex and use condoms.
What are some common signs of infection?

Some symptoms that may be related to infection include:
- body temperature greater than or equal to 101° F or 38.5 °C
- new onset of aches or pains
- uncomfortable or painful urination, cloudy or foul smelling urine, or an increase in frequency of urination
- nausea, vomiting, or diarrhea lasting more than 24 hours
- any flu-like symptoms such as cough, body aches or cold symptoms
- changes in wound appearance: increased drainage, redness, foul odor, and/or increasing pain over the site of the transplanted kidney

What infections are most common?

There are 3 types of organisms that cause infections: bacteria, fungus, and virus.

Bacterial Infections

Bacterial infections usually occur very early after transplant surgery and can be caused by central vein catheters, infections inside the abdomen, or wounds. Patients can develop pneumonia, particularly if they had complications during or early after surgery and had a prolonged stay in the intensive care unit. Urinary tract infections can occur from having a urinary catheter to drain urine.

If you have an infection caused by bacteria, your doctor will determine where the infection is and what type of bacteria is causing that infection. You will be given an antibiotic for several days to treat the bacterial infection. The antibiotic may be given through an IV or as an oral medication depending on the type and severity of the infection.

If you have been on peritoneal dialysis, your catheter may be left in place for several months after transplant. It is important to keep the peritoneal catheter exit site clean to avoid infection.

Fungal Infections

Fungal (yeast) infections are most common in the first three months after transplant. Candida albicans, a common fungal infection after transplant, looks like a white plaque or coating on the tongue and inside the mouth. This infection is also called thrush. It may make your mouth tender and sore and you might have difficulty swallowing. If thrush is not treated, it can spread to the esophagus, stomach, and intestines.
Fungus can cause vaginal infections (vaginitis) in women. The vaginal area may become very itchy and often produces a thick yellow or white discharge.

Transplant recipients who are highly immunosuppressed or taking high doses of prednisone are at risk for getting fungal infections. Fungal infections in the blood are rare and need to be treated with intravenous (IV) anti-fungal medications.

Most fungus infections are non-invasive, meaning that they do not get into the bloodstream. Fungal infections in the blood are rare and are treated with IV anti-fungal medications.

**Viral Infections**

**Cytomegalovirus (CMV)** is a common community-acquired virus and is not a serious illness for most people who are healthy. CMV is of more concern to people who are taking immunosuppressive medications.

CMV is a common infection that usually occurs within two to three months after transplant. Some patients are more at risk for CMV than others. The patients who are at highest risk are those who:
- are CMV-negative and have received a CMV-positive kidney or CMV-positive blood products
- have received high levels of immunosuppression
- have received OKT3 to treat rejection

Because CMV is such a common infection, transplant centers usually prescribe medication to prevent this infection, particularly in patients who are considered to be at high risk for getting the virus. Most CMV prevention plans include treatment with ganciclovir or valganciclovir (Valcyte®). Some centers continue preventative treatment for up to three months after transplant. Using these treatments to prevent CMV has decreased the rate of this infection. When possible, maintaining a lower level of immunosuppression will also decrease the risk of getting this virus.

Symptoms of CMV include fever, a low white blood cell count and a low platelet count. If CMV infects the lungs, common symptoms include fever, coughing, shortness of breath, or wheezing. If CMV develops in the gastrointestinal (GI) tract, it can cause diarrhea, nausea, vomiting, abdominal pain, and/or bloody stools. If CMV infects the liver, it causes hepatitis, with elevated liver function tests.
To check for a CMV infection, your doctor will complete a physical examination, obtain blood tests, ask you about your symptoms, and assess your risk factors for getting this virus. The diagnosis is confirmed through a special blood test called the CMV-PCR. This test detects CMV in your blood. Depending on symptoms, biopsies can also be taken of lung, liver, or intestine tissue to determine if the virus has infected that organ.

A CMV infection is treated with intravenous (IV) ganciclovir for 14 days or longer until the CMV-PCR shows that the virus has resolved. Some transplant centers prescribe 6 to 12 weeks of oral valganciclovir (Valcyte®) after the course of IV ganciclovir is completed. In some cases, immunosuppression may be lowered during the infection to help the immune system fight the virus.

EBV is usually a mild to moderate viral illness but in rare cases, can become a more serious condition. This form of EBV is called PTLD, or post-transplant lymphoproliferative disease. Tumor growth or lymphoma is seen with PTLD.

Patients who are at high risk of developing EBV-related complications are monitored closely through a blood test called the EBV-PCR. This blood test will be obtained regularly to check for EBV in the blood. Many transplant centers prescribe valganciclovir (Valcyte®) for three to six months after transplant for patients who are at high risk of developing an EBV infection.

Treatment for EBV and PTLD varies by transplant center, but usually includes decreasing immunosuppression and administering IV medications to help control the virus. Patients are monitored very closely during this time when their immunosuppression is decreased so that if they begin to reject, immunosuppression can be resumed or increased.
TRANSPLANT CLINIC

After discharge from the hospital, you will be followed as an outpatient at your center’s Transplant Clinic. Most patients are seen one to two times every week for up to a month, then less frequently as they improve and return home. Long-term patients who have good kidney function usually have check-ups once a year and labs every one to two months. Most transplant centers will continue to manage immunosuppression while the patient’s local physician and/or nephrologist will manage routine care. Some centers transfer all patient care to the local physician/nephrologist in the long term when the patient is doing well.

Clinic routines vary by center. Discuss the following questions with your coordinator before you leave the hospital.

• When is my first clinic appointment?
• Where is clinic?
• What should I bring with me to clinic?
  □ a list of my medications
  □ my medications
  □ my Kidney Handbook
  □ a record of my blood pressure measurements
  □ a record of my daily temperatures
  □ a record of my fluid intake by mouth
  □ a record of my urine output
  □ a record of my blood sugar
    (for patients with high blood sugar)
  □ a family member or caregiver
  □ ________________________________
  □ ________________________________

What is the usual Clinic routine?
What will happen in Clinic?
Every transplant center has a slightly different clinic routine. Patients are usually examined by a physician, blood tests are obtained, the plan of care is reviewed, and questions or concerns are discussed. For a typical transplant clinic appointment, you may be instructed to:
• report to the Transplant Clinic and register for your appointment
• have your blood tests drawn before taking your morning dose of tacrolimus, cyclosporine, or sirolimus
• have a physical examination by the transplant physician or another physician on the transplant team
• review your blood test results and medications with your physician
• meet with your transplant coordinator to:
  • review your medical care
  • answer questions or concerns
  • be aware of and understand any changes in your care or medications
  • get prescriptions or have any new medications or medication changes ordered
• schedule or report for any additional procedures or tests (biopsy, X-ray, etc.) that might be needed
• meet with other members of the transplant team as needed (social worker, clinical nurse specialist, dietician, pharmacist, physical therapist)
• attend support group meetings
VITAL SIGNS
When you leave the hospital, you may be asked to regularly check your temperature, pulse, and blood pressure - your vital signs. Understanding what each vital sign means and what your normal range is for each vital sign is important.

If you experience difficulty breathing or any chest pain or pressure, call Emergency Services (911 in the United States) and ask to be taken to the nearest Emergency Room. If you have these life-threatening symptoms, never try to drive yourself or have a caregiver take you to the hospital. You may require care as soon as possible and your caregiver may not be able to help you if he/she is driving. Always call Emergency Services in this case.

I should call ___________________ in the event of an emergency.

Blood pressure
Blood pressure is the measure of force in your arteries. It is a measure of two types of pressure, the systolic and the diastolic. The blood pressure measurement is written as two numbers, for example: 120/80. The systolic blood pressure is the “top number” of blood pressure measurement and measures the force of muscle contraction of the heart as blood is pumped out of the chambers of the heart. The diastolic blood pressure is the “bottom number” and is when the heart muscle is at rest between beats, expanding and filling with blood.

If you are asked to record your blood pressure, you and your caregiver will be taught how to take your blood pressure before you leave the hospital. Your center will provide you with a blood pressure cuff or instruct you on where you can purchase one. Cuffs may be manual (you pump them yourself) or digital (automatic). If you have a digital cuff, be sure to measure how accurate it is with the blood pressure cuff used by your nurse in the hospital or clinic. Accuracy varies in some of the digital pumps.

High blood pressure (hypertension) may occur early on after kidney transplant and is usually related to side effects of some medications or complications with the kidney transplant. It can usually be managed well with blood pressure medications and/or some adjustments in your diet, such as a low sodium diet.

What you should know about your blood pressure:
• A normal blood pressure for me ranges from a low of ________/_______ to a high of _______/_______.

• I should take my blood pressure ______ times every day and before I take blood pressure medicine. I will be taking my blood pressure at:
  • ____________________ AM
  • ____________________ PM
  • or as needed every ______ hours

• I should call my coordinator if my blood pressure is greater than ______/_______ or less than ______/_______.

• I should record my blood pressure as instructed and bring this record to clinic.
Temperature

Normal body temperature is 98.6°F or 37°C. If your temperature is rising, you may feel hot or cold, achy, and/or develop chills or sweat. Fever is an important symptom and can occur with rejection or infection.

What you should know about your temperature:

- How often should I take my temperature? ________________________________

- I should call my transplant coordinator or physician if my temperature is ______° F or ______° C or higher.

- If I am told to take acetaminophen (Tylenol®) or paracetamol my dose is:
  __________ mg or ____ tablets
  every ________ hours as needed
  for fever greater than or equal to ________.

  I should not take more than ________ doses in a 24 hour period.

- I should not take any ibuprofen products (Motrin®, Advil®) unless instructed to do so by my doctor.

Pulse

Your pulse is created by your heart beat. When you take your pulse, you are feeling the pressure of your blood in an artery from the beating of your heart. The pulse rate is the number of times your heart beats in a minute, for example 72 beats per minute (bpm). Your pulse can be felt in your wrist or neck. You can also listen to your pulse with a stethoscope over your heart. You may be advised to take your pulse when you take your blood pressure or if you feel like your heart is beating too fast or “racing.” You may also be asked to take your pulse if you are on certain heart medications that affect your heart rate.

What you should know about your pulse rate:

- My normal pulse when resting is: ________________________________.

- My normal pulse when active is: ________________________________.

- I should call my coordinator if my pulse is greater than ________ or less than ________.
Weight

You may be asked to weigh yourself daily or two to three times a week to monitor for weight gain or loss. Your weight will also be monitored at every clinic visit. When you are home, you should check your weight as often as instructed on the same scale at the same time each morning. After you go to the bathroom, but before you eat breakfast is a good time. You may be asked to record your weight so that your doctor can follow any changes in your weight. Gaining or losing weight, particularly if this happens suddenly, can be a sign of problems in your recovery. A sudden weight gain could mean that you are holding in (retaining) fluid. This could be a side effect of medications or a sign that your transplanted kidney is not working well. A sudden loss could mean you are dehydrated which can be harmful to your heart and kidney. Call your transplant coordinator with any sudden weight changes.

What you should know about your weight:

- My ideal body weight is _________ lbs/kg.
- My weight at discharge from the hospital is ____________ lbs/kg.
- I should call my doctor or transplant coordinator if I have a sudden weight gain of greater than ______ lbs/kg within ______ days.
Blood tests are done frequently after transplant while you are in the hospital to monitor your recovery and progress. As you improve, your blood tests will be checked less often. Your blood tests may be repeated more frequently if you have rejection, infection, recent changes in your medications, or have other complications.

When you return home, you will have your blood tests done locally. Depending on your transplant center, it may be your responsibility to arrange this. Your coordinator will advise you on where to go and how to have your results sent to the transplant center. You may also want to keep a record of your results to help follow your care.

What I should know about my blood tests:

- I will get my blood tests done every ______________________________
- When I am at the transplant center, where will I get my labs drawn? ________________
- When I am at home, where will I get my labs drawn? ________________
- My lab results should be faxed to: ________________________________
- Who should I call to be sure my lab results have been reviewed?
  ________________________________
- If a tacrolimus, sirolimus or cyclosporine level is being drawn, I should have my labs drawn one to two hours before taking the morning or evening dose. I should not be more than one hour late in taking my dose.
  ________________________________

• Special instructions about my labs:
  __________________________________________
  __________________________________________
  __________________________________________
Tests that Monitor Kidney Function and Electrolytes

These tests monitor kidney function and fluid balance. Rejection and anti-rejection medications can sometimes effect how well your transplanted kidney works, so it is important that kidney function tests are checked regularly. If your kidney is not working well, you may also have abnormal electrolyte levels. Your physician will treat any problems with adjustments in your immunosuppression and/or other medications to correct electrolyte imbalances.

Measurement ranges of blood tests vary by center. Adjust the normal ranges in the tables below to your center’s guidelines. If your blood test results are out of the normal range, your physician or transplant coordinator will discuss the results with you. Some abnormal lab values may be acceptable as you recover from transplant or a related complication and should improve over time.

(Lab values are US and UK measurements.)

To help you read the charts below:

↑ An arrow going up indicates that the lab value being discussed is increased, or greater than the desired level. For example, when discussing creatinine, “↑ rejection” means that if the creatinine level is high, the kidney may be rejecting.

↓ An arrow going down indicates that the lab value being discussed is decreased or less than the desired level. For example: when discussing creatinine, “↓ muscle wasting” means that when the creatinine level is low, there may be symptoms of muscle wasting.
## Blood Tests

<table>
<thead>
<tr>
<th>Test</th>
<th>Name</th>
<th>Result</th>
<th>Normal Range (US)</th>
<th>Normal Range (UK)</th>
</tr>
</thead>
</table>
| BUN, Urea| Blood urea nitrogen   | ↑ rejection, kidney dysfunction, dehydration, high protein diet, side effect of some anti-rejection medications  
↓ liver disease; over-hydration, malnutrition | 8-25 mg/dl        | 3.4-8 mmol/L      |
| Cr       | Creatinine            | ↑ dysfunction, side effect of some medications, dehydration  
↓ muscle wasting                                                                 | Males: 0.6-1.3 mg/dl  
Females: 0.5-1.2 mg/dl | 134-146 mmol/L |
| Alb      | Albumin (serum)       | ↓ malnutrition                                                        | 3.5-5. g/dl       | 9-40 u/l          |
| TP       | Total protein         | ↓ malnutrition, kidney dysfunction                                    | 6-8.4 g/dl        | 60-80 g/l         |
| Na       | Sodium                | ↓ side effect of diuretics; kidney dysfunction, side effect of other medications | 135-145 mEq/L     | 3.4-5.2 mmol/L    |
| K        | Potassium             | ↑ side effect of medications; kidney dysfunction  
↓ side effect of diuretics; decreased intake, vomiting                | 3.5-5.0 mEq/L      | 60-126 umol/L     
3.4-5.2 mmol/L |
| Phos     | Phosphorus            | ↑ kidney dysfunction, high doses of phosphorus supplementation  
↓ low phosphorus due to improved kidney function and hyperparathyroidism | 3.5-5.5 mg/dL     | 0.8-1.4 mmol/L (phosphate) |
| Mg       | Magnesium             | ↑ kidney dysfunction, high doses of magnesium supplements  
↓ diarrhea; side effect of medications                                | 1.8-3.0 mg/dl      | 0.70-0.95 mmol/L  |
| Glu      | Glucose               | ↑ diabetes, problems with the pancreas, side effect of some medications  
↓ occurs in liver disease or with thyroid problems, side effect of treatment for diabetes | 70-115 mg/dl (fasting) | 3.5-6.0 mmol/L    |
| Ca       | Calcium (total)       | ↑ high intake of calcium often caused by taking too many antacids; bone disorders, thyroid problems, excessive secretion of parathyroid hormone (hyperparathyroidism)  
↓ kidney dysfunction, over-hydration, problems with the pancreas, severe malnutrition | 8.5-10.5 mg/dl     | 2.10-2.60 mmol/L  |
Complete Blood Count (CBC) or Full Blood Count (FBC)

The Complete Blood Count (CBC) or Full Blood Count (FBC) will be monitored with your routine labs to check for infection, the effects of anti-rejection drugs, a low red blood cell count (anemia), and to make sure you have the normal range of each type of blood cell.

<table>
<thead>
<tr>
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<th>Name</th>
<th>Result</th>
<th>Normal Range (US)</th>
<th>Normal Range (UK)</th>
</tr>
</thead>
<tbody>
<tr>
<td>WBC</td>
<td>White blood cell count: cells that fight infection; also involved in the rejection process</td>
<td>↑ may indicate bacterial infections, side effect of high-dose prednisone ↓ may indicate viral infection; may be a side effect of some medications, stress</td>
<td>4.5-11 WBC/mm³ x 1000</td>
<td>4.0-10 x 10⁹</td>
</tr>
<tr>
<td>Hct</td>
<td>Hematocrit: measures the percentage of oxygen-containing RBCs</td>
<td>↑ may cause blood clotting ↓ indicates anemia; may be a sign of bleeding, iron deficiency, kidney dysfunction</td>
<td>Males: 40-54% Female: 37-47%</td>
<td>0.37-0.47</td>
</tr>
<tr>
<td>Hgb</td>
<td>Hemoglobin: the oxygen-containing part of the RBC</td>
<td>↑ may indicate dehydration or a blood disorder ↓ indicates anemia; may be a sign of bleeding, iron deficiency, kidney dysfunction</td>
<td>Males: 14-18 g/dl Female: 12-16 g/dl</td>
<td>Males: 14-18 g/dl Female: 12-16 g/dl</td>
</tr>
<tr>
<td>Plt</td>
<td>Platelets: component of blood that helps stop bleeding</td>
<td>↑ can make your blood “thick” and lead to clotting ↓ may be a sign of liver disease, bleeding, anemia, side effect of some medications</td>
<td>150,000-350,000</td>
<td>150,000-350,000</td>
</tr>
</tbody>
</table>
NUTRITION

A healthy diet is one that is made up of fruits, vegetables, whole grains, and low fat or fat free milk and milk products. It also includes lean meats, poultry (chicken, turkey), fish, eggs, nuts, and beans. A healthy diet should be low in saturated fats, trans fats, salt, added sugar, and cholesterol.

Good nutrition is an important part of a complete recovery following kidney transplant. As you recover, your body has increased nutritional needs for wound healing, to regain any weight you lost due to kidney disease and the stress of surgery, and to help your body fight infection. After kidney transplant, patients need a diet high in protein to rebuild muscle tissue and restore protein levels. Dietary requirements are different for everyone, so your dietician will meet with you after transplant to discuss your specific nutritional and caloric needs and any dietary restrictions you may have. Most patients will need to increase their calcium, phosphorus, magnesium and protein intake.

During the first few weeks after transplant, some patients have trouble eating due to loss of appetite, feeling full or nauseated, or because they have changes in taste. This is quite common and will resolve over time as patients recover and activity increases.

Here are some helpful hints if you are having trouble eating:

- If you have a poor appetite, try to eat several small meals a day, snack between meals on high calorie and high protein foods, and/or drink higher calorie liquids such as milk or juice rather than water. Your dietician can help you plan your meals and snacks.

- If you feel full or bloated, try to eat frequent small meals, avoid foods that may cause additional gas, eat foods that are high in carbohydrates and proteins rather than fats, or sip on fluids between meals instead of during meals.

- If you are nauseated, foods high in carbohydrates such as pasta, cereal, bread, pretzels, and fruit may help. Nausea may also be decreased by drinking ginger ale and lemon-lime sodas. Spicy and fatty foods should be avoided if you are nauseated. If you continue to have problems with nausea, your physician may order a medication to help decrease this feeling.

- If you are experiencing changes in taste, try using seasonings and spices to enhance the flavors of your food. Marinating meat, poultry, or fish can also be helpful. If you seem to always have a bad taste in your mouth, drinking cold fluids or sucking on hard candies may also help.
After a kidney transplant, most transplant recipients have few restrictions or limits in what they are allowed to eat, and many less restrictions than what they had with a renal failure diet before transplant. Your dietary guidelines are much the same as for any person who is trying to eat healthy. If you have other health problems, such as high blood sugar or high blood pressure, your transplant team will give you special instructions about your diet. Fad diets, diet supplements, and herbal products should be avoided.

The level of some anti-rejection medications is affected when taken with grapefruit or grapefruit juice. All transplant centers and pharmacists recommend that transplant recipients avoid all forms of grapefruit and any drinks that contain a significant amount of grapefruit juice if they are taking cyclosporine or tacrolimus.

While it is important to regain lost weight and rebuild your protein stores, your weight should stay within your appropriate weight range. Being overweight may contribute to other health complications such as heart disease and diabetes.

Patients often have high potassium levels in their blood following kidney transplant. An increased potassium level (hyperkalemia) could be due to anti-rejection medications or kidney dysfunction. High levels of potassium may cause the heart to beat irregularly. If your potassium level is high, it will be controlled by a medication called fludrocortisone (Florinef®). You may also be asked to limit or avoid high potassium-containing foods. Your dietician will advise you on how many servings of these foods you may have daily if your potassium level is high.

Some kidney transplant recipients have low levels of potassium, especially if they are taking diuretic medications (“water pills”) or sirolimus. Low potassium can cause heart palpitations. In this case, patients may be encouraged to increase their intake of high-potassium foods.

### High Potassium-Containing Foods

- apricots
- bananas
- cantaloupes
- dates
- dried fruits
- figs
- honeydew
- kiwi
- nectarines
- oranges
- prunes
- raisins
- artichokes
- beans
- brussels sprouts
- lentils
- peas
- potatoes
- pumpkin
- soybeans
- spinach
- squash
- tomatoes
- ketchup
- cocoa
- coffee
- nuts
- cereals with fruits and nuts
- salt substitute
After kidney transplant, some patients have low phosphorus levels. This is because the healthy transplanted kidney is able to get rid of extra phosphorus and may be over stimulated by parathyroid hormone. Patients with low phosphorus levels after transplant are encouraged to increase foods that are high in phosphorus. This can be confusing because it is the opposite recommendation from before transplant when phosphorus levels are high.

### High Phosphorus-Containing Foods

- Almonds
- Bran cereals
- Cheeses
- Chocolate
- Cottage cheese
- Cream soups
- Dark colas
- Dried beans and peas
- Hot dogs, sausages
- Ice cream
- Liver and organ meats
- Milk
- Peanut butter
- Pizza
- Whole grains
- Yogurt and puddings
ACTIVITY

Exercise
Exercise improves your overall health. It makes you feel better and can help control stress. Regular exercise can help you maintain a weight that is right for you. It can also help prevent bone disease (osteoporosis). Any physical activity that you can do is beneficial. Walking, swimming, riding a bicycle, lifting weights, playing golf or tennis, participating in yoga classes or even doing housework counts as exercise! Staying active is key to living a full and healthy life.

It is common to feel tired or weak as you recover from kidney transplant. If you have been sick or on dialysis for a long time before or after your transplant, you may have lost some muscle mass from being chronically ill. You may also find that your sleep pattern is disturbed. Regular exercise and good nutrition will get you back to a more active routine and help you eventually return to your home routine, work, or school.

Transplant recipients should discuss how to start an exercise program with their doctor and transplant team so that a safe exercise plan can be developed. It is important to talk with your transplant team about increasing your activity level and when to begin an exercise routine. Your team can help you develop a plan that is right for you. While you are in the hospital, you may receive physical therapy to help you regain strength and increase your activity level. Your physical therapist can help you organize and start a simple exercise routine.

For the first two to three months after transplant, you may be advised to avoid any strenuous activity, heavy lifting, or more intensive exercise programs. Check with your coordinator and physician for your center’s guidelines. The best activity in the first few weeks after transplant is walking. Most centers recommend that any activities or sports with a high risk of injury like football, wrestling, skiing, water skiing, or motorcycling, should be avoided for at least one year after transplant. Some centers restrict contact sports indefinitely.

To be healthy and fit is an important goal, but using common sense to reach this goal is just as important. Even months or years after your transplant, exercising when you are sick with a fever is not a good idea. If you ever experience any intense pain, chest pain, or shortness of breath while exercising, you should stop exercising immediately and seek medical attention or advice.
Returning to Work or School

Transplant recipients return to work or school at various times after recovery from transplant depending on the extent of their illness before transplant, recovery time, complications, and the type of work that is done. Most kidney transplant patients are ready to return to work or school within one to three months after transplant. When possible, it can be helpful to return to work or school on a part-time basis. You can gradually increase your hours as your energy and endurance improves. Discuss returning to work or school with your doctor and transplant coordinator. They can help you decide on the time that is best for you based on your workplace and responsibilities.

Driving

Most kidney transplant recipients can resume driving within four to six weeks after transplant, depending on their recovery period, complications, and medications. Reflexes and judgment may be affected from a prolonged hospitalization or from certain medications, so it is best to discuss this issue with your doctor and coordinator before getting behind the wheel. It is a good idea to practice driving in an open lot or away from other traffic for the first time as you get used to driving again. It may be helpful to have another licensed driver in the car with you for the first few times that you drive after transplant.

When driving or in a car, always wear a seat belt even if you still have an open wound. Padding your abdomen with a towel or small pillow will help cushion your abdomen from the seat belt. The seat belt will provide a safe restraint in case of an accident.
Sexual Activity

Sexual activity is an important part of adult life. Before transplant, many patients experience a decreased desire (libido) to have sex or are unable to have sex (impotence) because of health problems. After transplant, both men and women find that their desire and ability to have sex returns. Most transplant centers advise that patients wait for six to eight weeks before resuming sexual activity. How quickly you are ready to have sex after transplant depends on how you feel. Ask your transplant doctor or coordinator when it is medically safe for you to have sex. When you are ready to resume sexual activity, it may be helpful to discuss any concerns you may have with your partner.

Safe sex practices are important for everyone who is sexually active to avoid the risk of contracting sexually transmitted diseases (STD). Transplant recipients have an increased risk of getting a STD because their immune system is suppressed. Practicing safe sex is the best way to prevent STDs. Safe sex practices include:
- having sex with only one partner (a monogamous relationship)
- washing your genitals before and after sex
- always using latex condoms with spermicide
- avoiding sex with anyone who has sores, a rash, or a foul discharge from their genitals
- avoiding anal sex

There are some additional considerations for transplant recipients who have hepatitis B or hepatitis C. Sexual partners of patients who have hepatitis B may wish to be tested for the virus and should be vaccinated if they are not immune. Sexual transmission of hepatitis C is rare but can occur. Sexual partners may be tested for this virus. However, if you have been in a long-term monogamous sexual relationship and your partner/spouse does not have the virus, the risk of contracting the infection may be low. You may wish to talk to your transplant doctor or coordinator if you and your partner are considering whether or not to use condoms.
YOUR LIFESTYLE AFTER KIDNEY TRANSPLANT

Sun Exposure and Skin Cancer Screening

Transplant recipients have an increased risk of developing skin cancer. This risk is up to 65 times greater than in people who have not had a transplant. The medications that transplant recipients take to suppress their immune system cause this increased risk. Your chance of developing skin cancer is also related to how old you are at the time of transplant, the types of anti-rejection meds you have taken, how long you have taken anti-rejection medications, and the amount of immunosuppression you have received. Additional risk factors for skin cancer include having:

- fair or easily burned skin
- lots of freckling
- red or blonde hair
- blue, green or hazel eyes
- history of extensive sun exposure
- family history of skin cancer
- previous skin cancers

Almost all skin cancers can be cured if detected early. Transplant recipients should examine their skin every month. Look for any new or changing growths including pink patches or spots, scaly growths, bleeding spots, or changing moles. Your doctor should thoroughly examine your skin during your annual check-up or refer you to a dermatologist. If you are at high-risk for developing skin cancer, you may be asked to see a dermatologist regularly. Transplant recipients should always use a sun screen with a high sun protection factor (SPF) of at least 30 to protect their skin from light rays that are damaging to the skin. Sunscreen should be used on all exposed areas of skin. It is also important to wear sunglasses, a broad-rimmed hat, and protective clothing. Outdoor activities should be avoided or limited during the time when the sun’s rays are the strongest, between 10:00 AM and 4:00 PM. Transplant recipients should not use tanning booths.
Travel

As you recover and return to a more normal routine, you may consider traveling or going on a vacation. Check with your transplant coordinator for your center’s guidelines on traveling early on after your transplant. Some centers recommend waiting for 6 to 12 months before you take an extended vacation, particularly one that may be further away from major hospitals or transplant centers.

If you are planning a vacation, you may be advised to have your routine blood tests taken before you travel. Call your coordinator to review your medications, blood test results, or to discuss any specific care needs. If you are traveling to a different time zone, talk to your coordinator about how to adjust your medication times. Before you leave, be sure you know where the closest hospital and/or transplant center is located in case of an emergency. Take enough medication to last your entire trip plus some extra in case your trip is extended. If you are traveling by plane, pack your medications in a carry-on bag. Check with your airline to see if there are any restrictions in taking your medications on the plane.

Taking extra medications and packing them in a different bag may also be helpful should you or the airline misplace your luggage. Take your important phone numbers with you in case you need to call your transplant center while you are away. You may want to drink bottled water if you are traveling in areas where the sanitation is of concern.

Most transplant centers discourage travel to third world countries for patients who are immunosuppressed. The risk of acquiring infections in these areas is high and appropriate healthcare may not be available. Additionally, some foreign travel may require immunizations that are not safe for patients who are immunosuppressed, such as measles and smallpox. If you plan to travel in this type of area, please discuss this with your transplant doctor and coordinator so that you are fully informed of the risk. It would also be helpful to learn more about the health concerns in your desired area of travel through the Travelers’ Health website sponsored by the Centers for Disease Control at http://www.cdc.gov/travel/destinat.htm. This site discusses current illnesses and diseases occurring in that region, required vaccinations, health risks, and how to stay healthy during your visit.

Another helpful website on travel includes the Transportation Security Administration at www.tsa.gov. Click on Our Travelers, then Air Travel, then Travelers with Disabilities and Medical Conditions.
Safe Food Handling

Safe food handling is important for everyone. However, transplant recipients may be at an increased risk of getting a food-born illness because their immune system is suppressed. The following guidelines will help decrease your risk of getting an infection from food:

- Always follow the safety instructions on food packaging.
- Avoid raw or undercooked meat, fish (sushi, oysters), poultry, or eggs.
- Foods should be cooked thoroughly and served hot.
- Always check labels on meats, fish, and dairy products for freshness and “sell by” dates.
- Eat only pasteurized milk, cheese, and fruit juices.
- Store foods appropriately. Place foods in the refrigerator or freezer as soon as possible if they require cold storage.
- Wash your hands thoroughly with warm water and soap before and after preparing food and particularly after you touch raw meat, fish, or poultry.
- Wash all surfaces that come in contact with raw meat, fish, or poultry.
- Scrub all raw fruits and vegetables before cooking or eating them.
- Avoid eating from salad bars or buffets due to possible contamination by others and unsafe food temperatures.
- Do not eat food purchased from street vendors.

Drinking Water

It is safe for you to drink treated municipal tap water after your kidney transplant. If you live in an area that has well water, it is best to boil that water to a rapid boil for at least 1 minute before using it for drinking water. Well water should be tested by your local water authority every 6 to 12 months, even if you are not using it for drinking water. Some transplant centers advise transplant recipients to boil well water if they are using it for brushing teeth, washing fresh fruits and vegetables, or for making ice cubes or cold drinks. If you have any concerns about your drinking water, contact your local health department. They will be able to advise you about the safety of your water and the need for further testing.

Pets

Pets can be an important part of family life. Research has shown that pets help relieve stress and have positive physical and psychological benefits, as well as possibly improving our quality of life. One study has reported that older adults who had pets were better able to handle crisis situations.

Although animals do carry a number of diseases that can be transmitted to humans, few are life-threatening. If you follow some common-sense guidelines, your risk of acquiring an infection will be decreased.

- Wash your hands thoroughly after petting or playing with your pet, particularly before you eat, drink, or handle food.
- Be sure that your pet is healthy, has regular check-ups, and has received its required immunizations. If your pet is ill, have him examined by your veterinarian as soon as possible.
• Groom and/or bathe your pet regularly. If you have a cat, have your vet trim your cat’s claws regularly.
• If possible, avoid your pet’s bodily fluids (urine, feces, vomit). If your pet has an accident, ask someone else to clean the area. If you must clean the area, wear gloves and clean the area with a disinfectant. Wash your hands well after cleaning.
• Do not let your pet lick your face.
• If possible, have someone else change your cat’s litter box. The litter and liner should be replaced frequently. The litter box should be cleaned at least monthly with a disinfectant or boiling water. If you need to clean the litter box, wear a mask and disposable gloves.
• Avoid cleaning fish tanks. If you must clean your fish tank, wear disposable gloves.
• Contact your physician immediately if you are bitten by any animal.
• Avoid stray or sick animals and exotic animals.
• Some pets should be avoided by transplant recipients. The following animals are considered high-risk pets by the Centers for Disease Control for people who are immunosuppressed:
  • Reptiles, including lizards, snakes, and turtles
  • Baby chicks and ducklings
  • Exotic pets, including monkeys
  • Some transplant centers also restrict amphibians (frogs), hamsters, guinea pigs, and caged birds as pets in the home.

Plants and Gardening

Many centers recommend that transplant patients avoid exposure to live plants and soil for three to six months after transplant. If you have a cut on your skin while working in your garden, you are at greater risk of infection since many types of organisms grow in the soil. If you are a gardener, be sure to wear gloves whenever you are working in the soil. It is also helpful to wash your hands every so often while gardening. Avoid working around compost piles, wet leaves, and rotting organic matter when possible. These materials may contain mold which can cause significant respiratory infections in immunosuppressed patients. Check with your transplant coordinator for your center’s guidelines about gardening.
Routine Screenings and Examinations

When you return home, you will resume routine care with your local physician and other health professionals. Some transplant centers prefer to manage immunosuppression and any transplant-related care such as episodes of rejection, kidney biopsies, and transplant-related infections. Other centers will eventually transfer all care to the local physician and/or nephrologist. Check with your coordinator so you know whom to call when you have any signs or symptoms of illness. You may be told to see your local doctor first, then if necessary, return to your transplant center for further evaluation. Your local doctor may be asked to obtain certain tests and send the results to the transplant center.

Medic-Alert Identification

Many centers recommend that patients wear a Medic-Alert necklace or bracelet to be identified as a transplant recipient in case of an accident or if emergency care is required. Medic-Alert is a nonprofit membership organization in the United States that is recognized internationally. The organization’s goal is to protect and save lives by providing information during emergencies. These tags are recognized by emergency operations teams as they care for patients who are unable to communicate their health issues. Your coordinator can provide you with information about Medic-Alert or you can contact them at 1-800-432-5378 or through the website at http://www.Medicalert.org to become a member. As a member, you can order Medic-Alert tags and submit information about your kidney transplant, allergies, your current medications, and other health conditions that will be included in your file.
Your Local Primary Care Physician (PCP)

Your local physician may be an internal medicine physician (internist) or a nephrologist who will see you for routine medical care and follow the recommendations of the transplant center. This physician usually manages preventative healthcare, routine physical examinations, immunizations, and complications related to high blood pressure, diabetes, high cholesterol, or bone disease. You may be asked to see this physician within the first month of returning home.

Your transplant coordinator should have the contact information for your local physician before you leave the transplant center. The coordinator will forward information to your local physician about your transplant surgery, post-operative complications, and your current care. Your coordinator or physician will also inform your local physician about the role of the transplant center in your care and how the physicians can work cooperatively to be sure you do well. Your local physician plays an important role in examining you for any possible complications. Be sure to see this doctor regularly and have reports of your visits forwarded to your transplant coordinator.

Dental Care

Maintaining healthy teeth and gums is an important part of your care after kidney transplant. As in the general population, kidney transplant recipients can develop gum disease, tooth decay, mouth ulcers, dry mouth, and mouth infections. Some dental problems may be related to side effects of some of the medications you take after transplant. You can also develop infections more easily because your immune system is suppressed. Bacteria that are commonly in the mouth can cause infection.

It is important to visit your dentist and dental hygienist for regular check-ups and cleanings every six months. If you develop problems, you may need check-ups every three or four months. Examine your mouth regularly and call your physician and/or dentist if you have chipped or cracked teeth, tooth pain, swellings or sores in your mouth, red or swollen gums, bleeding, or white patches on your tongue or the lining of your mouth. Be sure to brush your teeth at least twice a day, particularly after meals and before going to sleep. Floss between your teeth daily to remove food particles and plaque.

If you are having your teeth cleaned or having a procedure that may injure your gums, some transplant centers recommend taking an antibiotic before the procedure to prevent infection. This is called prophylaxis, or preventative treatment. Your dentist will prescribe the appropriate antibiotic. Contact your transplant coordinator about your center’s protocol for infection prevention before dental procedures.
Eye Care

Eye and vision examinations are important for everyone. Vision screenings (checking how well you see) can be completed regularly by a health care professional to detect problems. The need for a dilated eye examination by an eye doctor (ophthalmologist) is usually determined by age or a specific eye problem. For this test, the eye doctor uses eye drops to temporarily enlarge the pupil (the black center) of the eye. When the pupil is enlarged, the eye doctor can see the inside of the eye more easily. The dilated eye examination can detect serious problems such as glaucoma, cataracts, diabetes, infection, and cancer.

Transplant recipients may have an increased risk of developing eye problems because their immune system is suppressed and as a side effect of some medications. Discuss the risk of developing eye problems with your transplant physician or transplant coordinator. Some transplant centers recommend ophthalmology exams every year for those at risk. You and your doctor should decide on the frequency of an examination by an eye doctor that best meets your needs as a transplant recipient. Diabetic patients should have a dilated eye examination with an eye doctor at least once a year.

The most common eye problems seen after transplant include cataracts, changes in the pressure of the eye (intraocular pressure) leading to glaucoma, scarring in the layer of blood vessels behind the retina, and damage to the small blood vessels in the retina due to diabetes (diabetic retinopathy). Eye infections have also been reported but are not as common now due to improved anti-rejection protocols and treatments to prevent infection.

Call your primary care physician and/or eye doctor if you have any symptoms of eye problems including:
- eye pain
- changes in vision such as blurring, double vision, or fading of colors
- flashes of light
- sensitivity to light
- seeing spots
- the appearance of dark spots in your vision
- distorted or wavy lines or edges of objects
- dry eyes with redness, itching, and/or burning

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- distorted or wavy lines or edges of objects
- dry eyes with redness, itching, and/or burning
GYNECOLOGICAL CARE

Gynecologic Examinations

Recommendations for routine gynecologic and breast examinations vary by country, so it is important that you follow your doctor's advice and guidelines. Many transplant centers advise their female transplant recipients who are 18 years of age or older and/or are sexually active have a gynecologic examination every year. This examination is the same as for the general population and should include a pelvic exam to detect any abnormalities of the uterus, a breast examination to evaluate changes in the breast tissue, and a Papanicolaou's smear (Pap smear) to detect any abnormalities of the cervix. Women ages 18-39 should have a professional breast exam every three years, or as needed, and should perform monthly breast self-examinations. Women 40 years of age and older should also have a yearly mammogram and perform monthly breast self-exams. Physicians may advise women who have a family history of breast cancer or other risks to have a mammogram before the age of 40, or more frequently.

Sexual and Reproductive Concerns

Fertility and libido
Fertility for both men and women may return quickly after kidney transplant. Studies report that regular menstrual cycles start within a few months to a year after transplant for most women. Many men who had difficulty with sexual activity before transplant report improvements in erections. It is common for men and women before transplant to have low levels of sexual activity because of their illness and low desire (libido). Although some differences are reported with the type of organ transplant, most men and women report an improvement in their desire for sexual activity and in their sexual functioning after they have recuperated from transplant.

There are many reasons why patients can have problems with sexual activity. Difficulties could be from complications related to their original disease, medications, or problems in their relationship with their partner. If you have any questions or concerns about resuming sexual activity, be sure to talk with your doctors.

Birth control and pregnancy
When you resume sexual activity after kidney transplant, an appropriate method of birth control should be used. Barrier methods (condoms, diaphragms, and spermicidal jellies) are most often advised. When one or more barrier methods are used, it is possible to prevent conception as well as provide protection from sexually transmitted diseases. Some transplant centers have approved the use of low-dose
oral contraception (“the pill”). However, oral contraceptive pills place the transplant recipient at greater risk for blood clots, high blood pressure, gastrointestinal (GI) problems, coronary artery disease, and depression. Cyclosporine levels may be higher in patients who take cyclosporine and oral contraception. Additionally, it is important to remember that the pill prevents pregnancy when taken correctly, but it does not protect against STDs.

Generally, becoming pregnant or fathering a child can be safe and successful for women and men who have received solid organ transplants. Pre-pregnancy counseling is important so that you can plan your pregnancy to achieve the best possible outcome for you and your baby. Most transplant centers advise that female transplant recipients wait one to two years following transplant to become pregnant. This allows for a reasonable amount of time to be sure that the transplanted organ is healthy and functioning well. Immunosuppression levels should be stable and at a maintenance level.

When considering pregnancy, female kidney transplant recipients should have:
• good function of the transplanted kidney with no recent episodes of rejection
• a stable level of immunosuppression
• normal blood pressure or well-controlled high blood pressure
• normal blood glucose levels or well-controlled diabetes
• overall good health

If you are thinking about getting pregnant after your kidney transplant, it is important to remember that each pregnancy has its own unique concerns and possible risks. There are many issues to consider about your current health, the function of your transplanted kidney, and your medications. Planning with a complete understanding of the issues and with appropriate medical care before, during, and after pregnancy can lead to the best outcome for you and your child.

Pregnancy outcomes of transplant recipients in the United States are being followed through the National Transplantation Pregnancy Registry (NTPR). You may contact the NTPR through the registry’s toll free number at 877-955-6877 to request additional information. Your transplant team can discuss the findings of this group in greater detail with you if you are considering becoming pregnant.

For more information about pregnancy, refer to Pregnancy and Parenthood After Transplant; What You Should Know. 2006. Published by the International Transplant Nurses Society. Available at: http://www.itns.org/education/patient-materials
Prostate screening

The prostate is a walnut-sized gland that is part of the male reproductive system. It is located in front of the rectum and below the bladder. The prostate makes the fluid that carries sperm. Prostate cancer is one of the most common forms of cancer in men. Although the cause of prostate cancer is not known, some risks have been identified. These include:

- **Age:** The risk of getting prostate cancer is greater as men get older.
- **Family history:** A man is more likely to develop prostate cancer if his father or brothers had prostate cancer.
- **Race:** Prostate cancer is more common in some racial and ethnic groups. It is more common in African American men than Caucasian men. Men of Hispanic, Asian, Native American, or Pacific Islander descent are less likely to develop prostate cancer than Caucasians.

A blood test called the prostate-specific antigen test (PSA) is used to screen for prostate cancer. This test measures the level of a substance (enzyme) produced by the prostate and checks whether or not this level is within the normal range. Another test used to screen for prostate cancer is the digital rectal examination (DRE). For this examination, the physician inserts a gloved lubricated finger gently into the rectum to feel the back of the prostate. The physician checks the size of the gland and feels for any irregularities.

The screening recommendations for prostate cancer based on scientific studies are unclear. Some physicians who support regular screening believe that the research shows that finding and treating prostate cancer early may save lives. These physicians recommend that all men who expect to live for at least 10 more years should be given the opportunity to have the PSA blood test and DRE every year, starting at age 50. Men who are African American or have a family history should be tested earlier. However, some physicians do not recommend regular screenings because they believe that finding and treating prostate cancer early may not save that person’s life. They believe that the side effects of treatment are worse than the possible benefits because most prostate cancers grow very slowly and may never affect the man’s life.

It is important that you discuss prostate screening with your physician. You should know your risk factors for prostate cancer and the pros and cons of screening to make the best decision for you.
**Colorectal Screening Tests**

Recommendations for colorectal screening vary by country, so it is important that you follow your doctor’s advice and guidelines. Colorectal screening (examination of the large intestine and rectum) is recommended for both men and women 50 years of age and older to detect signs of colorectal cancer. This cancer is an abnormal growth of tissue that occurs in the colon (large intestine) or rectum. It is the third most common cancer after prostate cancer and lung cancer in men. In women, it is the third most common cancer after breast cancer and lung cancer. Colorectal cancer is very treatable when diagnosed at an early stage. It can be prevented through regular screening tests that can find abnormal growths (*precancerous polyps*). These growths, or *polyps*, can be removed before they turn into cancer. Screening is important because polyps and colorectal cancer may not cause any symptoms, particularly in the early stages.

There are several tests or procedures used to screen for colorectal cancer. Your doctor will advise you about when you should be screened for colorectal cancer and which test or tests are right for you. In addition to routine screening, it is very important to tell your doctor about any changes in your stools or bowel routine including:

- an increased or decreased amount of stool
- a change in stool color
- a change in the firmness or texture of your stool (hard stools or liquid/watery stools)
- the appearance of blood

**Bone Density Screening**

Osteoporosis is a disease in which the bones become fragile and more likely to break or fracture. Most people think that osteoporosis occurs only in women, but men can develop this condition as well. Although any bone can be affected by osteoporosis, the bones of the hip, spine, and wrist are at greatest risk. Osteoporosis can progress painlessly until a bone breaks if not prevented or if left untreated.

Risks factors for developing osteoporosis include:

- **Age:** Your bones become weaker and less dense as you age.
- **Gender:** Women are more likely to develop osteoporosis because of the effects of menopause and because they have less bone tissue than men.
- **Family history:** Osteoporosis tends to run in families.
- **Race:** Caucasian and Asian women are at greater risk. Hispanic and African-American women have a lower risk.
- **Bone structure and weight:** Small framed women weighing less than 127 pounds/58 kilograms are at greater risk for osteoporosis.
- **Menopause:** Women lose up to 20% of their bone mass within the first five to seven years after menopause.
Routine Health Care

- **Lifestyle:** Smoking, high alcohol intake, not getting enough calcium in your diet, and not exercising or having an inactive lifestyle can contribute to osteoporosis.
- **Medications:** Certain medications, such as steroids, can increase the risk of osteoporosis.
- **Chronic disease:** Some long-term health conditions, such as chronic kidney disease and chronic liver disease, can increase the risk of osteoporosis.

Transplant recipients are at an increased risk for developing osteoporosis. Some anti-rejection medications can cause osteoporosis, particularly in the first 6 to 12 months after transplant when immunosuppressant levels are high. Prednisone, cyclosporine, and tacrolimus are all associated with osteoporosis. Your chance of developing osteoporosis depends on your general risk factors as well as the amount of immunosuppression and length of time you are prescribed high levels of these medicines.

There are several things you can do to prevent osteoporosis.
- **Eat a well-balanced diet that is rich in calcium and vitamin D.** Talk to your transplant dietician for advice on the amounts and types of foods that are right for you, particularly if you have additional health problems.
- **Be active!** Exercise daily and include aerobic and weight-bearing exercises in your routine.
- **Live a healthy lifestyle.** Do not smoke. Avoid alcohol or follow your transplant center’s guidelines on alcohol intake.
- **Ask your doctor about your need for having a bone mineral density (BMD) test.** Recommendations for having this test are based on your age, risk factors, and any recent fractures. A BMD measures the density of your bones, or bone mass, and is painless, safe, and noninvasive.
- **Medications may be helpful in some people.** Although osteoporosis cannot be cured, there are several types of medications that treat this condition.

Your doctor and transplant team will always monitor your immunosuppression levels and your risks for developing osteoporosis. In some cases, medications or dosage may be changed to decrease your risk. Never discontinue or change these medications on your own. Talk to your transplant team about your risks for developing osteoporosis after kidney transplant.

**Immunizations**

Immunizations are an important part of routine healthcare for everyone. Adult transplant recipients have usually received all required immunizations before transplant but infants and young children may not because of their age or being too ill. If a transplant recipient needs immunizations, there are some important exceptions. Transplant recipients can not receive immunizations that contain a live vaccine. Receiving a live vaccine may cause serious health complications because a transplant recipient is at an increased risk for developing osteoporosis. It is important to discuss these options with your transplant team.
recipient could develop the virus that he/she is being immunized against. This is because live vaccines contain a small amount of the live virus that is weakened.

There are several live vaccines. The most common live vaccines that immunosuppressed patients should never receive are:

- **oral polio** (Sabin): The oral polio (Sabin) vaccine contains a live but weakened form of the polio virus that is given to provide immunity against the polio virus (*poliomyelitis*). The Salk injection is an inactivated polio vaccine that contains “killed” polio virus. This “shot” form of the polio vaccine should be used in all immunosuppressed patients instead of the oral vaccine. This injection does not pose a risk to someone who is immunosuppressed. Some centers recommend that transplant recipients avoid contact with anyone who has had the oral polio vaccine for up to eight weeks since the virus might be shed in their stool and saliva. Transplant recipients who have infants should be sure that their child receives the Salk injection.

- **MMR** (measles, mumps, rubella): The MMR is a live vaccine given to children at 12 to 15 months of age and again at four to six years of age. As an adult, you should not need this vaccine. You do not need to avoid a child who has recently received the MMR.

- **Varivax®** (chickenpox or varicella vaccine): This is a live vaccine given to children at one year of age to immunize them against chickenpox (varicella). People who are immunosuppressed should not receive this vaccine. Some centers advise transplant recipients to avoid close contact with a child who has received the Varivax® injection. Check with your coordinator for your center’s guidelines.

The general public is advised to get a tetanus booster every 10 years. Transplant recipients may get the tetanus vaccine. If you get a dirty injury or cut or are bitten or scratched by an animal, you should get the tetanus vaccine.

**The Influenza Vaccine (“flu shot”)**

The flu shot or injection is an inactivated (killed) vaccine that contains three influenza strains (types) that are expected to be seen most often in that year. People who want to decrease their risk of getting the flu should get the flu shot. Older people, very young children, and people with certain health conditions are at high risk for becoming very sick with the flu.
Transplant recipients are usually advised to get the flu shot every year. Ask your transplant team for your center’s recommendations. The best time to get the vaccine is in October or November, although your doctor may advise you to get it earlier. It takes about 2 weeks for protection to develop in your body and this can last for almost a year. Most transplant centers recommend that caregivers and other people in the household who have close contact with the transplant recipient also get the flu vaccine.

People should not get the influenza vaccine if they have had:
- a severe allergic reaction to eggs
- an allergic reaction to the flu shot in the past
- Guillain-Barré Syndrome (a disease that results in muscle weakness and sometimes paralysis)

Check with your transplant team about getting the flu shot if you are within the first three months after transplant or if you have recently been treated for rejection. You should not get the influenza vaccine if you have a fever when you visit the doctor’s office for your shot. Be sure to reschedule an appointment to get the vaccine at a later date when you are feeling better.

A new form of the flu vaccine that is given as a nasal spray has been available since 2003 for use in healthy people, ages 5 through 49 years. Transplant recipients and people with suppressed immune systems can not get this form of the flu vaccine. The nasal spray flu vaccine contains weakened live influenza viruses instead of killed viruses. This live vaccine may place them at high risk for complications from the flu.

Smoking

Smoking is a risk to everyone’s health with both active and passive contact. Smoking can cause cancer, heart disease, and lung disease. Additionally, smokers may have prolonged respiratory infections because of the effect of smoke on the lungs. Transplant recipients who smoked before transplant are strongly encouraged to stop smoking. Since nicotine is broken down or metabolized by the liver, there is a possibility that some medications, particularly tacrolimus and cyclosporine, may not be metabolized well. Levels of these medications may be lower in smokers. Nicotine affects the small blood vessels of the body, including the kidneys and accelerates kidney disease. You should never risk losing your healthy kidney for cigarettes.

Your transplant coordinator or social worker can help you find local support groups to help you stop smoking. You can also contact the American Heart Association (http://www.Americanheart.org), American Lung Association (http://www2.lungusa.org), or the American Cancer Society (http://www.cancer.org) for additional information and support. If you are interested in using any medications to help you stop smoking, discuss this first with your coordinator to check on your center’s recommendations.
Alcohol

Alcohol is metabolized, or broken down, in the liver. Drinking any type of alcoholic beverages can harm your liver. Many of your medications are metabolized by the liver. Liver cells may be destroyed with the additional stress of breaking down alcohol as well as your medications.

If you have had a problem with alcohol in the past, this was probably discussed at your transplant evaluation. You may have had to attend counseling sessions or you may have been enrolled in a rehabilitation program before you received a kidney transplant. It is important that you continue counseling as you recover from transplant to avoid any possible complications from drinking alcohol. There are many ways your transplant team and local physicians can help you recover and continue to do well after transplant.

Recreational/Illegal Drug Use

Drugs such as marijuana, cocaine, LSD, and Ecstasy are toxic chemicals that are harmful to our bodies. These toxic drugs will harm the liver and interfere with the break down or metabolism of transplant medications. Additionally, marijuana is known to carry a mold or fungus called Aspergillus which can cause a serious, life-threatening illness in people who have a suppressed immune system.

The illegal use of drugs is not tolerated by any transplant center. If you have had problems with recreational/illegal drugs in the past or are concerned you may want to use them again, discuss this issue with your transplant coordinator, social worker, or counselor. Help is available through counseling and support programs.
Understanding Your Emotions After Transplant

The kidney transplant process can be a very difficult emotional experience. Some transplant recipients experience more emotional difficulties and stress before transplant when they are waiting for a kidney. Others have more stress after transplant as they learn to cope with the changes in their life. In the early months after transplant, transplant recipients can experience a variety of emotions including anger, frustration, guilt, and depression.

These feelings can affect you for different reasons and in different ways. What is emotional or stressful for you may not be as stressful for another person. Some common symptoms people experience when they are dealing with emotional problems may include:

• feeling sad, depressed, angry, anxious, or overwhelmed
• crying frequently or easily
• being unable to focus or concentrate
• not sleeping well, sleeping too much, or being unable to fall asleep
• mood changes
• changes in appetite

Feeling emotional can also be related to side effects of medications or even an underlying medical problem. Talk to your doctor and transplant team about how you feel. They will consider how you are feeling emotionally when reviewing your blood tests, medications, physical examination, and reports from procedures. It is always important to check for any medical problem that can affect how you feel.

You can also help yourself! It is important to develop strategies to deal with your emotions and feelings after transplant. Some things you can do to help yourself include:

• Exercise regularly and be as active as possible.
• Participate in social activities with friends and family at home and in your community.
• Eat a healthy diet.
• Establish a good sleeping routine. Take naps if needed and get adequate rest.
• Find a way to relax through music, social activities, arts and crafts, yoga, and/or meditation and deep breathing.
• Recognize and understand how you feel.
• Let your family and friends know that you need their support. Talk to them about how you feel. Talking or just spending time with them can be helpful.
• Talk to other transplant patients through support groups. Sometimes it is helpful to talk to other people who have shared the same experience.
• Talking to a professional counselor may also be helpful. Your transplant team can refer you to someone who can help.
Kidney Handbook

Pancreas-kidney Transplant

A GUIDE TO YOUR HEALTHCARE AFTER PANCREAS TRANSPLANT

Your care after a simultaneous pancreas-kidney (SPK) or pancreas-after-kidney (PAK) transplant is generally the same as care following a kidney transplant, but there are some important differences. This section of the Kidney Handbook will discuss these differences.

Why is the pancreas important?

The pancreas lies below the stomach and above the intestine. It makes digestive juices (pancreatic enzymes) and insulin.

Most of the food we eat is broken down by the digestive juices into glucose, a simple sugar. Glucose is the body's main source of fuel. After digestion, glucose passes into the blood stream, where it can be used as fuel for growth and energy. It cannot do this without insulin. Your body must have insulin to use glucose.

When you eat, your pancreas is supposed to send out the right amount of insulin to move glucose from your blood into your cells. Sometimes the pancreas does not produce insulin in the right amount. This condition is called Type I diabetes. Because there is not enough insulin, glucose cannot get into the cells. This causes glucose to build up in the blood, leaving the cells starving for fuel.

People who have Type 1 diabetes must inject insulin into their body daily to make sure the cells get the energy they need. Type 1 diabetics must also control their diet and test their blood glucose level several times a day. Sometimes people with Type 1 diabetes need a pancreas transplant.
How will a simultaneous pancreas-kidney transplant help me?

An SPK transplant corrects two problems at the same time. The transplanted kidney will filter toxins or waste products out of your body and help maintain fluid and electrolyte balance. The transplanted pancreas will produce the right amount of insulin that your body needs. A successful SPK transplant will eliminate the need for dialysis and daily insulin shots. Many patients report that their quality of life is much better after SPK transplant even though they are now transplant recipients and have a suppressed immune system.

SPK transplantation is an operation that can significantly improve your quality of life. However, if either your transplanted pancreas or kidney fails, you can return to your previous treatment for diabetes and kidney failure. You may be able to have another transplant in the future.

Where are the transplanted kidney and pancreas placed in the body?

The transplanted pancreas is placed in the mid-right side of the abdomen. The native pancreas is not removed and will continue to produce enzymes. The transplanted kidney is usually positioned in the left lower abdomen. Both organs are placed through a single mid-line abdominal incision.

How does the transplanted pancreas drain enzymes?

In addition to making insulin, the pancreas makes enzymes (amylase and lipase) that help digest food. There are two ways that the transplanted pancreas can be connected to drain these digestive enzymes. The enzymes can drain into the intestine, which is called enteric drainage, or into the urinary bladder.

**Enteric drainage:** Draining the pancreas enzymes into the intestine is the most common surgical technique for pancreas transplant. This drainage method is similar to your natural anatomy. Amylase and lipase, the pancreatic enzymes, are drained through the intestine and are passed with stool. The advantages of enteric drainage include:

- fewer complications related to electrolyte and fluid imbalance
- a lower incidence of pancreatitis, an inflammation of the pancreas
- fewer complications of the urinary tract
Pancreas-kidney Transplant

Disadvantages of enteric drainage are that it is more difficult to monitor for rejection of the pancreas and there is a greater risk for leaks at the connection site. If the connection site of the pancreas to the intestine does not heal properly, a leak may develop. This is called an anastomotic leak and can occur within the first six months after transplant. If there is a leak at this site, intestinal contents can flow into the abdomen and cause infection. This is a rare complication, but it can be life-threatening. Symptoms include fever, abdominal pain, and a high white blood cell count.

If a leak occurs, surgery is needed to repair the leak. If the leak can not be repaired, the transplanted pancreas will be removed. In the event that the pancreas is removed, the patient will need to resume insulin injections to control blood glucose levels. The infection caused by the leakage of fluid into the abdomen is treated with intravenous (IV) antibiotics.

It is always important to report fever and any new or worsening abdominal pain to the transplant team immediately.

Bladder drainage: In this method of pancreas drainage, the pancreas is attached to the urinary bladder. The digestive enzymes drain into the bladder and then pass out of the body in urine. It is easy to monitor for rejection with this type of drainage. However, pancreas recipients with bladder drainage may have frequent urinary tract infections and can become dehydrated easily.

Because digestive enzymes are draining into the bladder with urine, the urine will not have its usual appearance. It may look cloudy and appear thick or stringy and contain small particles. It is important to tell your doctor about any change in the appearance of your urine.

Urine leaks can occur in patients with bladder drainage. The most common symptom is abdominal pain. Amylase levels in the blood increase. If a urinary catheter is placed and the pain is relieved, it is probably a urine leak. If the pain is not relieved, the symptoms may be related to rejection. A CT scan will confirm the diagnosis of a urine leak.

Some patients with bladder drainage may have complications due to the presence of digestive enzymes in the bladder and because the enzymes are passing out of the body. Complications may include:

- Increased risk of dehydration. Patients with bladder drainage may lose a quart/liter or more of pancreas fluid every day. The digestive enzymes contain bicarbonate. Because these enzymes are being drained into the bladder, bicarbonate will be lost through urine. This leads to dehydration. To avoid becoming dehydrated, patients are advised to drink 3 to 4 quarts/liters of liquid every day. Bicarbonate supplements may also be prescribed. Patients who become severely dehydrated may need to return to the hospital for IV fluids.
• Urinary tract (urologic) complications
• Urinary tract infections (UTI) are more common with bladder drainage
• Cystitis or urethritis is an irritation of the bladder or urethra, the tube draining urine from the bladder out of the body. This is caused by the effect of the digestive enzymes on the lining of the urinary tract. Urethritis is more common in men.
• Blood in the urine, or hematuria, can be significant and should be reported immediately.

• If you have a bladder-drained pancreas and cannot urinate, contact your transplant team or doctor immediately. This is considered an emergency situation. Your physician will place a catheter into your bladder to drain your urine.

• Perineal excoriation. In females, the skin around the urethra, vagina and rectum may become irritated by the digestive enzymes and break down. Vaginal yeast infections may develop and worsen skin breakdown.

• Graft pancreatitis. This is an inflammation of the transplanted pancreas that is caused by the surgery itself or urine backing up into the pancreas. It is often associated with a bladder infection. Symptoms include: moderate to severe pain over the transplanted pancreas, elevated amylase levels in the blood and urine, and elevated glucose levels. Patients who have pancreatitis are usually made NPO (nothing by mouth). Being NPO allows the pancreas to “rest” because it is not being stimulated to produce digestive juices. During this time, nutrition is provided through an intravenous (IV) solution called total parenteral nutrition (TPN) until the episode of pancreatitis resolves and the patient can resume eating.

Perineal excoriation and graft pancreatitis are treated by placing a catheter into the bladder to manage the flow of fluid until the problem resolves. If these complications become unmanageable or more serious, the surgeon may recommend surgery to reconnect the pancreas to the intestine.

The risk of developing these complications can be decreased by keeping your bladder empty. You should empty your bladder completely every two to four hours during the day. Double voiding is a helpful technique to empty your bladder completely. This is done by urinating, then waiting five to ten minutes, followed by voiding again. Prevention of these complications of bladder drainage is the best treatment.

**Will I still need to monitor my glucose levels after SPK?**

Just as your transplanted kidney should begin to make urine right away, your transplanted pancreas will begin making insulin. You will most likely have normal blood glucose levels soon after surgery. However, many transplant centers use a continuous infusion of insulin through an IV for the first few days after transplant. This does not mean that the pancreas is not working, but that it is being spared from working too hard in the early days after transplant. Giving IV insulin during this time is associated with fewer postoperative complications.

Some patients may need to take insulin for a short time after SPK transplant. To make
sure your pancreas is working well, you will be asked to continue to monitor your blood glucose levels, although not as frequently. Most transplant centers provide a glucose monitoring program for patients to follow and guidelines for contacting the physician or transplant coordinator.

**Immunosuppression for SPK transplant**

Taking medications to suppress your immune system is as important after a SPK transplant as after a kidney-only transplant. Your body recognizes the transplanted kidney and pancreas as foreign objects and tries to reject them. To prevent rejection, you must take your immunosuppressant medications daily as prescribed.

The anti-rejection medications taken after a SPK transplant are similar to those taken after a kidney-only transplant. Most transplant centers have combination protocols used tacrolimus or cyclosporine, plus mycophenolate mofetil or sirolimus, with or without prednisone. This combination therapy has improved survival of the transplanted organs and has greatly reduced the rate of rejection. *Induction* therapy (immunosuppression given before transplant surgery to “pre-treat” the immune system) with antibodies has been used in some centers. This treatment has helped achieve excellent long-term function of the transplanted pancreas, although rejection is still seen.

See the medication section of this handbook for more detailed information about these immunosuppressive medications.

**Rejection after SPK transplant**

Rejection is always possible after a SPK transplant, just as it is after a kidney-only transplant. If rejection occurs, the pancreas and kidney usually reject at the same time.

Symptoms of pancreas rejection include:
- increased levels of amylase and lipase in the blood
- decreased amylase levels in the urine
- pain in the upper right side of the abdomen
- increased blood glucose (a late sign of rejection)

See page 36 of this handbook to review the symptoms of kidney rejection.

Rejection is diagnosed through a kidney biopsy in patients with SPK. This is because rejection of both organs happens at the same time and the kidney is easier to access than the pancreas. Also, obtaining a biopsy of the pancreas poses a risk for puncturing the intestine since it is often wrapped around the pancreas. Treatment varies by transplant center but usually includes increased levels of immunosuppression, steroids, and/or antibody therapy. Treatment is usually successful with early diagnosis.
As a SPK recipient, you may have a higher risk of early rejection than a kidney-only recipient would have and most episodes of early rejection are able to be treated. Taking your medications as prescribed, reporting any symptoms or problems, and having your blood tests obtained as requested will lead to a better outcome.

Infection after SPK transplant

Infection is always a risk when you are immunosuppressed. If you are taking higher doses of immunosuppression to prevent rejection, you will need to be careful to avoid infection. Good hand washing and avoiding people who are ill will help. The infections most commonly seen following SPK are the same as for kidney-only transplant. You can read about these infections in the Complications section of this handbook.

Nutrition

Although it is important to eat healthy after SPK, you will probably be able to be a little more relaxed about your diet. Pancreas transplant recipients are asked to follow a low-fat and low-sugar diet. A healthy diet is important for preventing many diseases, not just for controlling diabetes, so follow your transplant team’s instructions carefully.

Foot Care

Even though the transplanted healthy pancreas may keep your blood glucose levels within a normal range, studies show that SPK recipients are still at risk for foot complications, including infection. Follow these guidelines to continue to take good care of your feet after SPK:

- Wash your feet every day and dry them thoroughly, especially between the toes.
- Examine your feet carefully every day for cuts, scratches, blisters, ingrown toenails, puncture wounds, or warts. Call your doctor if you have any of these problems.
- Call your doctor if you notice any signs of infection, burning, tingling, or numbness in your feet.
- Do not try to remove or treat corns or calluses by yourself. Make an appointment with a podiatrist or your doctor to have them removed.
- Wear comfortable, well-cushioned shoes. Do not wear high heels and do not walk barefoot.
- Wear clean cotton socks to absorb moisture. Be sure to change your socks every day.
GLOSSARY OF TERMS

A

ABO testing  Blood tests that classify human blood into one of four groups: A, B, O or AB.

Acute tubular necrosis (ATN)  Reversible tissue damage of the kidney that results in delayed graft function. Prolonged organ storage and some anti-rejection medications can cause ATN.

albumin  A protein made by the liver that helps maintain fluid balance in the body. It is an indication of nutritional status.

allograft  An organ or tissue transplanted from one person to another person; also called a graft.

amylase  A digestive enzyme that is produced by the pancreas.

anemia  A decreased amount of circulating red blood cells in the body. Anemia may result from blood loss, destruction of red blood cells, or a decrease in the production of red blood cells. The hemoglobin and hematocrit levels are decreased in patients with anemia.

antibody  A protein produced by the immune system in response to specific antigens. Antibodies help the body fight foreign substances and organisms that cause infection.

antigen  A substance, usually found on the surface of cells, that identifies the cell as “self” or “non-self.” The antigen causes an immune response through antibody production against the antigen.

B

B cells  A type of lymphocyte, or white blood cell, that develops in the spleen; responsible for the body’s immunity. B cells produce antibodies which help fight infection and foreign substances.

biopsy  A procedure that provides a small amount of tissue from an organ, tumor, bone, or other body tissue to find out more information about that organ or tissue. A core needle biopsy is usually performed to examine kidney tissue. A tiny cylinder of tissue, showing kidney cells and how they are arranged, is removed through puncture with this needle. This tissue is examined under the microscope by a pathologist.
to determine the cause of kidney dysfunction. It is used to find evidence of rejection, infection, or medication effects.

| **bladder** | A sac-like structure that receives urine from the kidneys and stores it until urination occurs. |
| **blood urea nitrogen (BUN)** | A test that indicates kidney function. The BUN is a product of protein breakdown, or waste product, normally excreted by the kidney. |

| **C** |
| **calcium** | A mineral measured in the blood that is required for bone growth and for blood clotting. It is also needed for the heart and nerves to function properly. |
| **catheter** | A flexible tube that enters or exits the body. Catheters may be used to drain body fluids (a urinary catheter drains urine) or to administer fluids or medications through a vein (a central venous catheter). |
| **chronic** | Having a disease for a long period of time. Chronic disease may worsen slowly over time. It may be treatable but is usually not reversible. |
| **chronic kidney disease** | Permanent irreversible damage to the kidneys that is treated with dialysis or transplantation. |
| **complete blood count (CBC)/ full blood count (FBC)** | A blood test that measures many parts of your blood count including the hemoglobin (Hgb), hematocrit (Hct), platelets (Plt), and the types of white blood cells (WBC). |
| **creatinine** | The creatinine level is an indication of kidney function. It is a waste product produced by the muscles and released into the blood stream. Creatinine levels may be increased with kidney disease. Abnormal creatinine levels are also seen in patients with kidney dysfunction caused by other illnesses or medications. A creatinine clearance is obtained to get a more accurate measure of kidney function. This test does not rely on muscle mass. Urine is collected for 12-24 hours instead of blood to measure the creatinine level. |
| **crossmatch** | A test that examines the compatibility of the transplant recipient's blood with that of the donor. A high positive crossmatch may indicate the need for higher levels of immunosuppression for the kidney recipient. A negative crossmatch means that there is no reaction between the donor and recipient. |
### Glossary

<table>
<thead>
<tr>
<th>term</th>
<th>definition</th>
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</thead>
<tbody>
<tr>
<td>cytomegalovirus</td>
<td>CMV; a virus commonly seen following transplantation that can cause an infection in the gastrointestinal tract, blood, liver, kidneys, lungs, and/or eyes. CMV is a type of herpes virus.</td>
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<tr>
<td>diabetes</td>
<td>A disease originating in the pancreas related to insulin production and/or the body’s resistance to insulin that causes high levels of glucose (sugar) in the blood.</td>
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<tr>
<td>dialysis</td>
<td>A procedure to remove waste products from the blood in patients with kidney disease.</td>
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<tr>
<td>diastolic</td>
<td>The “bottom number” of blood pressure measurement when the heart muscle is at rest, expanding and filling with blood.</td>
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<tr>
<td>diuretic</td>
<td>A medicine that helps remove excess fluid from the body tissue by causing the body to excrete sodium. Furosemide (Lasix®) and spironolactone (Aldactone®) are diuretics. These medications will increase urine output.</td>
</tr>
<tr>
<td>edema</td>
<td>Swelling of tissue, particularly in the face, hands, legs, and ankles. Diuretics may help to decrease edema.</td>
</tr>
<tr>
<td>electrolytes</td>
<td>The dissolved form of a mineral found in the blood that helps maintain bodily functions and fluid balance. Sodium, potassium, chloride, magnesium, calcium, and phosphorus are some of the electrolytes found in your body.</td>
</tr>
<tr>
<td>electrocardiogram</td>
<td>A noninvasive test that records the electrical activity of the heart. Following a heart attack, an EKG can show signs of heart damage. It can also show irregular heart rhythms.</td>
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<tr>
<td>EKG/ECG</td>
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<tr>
<td>enzyme</td>
<td>A protein made in the body that is capable of changing a substance from one form to another. The ALT and AST are enzymes found in liver cells.</td>
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</tbody>
</table>
Epstein Barr Virus (EBV)  A virus of the herpes family that causes mononucleosis. Symptoms of infectious mononucleosis are fever, sore throat, swollen lymph glands, an enlarged spleen, and/or hepatitis. EBV is associated with post transplant lymphoproliferative disorder (PTLD) in transplant recipients. Transplant recipients are at risk for EBV and PTLD if they have had high levels of immunosuppression.

gingival hypertrophy  Swelling or enlargement of the gums. Gingival hypertrophy is a side effect of cyclosporine and some seizure medications. Gum overgrowth may be controlled or decreased through good oral hygiene, surgical gum reduction, and changes in immunosuppression.

glucose  A type of sugar in the blood that supplies energy to the cell. Glucose levels may vary with diet, medications, stress, and organ dysfunction.

graft  An organ or tissue that is taken from one person and placed into another (transplantation). A graft between humans or the same species with different genetic material is called an allograft. A graft between different species, such as a baboon to human, is called a xenograft.

hematocrit  A measurement of the amount of red blood cells in the blood.

hematoma  A bruise; swelling caused by the accumulation of blood in tissue.

hemoglobin  A substance in red blood cells that gives blood its characteristic red color; contains iron and protein. Hemoglobin carries oxygen from the lungs to the tissues and carbon dioxide from the tissues to the lungs.

herpes  A family of viruses that cause infection in humans.

hirsutism  Excessive hair growth. Hirsutism is a common side effect of cyclosporine and is seen in both male and female transplant recipients who receive cyclosporine. In women, increased hair growth is often seen as male-patterned growth.
<table>
<thead>
<tr>
<th><strong>Human Leukocyte Antigen (HLA)</strong></th>
<th>Molecules that are found on most cells of the body that characterize each individual as unique. These antigens are inherited from your parents. HLA determines the compatibility of tissues for transplantation from one individual to another.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>hyperlipidemia</strong></td>
<td>A high level of fats (cholesterol, triglycerides, LDL, HDL) in the blood; can be caused by diet, genetic disorders, or medications.</td>
</tr>
<tr>
<td><strong>hypertension</strong></td>
<td>High blood pressure.</td>
</tr>
</tbody>
</table>

<p>| <strong>immune system</strong>               | A specialized system of cells and proteins that protect the body from organisms that may cause infection or disease. |
| <strong>immunity</strong>                    | The ability of the body to resist a specific disease.                                           |
| <strong>immunization</strong>                | Providing the body with protection from certain diseases through vaccinations.                  |
| <strong>immunosuppressed</strong>            | Describes the immune system of a transplant recipient which is weakened or inhibited by certain medications. Specific medications (such as cyclosporine, tacrolimus, sirolimus, mycophenolate, and prednisone) are used to lower the ability of the immune system to attack foreign cells (the transplanted tissue). Immunosuppression will help decrease the body’s ability to reject the transplanted organ. |
| <strong>infection</strong>                   | Organisms such as bacteria, fungi, and viruses that invade the body and reproduce, causing a variety of symptoms. |
| <strong>insulin</strong>                     | A hormone secreted in the pancreas by the Islets of Langerhans that regulates sugar metabolism. Insulin helps the body use sugar and other carbohydrates. As insulin is released in the body, the blood glucose level decreases. |
| <strong>intravenous (IV)</strong>            | Within the blood stream; fluids and medications may be given intravenously as well as by mouth (PO). |
| <strong>lymphocele</strong>                  | A collection of lymph fluid that may collect near the kidney after transplant surgery. It collects because of leakage from the lymph vessels that are cut during the surgery. |</p>
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>lymphocytes</td>
<td>Cells produced by the lymph glands that are responsible for immunity and defend the body against infection and foreign substances by producing antibodies and other substances.</td>
</tr>
<tr>
<td>magnesium</td>
<td>A mineral required for normal bodily function. Magnesium is involved in nerve, skeletal muscle, heart, and cell function. It is also involved in blood clotting and the metabolism of carbohydrates and proteins.</td>
</tr>
<tr>
<td>nephrologist</td>
<td>A medical doctor who specializes in the diagnoses, treatment, and management of kidney diseases.</td>
</tr>
<tr>
<td>nephrotoxicity</td>
<td>Kidney damage, usually as a result of medications or other substances.</td>
</tr>
<tr>
<td>nonadherence</td>
<td>Failure to follow instructions for medical care after transplantation. This may include not taking medications as prescribed, not obtaining labs as instructed, or missing clinic appointments and tests. Nonadherence is a significant post-transplant issue that often results in rejection, infection, an ultimately loss of the graft.</td>
</tr>
<tr>
<td>pancreatitis</td>
<td>Inflammation of the pancreas.</td>
</tr>
<tr>
<td>panel reactive antibody (PRA)</td>
<td>The percentage of cells from a panel of donors to which a potential recipient’s blood reacts. The more antibodies in the recipient’s blood, the higher the PRA. The higher the PRA, the less chance there is of obtaining a negative crossmatch.</td>
</tr>
<tr>
<td>platelet</td>
<td>A type of blood cell that is involved in the clotting process. Platelets help stop bleeding at the site of the injury by clumping and forming a clot. If the platelet count is low, there is an increased risk of bleeding.</td>
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<tr>
<td>Pneumocystis jerovecti pneumonia (PJP)</td>
<td>A bacterial infection of the lungs that is more common in immunosuppressed patients. Transplant recipients are usually prescribed an antibiotic (TMP/SMZ, Bactrim® or Septra®) to prevent this type of pneumonia.</td>
</tr>
</tbody>
</table>
### Kidney Handbook

**PTLD**
Post-transplant lymphoproliferative disease; a wide spectrum of viral disorders associated with the Epstein Barr Virus (EBV) that may range from a self-limiting mononucleosis ("mono", glandular fever) to a type of lymphoma, or cancer of the lymph nodes. PTLD is a complication of a suppressed immune system and occurs in only a small percentage of patients. Treatment includes lowering immunosuppression and administering antiviral medications.

**potassium**
A mineral required for normal body functioning. Potassium is important in helping the heart, nerves, and muscles function properly. Potassium also helps change carbohydrates into energy and in forming proteins. The kidneys excrete any extra potassium in the body. It is important to follow potassium levels after transplant because some anti-rejection medications can cause an increase in the potassium level. If the potassium level is too high, there is a risk for abnormal heartbeat patterns (arrhythmias). Some diuretics can cause low potassium levels.

**prophylaxis**
Preventative treatment; antibiotics, antifungals, or antivirals that are prescribed to prevent certain infections in a specific group of patients who are at a higher risk for these infections.

**pruritis**
Itching; patients with chronic kidney disease may have increased itching due to an increased accumulation of urea and high phosphorus levels in the blood.

**rejection**
A process in which the body's immune system attacks the transplanted organ, usually resulting in damage to that organ.

**renal**
A term that refers to the kidney or having to do with the kidney.

**shingles**
A viral infection caused by the herpes zoster virus that usually affects an area by a nerve, resulting in fluid-filled blisters and pain. Shingles are most commonly seen on the neck, abdomen, and legs. The virus can also affect the nerves of the eye.

**sodium**
A mineral found in the blood and required by the body to maintain the balance between electrolytes and water.
spleen  
An organ located under the rib cage on the left side of the abdomen. The spleen removes old or deformed red blood cells, white blood cells, and platelets. It also makes lymphocytes, a type of white blood cell, that help produce antibodies.

stenosis  
The narrowing of a tube or vessel in the body which limits the flow of fluid or blood; may occur in a blood vessel (renal artery stenosis) or in a drainage tube (ureteral stenosis).

stent  
A slender rod or tubular devise that is placed inside the transplanted ureter to provide support. The stent helps maintain the flow of urine through the ureter and to the bladder.

steroids  
Corticosteroids; hormones secreted by the adrenal gland, located above the kidney. This hormone can also be manufactured and prescribed through medications such as prednisone/prednisolone. Steroids can help prevent rejection and may also be prescribed in higher dosages to treat rejection.

systolic  
The “top number” of blood pressure measurement. The systolic pressure measures the pressure as the heart muscle contracts to pump blood around the body.

T  
T cells  
T cells are a type of lymphocyte, or white blood cell, that develop in the thymus gland which is located in the upper chest in front of the heart. T cells are associated with acquired immunity, or the ability of the body to fight an infection or foreign substance that it was exposed to in the past. T cells play a major role in the rejection process.

thrombosis  
The formation of blood clots in a blood vessel, blocking blood flow. For example, deep vein thrombosis is a blood clot in a vein and is commonly seen in the leg. Vascular thrombosis of the artery or vein of the kidney blocks blood flow through the kidney.

thrush  
*Candida albicans*, yeast; a fungal infection that looks like white plaques or spots in the mouth (oral mucosa), throat, and on the tongue. Patients who are immunosuppressed are more at risk for developing thrush.
| **U** | **ultrasound** | A test that displays internal bodily organs, blood vessels, and ducts using sound waves. An ultrasound of the kidney may be done to evaluate the size of the kidney, blood flow in the kidney, signs of fluid collections near the kidney, flow of urine out of the kidney, or to guide the biopsy procedure. |
| **ureter** | The tube that transports urine to the bladder from the kidneys. |
| **urethra** | The tube from the bladder in which urine flows from the body. |
| **V** | **vital signs** | The measurement of temperature, blood pressure, heart rate, and respiratory (breathing) rate. |
| **W** | **wean** | To slowly withdraw or reduce; Immunosuppression, particularly steroids, may be weaned slowly over time in selected kidney transplant recipients who have not rejected their kidney. |
| **white blood cell** | A type of blood cell that fights infection or causes rejection. T cells, B cells, and lymphocytes are examples of white blood cells. |
# VITAL SIGNS FORM

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# APPOINTMENT DIARY

NAME: ________________________________________________

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# MY TRANSPLANT TEAM

My Transplant Center: ________________________________

Address: __________________________________________

Phone: ____________________________________________

Fax: ______________________________________________

Website: http://www________________________________

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<tr>
<th>NAME</th>
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# MY LOCAL HEALTHCARE TEAM

NAME: ______________________________________________________

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