

Kidney Handbook

Your Kidney Transplant

A basic overview of your daily
healthcare, medications, and monitoring



I T N S



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Introduction

We are pleased that you are using this educational material to learn about your transplant. We want you to know that this booklet is intended for use of transplanted people around the world. You will see throughout the teaching material that certain words are used for position titles and procedures. This table will let you know internationally, what you can refer to and what we have chosen to call positions within the health care team. If you have any questions, ask your transplant team.

Donor Coordinator = Organ Procurement Organization (OPO)

Transplant staff who are responsible for the retrieval, preservation, placement and transportation of organs for transplantation.

Recipient Coordinators = Clinical Coordinators = Transplant Sister

These coordinators manage your assessment and evaluation for transplant and will

follow your care while you are in the hospital. Your transplant coordinator will also follow you as an outpatient in the clinical setting.

Transplant Nurse = Staff Nurse

Transplant nurses will care for you while you are in the hospital. They will help you to get up and around and to learn about your new transplant. These nurses will help you with discharge plans and teach you to care for yourself at home.

Nurse Practitioner = Transplant Sister

These members of the transplant team are specially trained nurses who are able to do more than a transplant nurse; they may see you pre-transplant, at the time of your transplant and post operatively in the clinic.





Congratulations On Your Kidney Transplant!

Now that you have received a new kidney and are about to go home, it is important to understand that having a new kidney brings new responsibilities.

Your transplant team will continue your kidney care. At this point, though, the most important member of the team is YOU! Without your active support, the team's best efforts cannot succeed. As the lifetime caretaker of your new kidney, you will need to:

- Make sure you have healthy daily habits that include a good diet and regular exercise
- Follow your medication schedule
- Check your weight, temperature, blood pressure, and pulse periodically
- Talk to your transplant team regularly
- Keep to your schedule for lab tests and checkups
- Make sure all of your doctors, your dentist and your pharmacist know about your medications and your care.

PURPOSE OF THE HANDBOOK

This handbook will give you a basic overview of your daily healthcare routine, medications, monitoring, and other activities. It also has tips on recognizing problems that may necessitate immediate medical attention. Every patient has individual needs that should be dealt with. You will be

expected to ask your transplant team lots of questions and seek detailed guidance on your particular routine.

You may want to use this handbook for:

- Recording lab results
- Keeping track of medications, dosage changes, etc
- Making notes about special instructions
- Writing down questions you may want to ask
- Reviewing general health guidelines and precautions

YOUR TRANSPLANT COORDINATOR

Once you leave the hospital, your transplant coordinator will be your main contact with your transplant team. The coordinator, a registered nurse, will teach you how to care for your general health and will answer most of your questions. Your transplant coordinator is involved in most aspects of your care and will put you in touch with other team members who can provide any other services you may need.



Information About Your Kidneys

Let's first review some facts about the kidneys.

WHAT THE KIDNEYS DO

Your kidneys are located at the back of your stomach area (abdomen), one on each side of the spinal cord. The lower ribs protect the kidneys from injury. Each kidney is about the size of your fist.

The kidneys' major jobs are to:

- Filter waste products and excess water out of the blood
- Make hormones that help regulate blood pressure and the production of red blood cells
- Control the balance of water, salt, and acid in the body



Kidney Failure

The kidneys usually fail because of a disease that has affected their function. The most common of these diseases includes diabetes mellitus, high blood pressure, glomerulonephritis, and polycystic kidney disease. Injury and birth defects are other causes of kidney failure. The disease generally has been attacking the kidneys for many years before a person begins to feel the effects of kidney failure. There are also conditions that can cause sudden loss of kidney function. When the kidneys stop working, waste products and excess fluids build up and become harmful to your body. You may begin to feel tired and fatigued. You may develop edema (puffiness) in your ankles and face. You may develop nausea and have a poor appetite.

Benefits of Kidney Transplantation

A kidney transplant is not a cure; it is a treatment option. A successful kidney transplant may prevent you from ever needing dialysis. If you have started dialysis, a transplant should allow you to stop. Your energy level should improve as your new kidney will promote the production of red blood cells. You will have fewer restrictions with your diet and with your fluid intake. You will hopefully be able to return to a more normal lifestyle with increased activity and independence.



Complications

A number of complications are possible after surgery. Your transplant team will do their best to reduce your chance of having complications and to treat any problems or difficulties right away. Following instructions carefully and keeping your transplant team informed of any problems will help you return quickly to your normal, active life.

INFECTIONS

Anti-rejection medications interfere with your natural immunity; therefore, you will be more likely to get infections after your transplant surgery. The following are some of the most common infections

Viral Infections:

Cytomegalovirus (CMV) - CMV is one of the viral infections that occur most often in transplant patients. The risk of CMV is highest in the first months after transplantation. Signs can include fatigue, fever, night sweats, aching joints, headaches, trouble seeing, and pneumonia. Treatment may include hospitalization, and you may have to take medicine intravenously or by mouth for several weeks or months.

Herpes-simplex virus type 1 and 2 - These viruses most often infect the skin but can also turn up in other areas like the eyes and lungs. Type 1 causes cold sores and blisters around the mouth, and type 2 causes genital sores. Herpes is an infectious disease and can be transmitted sexually. Herpes infections in transplant patients, however, are not necessarily transmitted sexually.

Most herpes simplex infections are mild, but can be severe. Although there is no cure

for herpes, it can be treated. Depending on the severity of the infection, the treatment is either by mouth, on the skin, or intravenous. Contact your transplant team right away if you think you have herpes.

Symptoms of herpes include feeling weak and having painful, fluid-filled sores in your mouth or genital area. Report any pain with swallowing. Women should also watch for any unusual vaginal discharge.

Precautions:

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

Herpes zoster (shingles) - Shingles appears as a rash or small water blisters, usually on the chest, back or hip. The rash may or may not be painful and may occur in people who have had chicken pox. Call your transplant team immediately if you have this kind of a rash.

Varicella zoster (chicken pox) - Chicken pox may appear as a rash or small blisters and usually occurs in childhood, giving immunity to further infection. Call your transplant team immediately if you have been exposed and have not had chicken pox previously - do not wait to see if you are going to get sick.



Fungal Infections:

Candida (yeast) - *Candida* is a fungus that can cause a variety of infections in transplant patients. It usually starts in the mouth and throat but may also be in the surgical wound, eyes or respiratory and urinary tracts. *Candida* is most severe in the blood-stream. If there is infection in the mouth or throat, it is called thrush. Thrush causes white, patchy lesions (raw areas), pain tenderness, a white film on the tongue, and difficulty swallowing. *Candida* can also infect the tube from the mouth to the stomach (esophagus) or, in women, the vagina. Vaginal infections usually cause an abnormal discharge that may be yellow or white and often itchy. Call your transplant team if you think you have a yeast infection. Treatment of severe fungal infections may include hospitalization where you may receive an IV medication.

Bacterial Infections:

Wound Infections - Bacterial wound infections happen at the surgical site. If you have a fever or notice redness, swelling, tenderness, or oozing at your incision, call your transplant team. After a test for bacteria is taken, you will be given an antibiotic if you have an infection.

Other Infections:

Pneumocystis carinii is a germ that is a lot like a fungus, and it is normally found in the lung. In people whose immune systems are suppressed, it may cause a type of pneumonia. Early in the illness, you might have mild, dry cough and a fever. If you think that you have a cold or flu-like illness that does not get better, contact your transplant team right away. Some transplant programs provide treatment to prevent this infection.

If you have been on peritoneal dialysis, your catheter may be left in place for several months after transplantation. It is important to continue to take regular care of your peritoneal catheter exit site to prevent infection.

REJECTION

Your body's immune system protects you from infection by recognizing certain foreign bodies, like bacteria and viruses, and destroying them. Unfortunately, the immune system sees your new kidney as a foreign substance also.

Rejection is an attempt by your immune system to attack the transplanted kidney and destroy it. To prevent rejection, you must take anti-rejection medications, as prescribed, for the rest of your kidney's life.

In spite of all precautions, rejection can occur. Up to half of all kidney-transplant patients will have at least one rejection episode. The first episode often happens within the first 6 months of surgery.

Rejection episodes are treated by changing the dosages of your anti-rejection medications or adding a new one temporarily. Kidney rejection does not necessarily mean kidney failure. Most episodes of rejection can be reversed with anti-rejection medications, if they are detected early enough.

You should look for the signs of rejection and call your transplant team promptly if you have the following:

- Pain or tenderness over your kidney transplant
- Fatigue/weakness
- Fever
- Less urine output than usual
- Swelling of your hands or feet



- Sudden weight gain
- Elevated blood pressure

You may not have any symptoms, but your kidney-function test may be abnormal, suggesting that rejection is happening. This is why getting lab tests done as scheduled is critical.

When your transplant team thinks you are having a rejection, they usually confirm it with a kidney biopsy. Based on the results, your transplant team will decide the best treatment for you.

DELAYED GRAFT FUNCTION

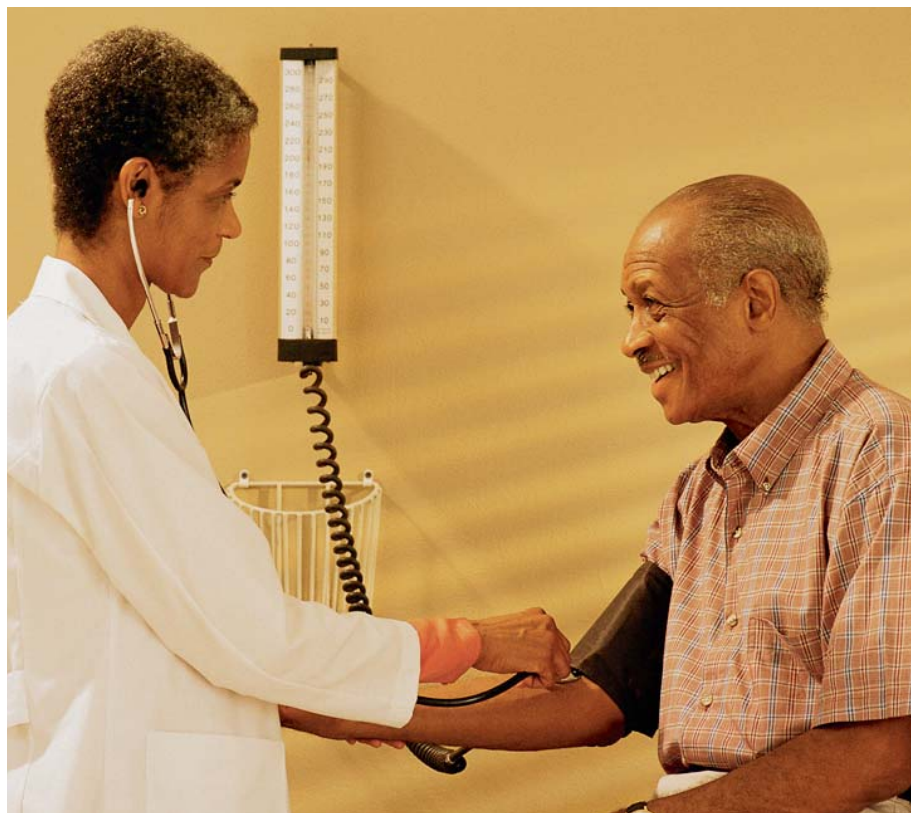
The functioning of your kidney transplant may be delayed, causing a need for dialysis until the kidney "wakes up". Delayed function may last from several days to several weeks.

DIABETES

Glucose is a simple sugar and is the main source of energy in the body's cells.

A condition called diabetes mellitus occurs if glucose accumulates because your body is not using it properly and/or not enough insulin is produced.

Some of your prescribed anti-rejection medicines may cause diabetes. The onset of diabetes post-transplant is usually mild; early signs include tiredness, thirst, weight loss, excessive production of urine, blurred vision and confusion. If you have any of these symptoms you should inform your transplant team, however you will be routinely monitored in clinic for this condition by regular blood and/or urine tests.





Post-transplant diabetes is often resolved by reducing some of your anti-rejection medicines or converting you to different ones, though you may need a specific oral diabetic medicine or insulin injections. Should you develop diabetes your transplant team will give you specific advice, however careful diet, weight loss and exercise are all helpful in controlling this condition.

If you were diabetic prior to your transplant, you may have problems with blood sugar control following your surgery. This will be discussed with you on an individual basis.

BLOOD PRESSURE

High blood pressure is a very common complication following kidney transplantation, particularly during the early months. This is why your blood pressure will be checked more frequently during this period.

It is vital to control high blood pressure; if left untreated you would be at an increased risk of heart disease or of having a stroke. Often high blood pressure does not produce symptoms, however some patients complain of headaches or blurred vision.

It can be associated with several problems, which include fluid overload, rejection and renal artery stenosis. It can also be a side effect of some of your medicines.

There are many different ways of treating high blood pressure:

- If your doctor thinks you are fluid overloaded you will be given a diuretic (water pill) which will drive your kidney

to increase your urine output and thus help lower your blood pressure.

- Blood pressure medicines - There are many different types of blood pressure medicine including vasodilators, beta-blockers and calcium channel blockers; your doctor will choose the most appropriate one for you. Many patients will need a combination of more than one blood pressure medicine.
- If your doctor suspects you have a rejection episode or renal artery stenosis, the appropriate diagnostic tests will be performed and treatment initiated.
- If your high blood pressure is caused by a side effect of your anti-rejection therapy, changes may be made to a different type of medicine.

It is important that you do not stop or change your prescribed medicines without discussion with your transplant doctors.

ANXIETY AND DEPRESSION

A serious operation such as the one you have had can put a lot of stress on you and your family. It is common for transplant patients to have anxiety and perhaps depression after their surgery, during their stay in the hospital, and/or upon return home. There are counseling services to help you adjust to life at home and to your return to work or school. Ask your transplant team for information about these services.



Information About Medications

You are responsible for taking the medications that have been prescribed for you. Talk to your doctor, pharmacist, transplant nurse, and/or coordinator so you understand:

- The name and purpose of each medication
- When to take each medication
- How to take each medication
- How long to continue taking each medication
- Main side effects of each medication
- What to do if you forget to take a dose
- When to order more medication so you do not run out
- How to get your medication
- What you should avoid (such as drinking alcohol or driving) while you are taking medication

When you return home, you will continue taking most of the medicines you began taking in the hospital after your surgery. Your immune system recognizes your new kidney as foreign and will try to reject it. Therefore, your immune system must be controlled with anti-rejection medications. You probably will have to take one or more of these drugs for the rest of your transplanted kidney's life, in addition to other medications.

REMINDER: Never stop taking your medications or change the dosage without your transplant team's approval. There is always a risk of rejection and loss of the new kidney.

GENERAL GUIDELINES FOR STORING YOUR MEDICATIONS

1. Keep medications in the original container, tightly capped. If you use a special container to hold your pills, keep the container tightly sealed.
2. Store in a cool, dry place away from direct sunlight.
3. Do not store medications in the bathroom - moisture and heat can cause them to lose their strength.
4. Do not allow liquid medications to freeze
5. Do not store medications in the refrigerator unless your pharmacist advises you to do so.
6. Keep all medications away from children.





BEFORE YOU TAKE YOUR MEDICATIONS

1. Ask your nurse, transplant coordinator, or pharmacist to help you choose the best times to take your medications.
2. Try to take each medication at the same time every day.
3. Follow a written schedule.
4. DO NOT cut or crush a tablet unless your are advised to do so.

NOTIFY YOUR TRANSPLANT TEAM IF YOU....

- Cannot take your medicines by mouth because of illness
- Have vomiting, diarrhea, or nausea for 24 hours or more)
- Think the directions on the label may be different from what you were told
- Have trouble removing child-resistant caps - contact your pharmacist first
- Have a reason to take aspirin, Advil®, Nurofen® (ibuprofen), other pain relievers, cold remedies, or diet pills
- Feel you are having a reaction to your medications
- Have had a change in health or eating habits
- Have a new prescription from your local doctor or a change in a current prescription
- Experience any unusual symptoms or side effects, since they may be related to the medication you are taking

Information About Specific Medications

This section is a general guide to each medication's function, proper use, dosage, precautions, and side effects. The information does not cover everything about each medication and does not replace your doctor's advice. Always follow the instructions given to you by your transplant team. Not all of the medications talked about in this handbook will be prescribed by your transplant doctor.

You probably will not experience all of the side effects listed for each medication, and can be reassured that side effects usually decrease with time.

ANTI-REJECTION MEDICATIONS

Tacrolimus (Prograf®, FK506)

Purpose:

Tacrolimus is used to prevent or treat rejection in people who have received kidney transplants. You may have to take it for the rest of your kidney's life.

How to take:

- Capsules -.5mg, (milligram) 1mg and 5 mg. If you take tacrolimus twice daily, doses should be 12 hours apart. Either oral or





intravenous tacrolimus may be given to you immediately after your transplant.

- Your transplant team will determine the right dosage for you based on your weight, your blood levels, other lab tests, and the possible side effects of tacrolimus.
- Tacrolimus should be taken regularly to keep drug levels steady. Do not take with grapefruit juice.
- Tacrolimus is usually taken with:
- Corticosteroids, such as prednisone (Deltasone®), prednisolone
- Azathioprine (Imuran®) or mycophenolate mofetil (CellCept®)

Precautions:

- You will have frequent lab tests during the first few months to keep watch on the effectiveness and side effects of tacrolimus.
- On a day when your tacrolimus level is to be measured, do not take your morning dose until your blood has been drawn. After your blood is drawn, take your prescribed dosage.
- Store tacrolimus at room temperature (59° to 86°F) (15° to 30°C) and away from children.
- Tacrolimus may interact with some commonly used drugs including those purchased over the counter. Check with your transplant team before starting any new medications or taking any herbal medications.
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to headaches, high blood pressure, nausea, diarrhea, high blood sugar, tremors, hair loss, trouble sleeping, infection, numbness and tingling of your hands or feet, elevated potassium level in your blood and abnormal kidney function.

Switching drugs:

Your transplant team may decide to give you tacrolimus instead of cyclosporine (Sandimmune®, Neoral®), because of side effects or rejection. If this happens, follow the instructions of your transplant team.

NOTES:

RAPAMYCIN (SIROLIMUS, RAPAMUNE®)

Purpose:

Rapamycin is a potent immune suppressant used to prevent rejection of kidney and pancreas transplant.

How to take:

It is given as a liquid mixed in orange juice or water and also available in capsules. If you are taking the liquid, it should be stored in a refrigerator. The daily dose should be given consistently with meals, either always with a meal or always on an empty stomach so that the medication will be consistently absorbed. Once a pouch or bottle of the medication is opened, it should be used within one month.



*Precautions:*

- High cholesterol and high triglyceride levels may be seen.
- Rapamycin therapy can cause a temporary decrease in certain blood cells that help platelets. This may result in unusual bleeding or bruising.
- Rapamycin can also cause a decrease in white blood cells, which can affect your ability to fight infection. Your transplant team will be monitoring your blood counts and adjusting medication doses as needed.
- Other potential side effects include headache, diarrhea, occasional joint pain and edema.

Cyclosporine (Sandimmune®, Neoral®, Gengraf®, Eon®)

NOTE: Sandimmune®, Neoral®, Gengraf® and Eon® should not be substituted for one another except under the direction of your transplant team.

Switching drugs:

Your transplant team may decide to give you cyclosporine instead of tacrolimus (Prograf®), or the other way around, because of side effects or rejection. If this happens, follow the instructions of your transplant team.

Purpose:

Cyclosporine is used to prevent rejection of a transplanted kidney. You may have to take it for the rest of your life.

How to take:

- Capsules - 10mg, 25mg, 50mg and 100mg.
If you take cyclosporine twice daily, doses

should be 12 hours apart. You may be given intravenous cyclosporine for the first few days after your transplant.

- Liquid - 100mg per ml (milliliter). Mix it with a room-temperature liquid in a glass or hard plastic container and stir it with a metal spoon. Ask your transplant team for suggested liquids to mix the medication with. Do not use a plastic foam container.
- Your transplant team will determine your dosage based on your weight, your blood levels, other laboratory tests, the possible side effects of cyclosporine and other medications you are taking.

Precautions:

- You will have frequent lab tests during the first few months to keep watch on the effectiveness and side effects of cyclosporine.
- On a day when your cyclosporine level is to be measured, do not take your morning dose until after your blood has been drawn.
- Store cyclosporine capsules below 77°F or 25°C, store liquid below 86°F or 30°C. Do not leave cyclosporine in your car or store it in a refrigerator or bathroom medicine cabinet or exposed to direct light. Good places to store this drug include the kitchen or your bedroom - away from heat, cold, moisture, and children.
- An open bottle of liquid cyclosporine is good for 2 months. You should not remove a capsule from a wrapper until you are about to use it.
- Cyclosporine interacts with many commonly used drugs including those





- purchased over the counter. Check with your transplant team before starting any new medications or any herbal remedies.
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, headaches, tremor, abnormal kidney function, high blood pressure, high blood sugar, high cholesterol, infection, elevated potassium level in your blood, excessive hair growth, trouble sleeping, swelling or overgrowth of the gums.

NOTES

Mycophenolate mofetil (CellCept®, MMF)

Purpose:

Mycophenolate mofetil is given to you with other medications to help prevent or treat rejection of your new kidney. You may have to take it for the rest of your life.

How to take:

- Capsules - 250 mg, 500 mg. If you take mycophenolate twice daily, doses should be 12 hours apart.
- Your transplant team will decide the right dosage for you based on your laboratory values and kidney function.

- May be taken with food if causes stomach upset or discomfort.

Precautions:

- Mycophenolate mofetil may lower some of your blood cell counts such as white blood cells, which fight infection and platelets, which help blood clot. You should report any unusual bruising or bleeding to your transplant team.
- Mycophenolate mofetil should not be used by pregnant women unless the possible benefits justifies the possible danger to the unborn baby. Women of childbearing age should use effective contraception before beginning CellCept®, during the time you are taking CellCept®, and for 6 weeks after you have stopped taking CellCept®. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, heartburn, stomach discomfort, infection, nausea, vomiting, and diarrhea. These side effects may decrease with dose reduction, as directed by your transplant team.

NOTES





Prednisone (Deltasone®) - prednisolone, a related drug

Purpose:

Prednisone helps prevent and treat rejection of transplanted kidneys. You may have to take it for the rest of your kidney's life.

How to take:

- Tablets come in several different strengths; your transplant team will decide the best tablet strength; liquid - 1 mg per ml; injectable forms are also available.
- It is best to take prednisone with food.
- If you take prednisone once a day, you should take it in the morning - ask your transplant team for specific directions. Your transplant team will determine the right dosage for you according to your weight, how well your transplant is functioning, and the length of time since your transplant.
- Missing doses may cause serious side effects.

Precautions:

- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, high blood sugar, increased appetite, weight gain, osteoporosis, high cholesterol, mood swings, anxiety, stomach ulcers and slow growth in children.

NOTES

Azathioprine (Imuran®)

Purpose:

Azathioprine may be given to you with other drugs to help prevent rejection of your new kidney. You may have to take it for the rest of your kidney's life.

How to take:

- Tablets - 50 mg; liquid - 10 mg per ml. Intravenous azathioprine may be given to you for the first few days after transplantation.
- Your transplant team will determine the right dosage for you based on your weight and white blood cell count.

Precautions:

- Azathioprine may lower some of your blood cell counts such as your white blood cells, which fight infection, and your platelets, which help your blood clot. You should report any unusual bruising or bleeding to your transplant team.
- Imuran may interact with some medications. Check with your transplant team before starting any new medications or herbal remedies. Check with your transplant team before taking any anti-gout medications.
- The benefits of taking this medication if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.





Main side effects:

These include, but are not limited to, nausea, vomiting and infection. Report any rashes, yellowing of your skin or whites of your eyes.

NOTES

Antithymocyte globulin (Atgam®, Thymoglobulin®, ATG)

Purpose:

Antithymocyte globulin may be given to you right after your kidney transplant to prevent rejection. It may also be used later to treat rejection.

How to take:

- This medication is given only intravenously. It takes 4 to 6 hours to administer.
- To reduce side effects, you may receive Tylenol® and/or Benadryl® or Hydrocortisone or Piriton before you are given antithymocyte globulin.
- Your transplant team will decide the right dosage based on your weight, how your transplant is functioning, your white blood cell count, and the possible side effects of antithymocyte globulin.

Precautions:

- Your transplant team may change the dosages of your other medications while you are taking antithymocyte globulin.
- The benefits of taking this medication if you are pregnant or breastfeeding must be

weighed against the possible danger to you, your unborn baby, or your infant. Inform your transplant team immediately if you think you are pregnant.

Main side effects:

Report any side effects to your nurse as soon as possible. These include, but are not limited to, difficulty breathing, fever, chills, rash, nausea, vomiting, diarrhea, muscle aches, infection and pain during infusion. Your platelet and blood cell levels may lower.

NOTES

OKT3 (Orthoclone OKT®3, Muromonab-CD3)

Purpose:

OKT3 may be given to you right after your kidney transplant to prevent rejection. It may also be used later on to treat rejection.

How to take:

- This medication is given only intravenously. It is generally given once a day for 5 to 14 days. It will be given over a few minutes.
- To reduce side effects, you may receive Tylenol® and/or Benadryl® before you are given OKT3.
- Your transplant team will decide the right dosage for you based on your weight, how your transplant is functioning, your white blood cell count, your platelet count, and the possible side effects of OKT3.





Precautions:

- Notify your transplant team at the first sign of wheezing, difficulty breathing, rapid heartbeat, difficulty swallowing, rash or itching. Most patients have some mild adverse during reactions to OKT3 with the first three doses.
- Your transplant team may change the dosages of your other medications while you are taking OKT3.
- The benefits of taking OKT3 if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, wheezing, difficulty breathing, chest pain, fever, chills, nausea, vomiting, diarrhea, tremor, headache, infection, fast heart rate, and muscle stiffness. The most uncomfortable side effects generally happen only during the first few doses or in the first 1 to 4 days. You may be able to finish this therapy without staying in the hospital.

NOTES

DACLIZUMAB (ZENAPAX)

Purpose:

Daclizumab is a medication that suppresses the immune system and prevents acute rejection.

How to take:

It is available only in injection form and is given intravenously at the time of transplant. It is then given up to four more times at 2 week intervals. It is usually given in combination with cyclosporine and prednisone. When you are discharged from the hospital, you will be given instructions on where to receive additional doses. The most common side effect of this drug is nausea but generally this drug is very well tolerated.

Precautions:

Since it is unknown if daclizumab is safe in pregnancy, women of child-bearing age should use effective birth control before, during, and for four months after completion of therapy.

BASILIXIMAB (SIMULECT)

Purpose:

Basiliximab is a medication that suppresses the immune system and prevents rejection. It is usually used along with cyclosporine and prednisone.

How to take:

This medication is given intravenously at the time of transplant and once again four days later. The most common side effect is nausea and some of the other same side effects of cyclosporine and prednisone.

Precautions:

As with the other anti-rejection medications, notify your transplant team of any signs of infection. It is not known if there are long term side effects on your body's response to bacteria, fungi, or viruses.





Since it is unknown if basiliximab is safe in pregnancy, women of childbearing age should use effective birth control before, during, and for two months after completion of therapy.

INFECTION-FIGHTING DRUGS

The medications you take to stop your body from rejecting your new kidney also reduce the normal ability of your body to fight bacteria, viruses, and other germs. As a result, you are at an increased risk of getting an infection. Your doctor may prescribe one or more drugs to protect you from infection or to control infection.

The following are some of the most commonly used antibiotics (antibacterial drugs), antiviral drugs, and antifungal medications.

Trimethoprim/sulfamethoxazole or TMP/SMX (Bactrim®, Septra®, Co-trimoxazole, Cotrim® - also available under other names)

Purpose:

TMP/SMX is used to prevent and/or treat pneumocystis carinii pneumonia and other infections. Transplant patients have more risk of getting this type of pneumonia because of the drugs taken to avoid rejection, which reduce their body's ability to fight infection.

How to take:

- This medication is taken by mouth and is available in pill or liquid form.

- Your transplant team will decide the right dosage and length of time for you to take TMP/SMX.
- Take plenty of fluids with this medication - check with your transplant team about the amount.

Precautions:

- Do not take TMP/SMX if you are allergic to sulfa. In that case, your transplant team may give you another drug.
- The benefits of taking TMP/SMX if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, rash, itching, and increase risk of sunburn.

Valganciclovir (Valcyte)

Purpose:

Valganciclovir may be given to help prevent or treat infections that are caused by a virus called Cytomegalovirus (CMV). The CMV virus is present in about 50% of the population. This virus is generally experienced in the form of a common cold or flu and most people are unaware that they have had this virus.

However, when a donor kidney with CMV is transplanted into a recipient who has not had CMV, the recipient is at risk for becoming infected with the CMV virus. If you acquire the CMV virus after your transplant, you are at risk for infection because you are taking anti-rejection medication.





By taking Valganciclovir, you are protecting yourself against the CMV virus and thus protecting yourself from infection.

How to take:

- It is given orally in 450 mg tablets. It is generally given once daily in the morning.
- Take this medicine with food.
- Swallow whole - Do not break, crush, or chew the tablet before swallowing.
- Your transplant team will advise you on how long to take this medication, generally 3-6 months.

Precautions:

This medication may reduce your number of platelets; platelets are the blood cells, which are necessary for clotting. This medication can also reduce the number of white blood cells and the number of red blood cells. Your transplant team will be monitoring your blood counts to make sure you are not having potential side effects.

Valganciclovir has caused birth defects in animals and may impair fertility. Since it may cause birth defects, both women and men of childbearing age should use effective birth control during and for 90 days following the use of Valcyte. If you suspect you are pregnant, contact your transplant team immediately.

Main side effects:

Side effects that may occur, but are not limited to, while taking this medication are: dizziness, nausea, diarrhea, and decrease red blood cell counts, platelets, and white blood cell's.

Ganciclovir (Cytovene®)

Purpose:

Ganciclovir is used to prevent or treat CMV, a viral infection.

How to take:

- Ganciclovir is given intravenously or orally. The first few doses are generally given in the hospital.
- Your transplant team will decide the right dosage and length of time you should take ganciclovir.
- Take plenty of fluids with this medication - check with your transplant team about the amount - and take with food to reduce stomach upset.

Precautions:

- Ganciclovir may lead to more risk of infection
- The benefits of taking ganciclovir if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, vomiting, diarrhea and lowering of your white blood cell count.

Acyclovir (Zovirax®)

Purpose:

Acyclovir is used to prevent or treat herpes simplex and shingles. Acyclovir will not get rid of the herpes virus, but it will lessen the pain and help heal the sores. Acyclovir is





also used to prevent and decrease the severity of CMV infection.

How to take:

- Capsules - 200 mg; tablets - 400 mg and 800 mg; liquid - 200 mg per 5 ml; and ointment. If you are taking acyclovir by mouth, you should take it with food and plenty of water to reduce stomach upset.
- Your transplant team will decide the right dosage and length of time you should take acyclovir.

Precautions:

- Acyclovir will not prevent you from spreading herpes to others. It is best not to have sex if either partner has any symptoms of genital herpes. Condoms may help prevent the spread of genital herpes, but vaginal jellies and diaphragms will not.
- The benefits of taking acyclovir if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, nausea, vomiting and lowering of your white blood cell count.

ANTIFUNGAL DRUGS

The lowered ability of your body to fight infection puts you at more risk of getting a serious fungus infection. This may take the form of thrush, or, in women, vaginal yeast infections.

Purpose:

Various drugs are used to treat or prevent fungus infections. Nystatin (Mycostatin®) and clotrimazole (Lotrimin®, Lotrisone®, Mycelex® and Amphotericin) are the most commonly used. Antifungal drugs interact with most anti-rejection medications, so an adjustment will be made in your medications when you start and stop taking the antifungal drugs.

How to take:

- Liquid - swish and swallow
- Troche or lozenge - dissolve in your mouth. Do not chew.
- The liquid or the lozenge should be taken after meals and other medications to allow liquids and lozenges to work in your mouth. Do not drink anything for at least 30 minutes.
- Vaginal suppository or cream - used as directed
- Severe fungal infections may require the use of intravenous antifungal drugs.
- Your transplant team will decide the right dosage and length of time for you to take antifungal medications.

Precautions:

The benefits of taking these medications if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn baby, or your infant. Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to nausea, vomiting, diarrhea and unpleasant taste.





DRUGS THAT PROTECT YOUR DIGESTIVE SYSTEM

Because some medications you take can cause stomach ulcers, you may need to take other medication to help protect your digestive system. These drugs will be prescribed by your transplant team when necessary.

ANTACIDS/ANTIULCER MEDICATIONS

Ranitidine (Zantac®), famotidine (Pepcid®), omeprazole (Prilosec®), and sucralfate (Carafate®) are medications used to prevent and sometimes treat stomach ulcers.

How to take:

- It is important to follow instructions about meals and other medications when taking any of these drugs.
- Your transplant team will decide the right medication, dosage, and length of treatment time for you.

Precautions:

- Do not take these drugs with other medications unless your transplant team has told you to do so.
- Do not make changes to dosage on your own.
- Call your transplant team immediately if you think you are pregnant.

Main side effects:

These include, but are not limited to, headache, nausea, vomiting, diarrhea, constipation, and gas.

OVER THE COUNTER MEDICATIONS

The following is a list of common complaints and recommended over the counter medications that you can take for these problems. Please check this list before taking any over the counter medication. The addition of any other medications or change in your current medications must be made through your transplant center.

Constipation - Metamucil, Fiber-Con, Senekot, Colace are medications that you may take. Increase fluids in your diet, increase fiber in your diet (bran, fresh fruits and vegetables). If constipation remains a problem, be sure to report to your transplant center.

Diarrhea - Imodium, Kaopectate, Donnagel are medication that you may take. Increase fluids to prevent dehydration until diarrhea goes away. If diarrhea persists for more than 2 days, please notify your transplant center.

Headache, Muscle Aches, other Aches and Pains - If headaches persist or accompanied by fever, please notify your transplant center immediately. Tylenol/Acetaminophen, Paracetamol, Aspirin are medications that you may take.





DO NOT TAKE IBUPROFEN, MOTRIN-IB, ADVIL, NUPRIN, MENADOL, MIDOL, GENPRIL, KETOPROFEN, ORUDIS-KT, ACTRON, NAPROXEN, ALEVE.

These medications interact with you immunosuppressants and may harm your kidneys.

Allergy, Cold Symptoms - Call your transplant center if symptoms persist or worsen. Over the counter medications that you may take include Actifed, Nyquil, Sudafed, Robitussin, Benedryl, Thera-Flu, Dristan, Formula 44.

Indigestion/Heartburn - Zantac 75®, Axid AR®, Pepcid AC® you may take.

NUTRITIONAL SUPPLEMENTS

Your transplant team may recommend you take vitamin and/or mineral supplements if your diet is not providing enough of the nutrients you need. Check with you transplant team before taking any nutritional supplement, including herbal preparations.

CAUTION: HERBAL PRODUCTS OR TEAS

Since there is little information about drug interactions between herbals and anti-rejection drugs, it is not recommended that transplant patients take herbal products.

Herbal products are not regulated by any government agency. This means that they are not tested for safety, side effects or drug interactions. St. John's Wort, for example, is an herbal known to increase the risk of

rejection by decreasing the amount of the anti-rejection drugs in your blood. Other products that may "enhance your immune system" may lead to rejection as well.

BLOOD SUGAR MONITORING AND INSULIN

Monitoring of blood sugar (glucose) after transplant is done to detect high levels of sugar in the blood called hyperglycemia. If you were taking insulin prior to transplant, you will continue to take insulin after transplant. If you were taking pills to control your blood sugar before transplant, you may need to take insulin after transplant for a time. Unless you receive a pancreas transplant, your surgery will not replace the need to control your blood sugars. Some of the drugs that you will be taking to prevent rejection may cause an increase in your blood sugar. Your blood sugar levels may return to normal as the dose of your medications is decreased. If your blood sugar remains high when you are ready to go home, you will be taught how to check your blood sugar, how to give yourself insulin, and how to change your diet to help control your blood sugar.

NOTES





Health Care After You Leave The Hospital

WATCHING OUT FOR YOUR HEALTH AND YOUR NEW KIDNEY AT HOME

After you leave the hospital, you may be asked to measure your:

- Temperature
- Pulse
- Blood pressure
- Weight

Temperature - Check and record your temperature any time you feel cold, hot, achy, or ill. This may be the first sign of infection. **WARNING: DO NOT USE Tylenol®, Ibuprofen (Advil®, Nurofen®), aspirin, or other such products unless your doctor tells you to, as these drugs may cause further symptoms or interact with your other medications. If your temperature is higher than _____ at any time, notify your transplant team or your doctor immediately.** This is considered an emergency, because a high temperature could mean you have a serious infection or rejection.

Pulse - If you are taking medication that affects your heart rate, your nurse or coordinator will teach you how to check your pulse at home. **Notify your doctor or transplant team if your pulse is faster than _____ or slower than _____.**

Blood pressure - Your nurse or transplant

coordinator will teach you how to measure your blood pressure, if necessary. The top number (systolic) is noted at the first sound you hear and the bottom number (diastolic) is noted when the sound changes (not stops). It is important that you know your normal blood pressure, normal changes, and when you should be worried. **You should notify your transplant team or doctor if your blood pressure is:**

Systolic - more than ____ or less than ____
Diastolic - more than ____ or less than ____

Note: If you have chest pain or difficulty breathing, call for an ambulance and go to the nearest emergency room. **DO NOT** try to drive yourself or have someone drive you.

Weight - You may be asked to weigh yourself on a standard bathroom scale at the same time every morning (after going to the toilet). Write your weight on the chart in this handbook. If you gain more than 2 pounds a day, you could be retaining fluid. Report this to your transplant team or doctor.

CLINIC VISITS

When you leave the hospital, you will receive a schedule of follow-up clinic visits for lab tests and checkups. The reason for these visits is to track your progress and find complications as early as possible.

Follow-up visits - On days when you are



scheduled for follow-up visits, bring your medication list and this handbook with you. You will be told about routine lab work (to keep track of your blood count, kidney and liver function, medication levels, etc) or special tests that you might need.

LAB TESTS

You will have some lab tests each time you go for a checkup. These can include blood and urine tests. Some of the things the tests look for are:

- Your white blood cell count, which can indicate whether you have an infection, side effects from medication, or over immunosuppression.
- How well your blood can clot (to avoid too much bleeding if you are injured)
- How well your kidney and liver are working
 - *Creatinine and Urea* tell how well your kidney works by measuring levels of creatinine and blood urea nitrogen, waste products normally removed from the blood by the kidneys.
 - *Bili* measures the level of bilirubin. The liver removes bilirubin from the blood and excretes it in the bile. When the liver is not functioning normally, bilirubin levels can increase, often resulting in jaundiced (yellowed) skin and eyes.
 - *Alk Phos* measures alkaline phosphatase, which is made in the bones, liver, pancreas, and intestines and removed from the blood by the liver.
 - *AST, ALT, and GGTP* test liver enzymes. These tests tell how well your liver is working.
- Whether you have enough minerals in your body
 - *Ca* measures calcium, which is necessary for strong bones and teeth, blood clotting, and heart and nerve function.
- *PO4* measures phosphate, which works closely with calcium to strengthen bones.
- *Mg* measures magnesium, which is necessary for normal functioning of muscle and for blood clotting.
- *K+* measures potassium, which is needed for normal heart and muscles function.
- *Na+* measures sodium, which helps maintain the balance of salt and water in the body.
- How much medication is staying in your bloodstream and for how long
 - Levels will be measured to check whether your specific immunosuppressant is too high or too low in your body. High levels could lead to toxicity or over-immunosuppression, and low levels may lead to rejection.
- How much sugar (glucose) is in your blood
- How much cholesterol and lipids are in your blood





ADDITIONAL TESTS AND PROCEDURES

Your transplant team may perform one or more of the following tests to keep watch on your transplant.

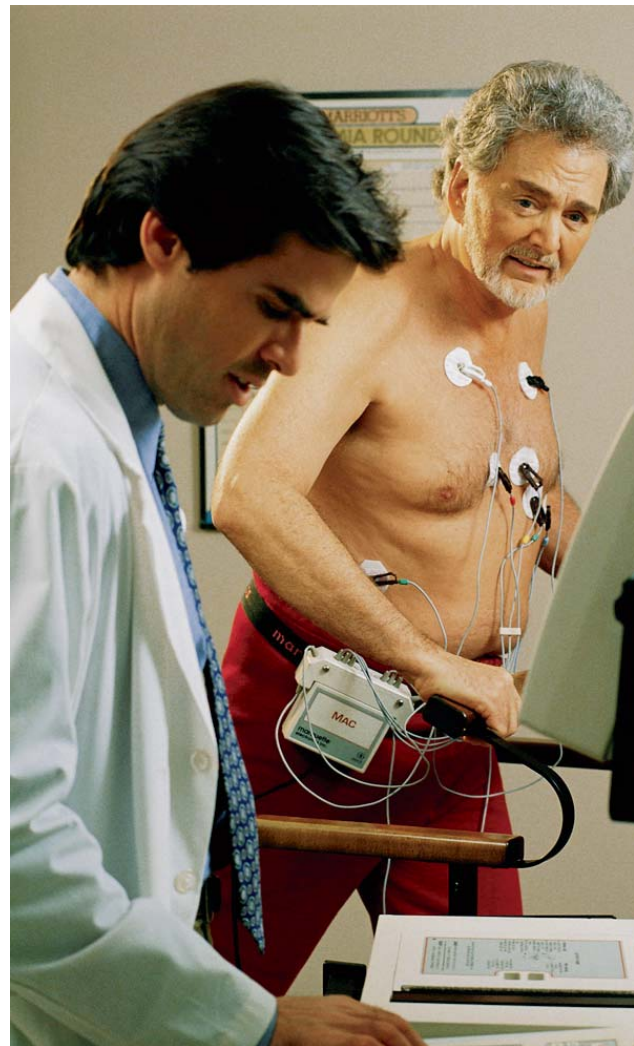
Ultrasound - This test is performed to make sure all the main blood vessels leading to your kidney are functioning normally. This test is also used to check for amounts of fluid around the kidney, and to check for blockage of the kidney. The test consists of placing a cool gel on your abdomen, over which a wand is moved to transmit sound waves. These are converted into images of your kidney and projected onto a television screen.

Kidney biopsy (test sample) - This test is usually performed to diagnose rejection or other possible problems. This procedure may be done in the hospital or in the outpatient/short-stay unit. You will receive special instructions about this test, and required after care. Before the test, you will receive a numbing injection (local anesthetic) over the transplanted kidney. Then a special needle will withdraw a small sample of kidney tissue that will be examined with a microscope. An ultrasound may be done at the same time.

Magnetic resonance imaging (MRI) - This is another type of test that produces an image. Somewhat like a CT scan (another imaging method), it also allows your kidney to be viewed from different angles and in three-dimensional images. A MRI shows soft tissues, such as the kidney, more clearly than a CT scan does.

Renal scan - This test is done to determine the amount of blood the kidney is receiving and to see how well the kidney is working. An intravenous infusion is needed for this test.

NOTES:





Resuming Normal Activities

AVOIDING INFECTION

Because anti-rejection medications interfere with your body's defenses, you need to make sure to protect yourself from infection after your surgery by taking the following precautions:

- Wash your hands often
- Keep your hands away from your face and mouth
- Stay away from people with colds or other infections.
- Ask friends to visit only when they are well.
- If you have a wound and must change your own dressing, wash your hands before and after.
- Wash your hands after coughing or sneezing, and throw tissues into the trash immediately.
- If someone in your family becomes ill with a cold or flu, have that individual follow normal precautions (using separate drinking glasses, covering their mouth when coughing, handwashing frequently, etc)
- Avoid handling animal waste and avoid contact with animals that roam outside. Do not clean bird cages or fish or turtle tanks or cat litter. The cat litter box should be covered and taken out of your home before it is changed. The feces of some animals contain parasites and the fungus can grow in a fish tank. All of these organisms can infect.
- **Avoid vaccines that have live viruses such as Sabin oral polio, measles, mumps, German measles, yellow fever, or smallpox. If you or any family member needs to receive any vaccinations, tell your transplant team or doctor.**

SPECIAL WARNING TO PARENTS OF CHILDREN WHO HAVE HAD

TRANSPLANTS: Ask the school nurse or other official to call you immediately if there are any communicable diseases (for example, measles or chicken pox) that may be going around in your school.

FOOD SAFETY

Food can carry bacteria, viruses, fungi and parasites. What may be safe to eat for the healthy person can be a risk for an immunosuppressed person. Specific guidelines can be followed to prevent contamination. The following is a list of suggestions that you should follow to prevent infections from the foods that you eat. Again, your hospital stay is a good time to meet with your transplant nutritionist to review your individual nutrition guidelines.

Dairy - drink only pasteurized milk, use only pasteurized milk products

Eggs - Yolks and whites should be cooked firm, pasteurized egg substitutes may be a better choice

Meat and Poultry - Avoid raw meats and poultry, juices from all meats should run clear

Fruits and Vegetables - Wash fruits and vegetables using scrub brush and chlorinated water, even when not eating the peel

Avoid Cross-contamination - Thoroughly clean counter tops and dishcloths

Suggestions for Dining Out - Order meat, seafood, poultry cooked to "medium". If animal flesh has any pink, send it back for additional cooking. Make sure shellfish is well cooked and firm.



DIET AND NUTRITION

Healthy eating is an important part of your recovery. A nutritionist can help you develop an eating plan that provides a balanced diet to meet your needs. The number of calories you need will be based on whether you need to gain, maintain, or lose weight and on your level of activity.

During the first weeks after your transplant, your body will require extra calories and protein. Meeting your increased nutritional needs will help your body to heal, fight infection, and gain back any weight you may have lost. Even if your appetite is not good after surgery, it is still important to eat. Think of food as another medicine to help you get well. The following are some tips to help you increase calories and protein in your diet.

- Try eating 5-6 small meals a day
- Ask your nutritionist about adding high calorie, high protein supplements and/or snacks with or between your meals. Good snack choices include:
 - Instant Breakfast
 - Low fat yogurt
 - Low fat cheese and crackers
 - Low fat peanut butter and crackers
- Choose high calorie drinks such as juice or milk rather than water

Healthy food - Use of salt, sugar, and fat -

A low-fat, low-sugar diet will help control your weight and blood sugar. Eating right will help keep you at a healthy weight and in the best shape. Certain medications you take may cause your blood pressure, blood sugar, cholesterol and weight to increase. To help regulate these things, it is important for you to limit your daily intake of saturated fat, salt and sugar. Your use of salt may be

restricted to help limit the amount of fluid your body holds and to control blood pressure and blood sugar. Consult your nutritionist about using salt, sugar, and fat in your diet.

Your diet should include a variety of foods, such as:

- 5 fruits and vegetables per day
- Whole-grain cereals and breads
- Low-fat or non-fat milk and dairy products or other sources of calcium
- Lean meats, fish, and poultry or other sources of protein; avoid/limit fried foods
- Egg whites or egg substitute
- Sugar free beverages and limit concentrated sweets
- Limit processed, "convenience" or canned foods; good salt free seasonings to choose include garlic & onion powder, pepper, vinegar and herb mixtures





Electrolytes - Levels of potassium, phosphorus and magnesium - Your medications may also affect the levels of potassium, phosphorus, and magnesium in your body. You may need to restrict or supplement your intake of these things to keep them in a desirable range. The following are examples of foods high in each category.

<u>Potassium</u>	<u>Phosphorous</u>	<u>Magnesium</u>
Cantaloupe	Milk	Shrimp
Oranges/	Cheese	Peanuts
Orange juice	Yogurt	Beets
Broccoli	Whole grains	Spinach
Potatoes	Raisins	Tofu
Tomatoes		

CARING FOR YOUR BONES

Research has shown that transplant patients are at increased risk of bone fractures. The feet and ankles seem to be particularly vulnerable, but other bones can break too. To lower your fracture risk, make sure you are getting enough calcium and vitamin D in your diet (unless your doctor says not to). Here are a few good dietary sources of calcium:

- Yogurt
- Ricotta cheese, part skim
- Skim or low-fat milk
- Provolone cheese
- Mozzarella cheese, part skim
- Sardines with bones, canned
- Salmon with bones, canned
- Calcium-fortified orange juice

EXERCISE

After transplant surgery, exercise is very important to your mental health and physical well being. Physical activity also helps decrease the effects of prednisone, which causes muscle weakness.

You need a daily exercise routine to avoid the muscle and total-body weakness that often happens after a long illness or time in bed. You should build or increase your levels of exercise. In this way, you will get all the benefits of exercise without causing strain or serious injury to your body. Before starting any exercise program, remember to check with your transplant team. They will advise you about an exercise routine that will best meet your needs.

WARNING: If you have any of the following symptoms, stop your exercise until you talk to your doctor.

- Pain or pressure in your chest, neck, or jaw
- A lot of fatigue that is not related to lack of sleep
- Unusual shortness of breath
- Dizziness or light-headedness during or after exercise
- Continuing rapid or irregular heart rate, new since your transplant, during or after exercise





RETURNING TO WORK OR SCHOOL

Returning to work or school must be discussed with your transplant team; they will help you to determine your readiness. The time frame will depend upon many factors including your recovery and the type of work you perform.

SEXUAL ACTIVITY

You may resume sexual activity as soon as you feel well enough. How quickly you feel ready will depend a lot on your recovery progress. You should discuss this during your clinic visits. Your sexual functioning may be affected by your transplantation. Certain medications can also interfere with sexual functioning. Some people avoid sexual activity because they are afraid of kidney rejection, of hurting the kidney, or of infection. If you have any of these fears, you may want to check with your transplant team. If you are sexually active and do not have a steady sexual partner, you must use condoms to reduce the risk of sexually transmitted diseases such as AIDS, syphilis, herpes, hepatitis, or gonorrhea. You must use contraception to prevent unplanned pregnancy also.

SKIN AND HAIR CARE

You will not need any special skin care unless you develop acne or dry skin. Generally, you should shower or bathe as often as necessary to keep your skin clean. Call your transplant team if you discover any unusual skin growths, rash, or discoloration.

Sun exposure - Transplant patients have more chance of developing skin and lip cancers. Since the risk gets bigger with time, you must always protect your skin

from the ultraviolet rays of the sun that cause skin cancer.

- Avoid midday (10 a.m. to 3 p.m.) sun, when ultraviolet rays are strongest.
- Wear a hat, long sleeves, and slacks when outdoors unless you are using a sunscreen.
- Use a sunscreen lotion with skin protective factors (SPF) rated at least 15.
- Use a sunscreen lotion and lip balm every day (rain or shine) and put them on any areas that are not covered, especially your face, neck and hands.

NOTE: Remember that sunscreen lotions wash off. Put the lotion on again as needed, especially after swimming.

Dry skin care - If you have problems with dry skin, use a mild soap and put on body lotion after bathing.

Cuts and scratches - Recommend electric razor to avoid cuts while shaving. Wash minor cuts and scratches daily with soap and water. For large cuts, see your doctor right away.

Hair care - Prednisone will probably change the condition of your hair. Permanent hair dyes, tints, wave lotions, and bleach may cause your hair to become brittle and to break. It is recommended that you wait until the prednisone dosage is lower than 10 mg a day before having a permanent or coloring your hair. Tell your hairdresser that you are taking prednisone and use a good conditioner on your hair.

Unwanted hair growth - If you get more facial hair, use a hair-removal cream (depilatory). Be sure to follow directions carefully to avoid eye or lip irritation.



Another way is to bleach extra hair growth with 50% peroxide solution. You might consider waxing or electrolysis to remove extra hair. Even if there is a lot hair growth, do not alter your medication. Call your transplant team about ways to deal with this problem.

ALCOHOLIC BEVERAGES

Drinking beer, wine, and liquor may damage your liver. Medications such as tacrolimus, cyclosporine, azathioprine, mycophenolate and TMP/SMX are broken down by the liver and, if combined with alcohol, could harm your liver. Call your transplant team for advice.

SMOKING

It has determined that smoking can be harmful to your health. (The Surgeon General of the United States / Chief Medical Officer of the United Kingdom) If you are a smoker, you may wish to join a stop-smoking group in your area. Look in the yellow pages of your telephone book. In the United States call the American Heart Association, American Lung Association, or American Cancer Society to find a local group. In the United Kingdom - Action on Smoking and Health (ASH)

PREGNANCY

A number of women who have had kidney transplants have had successful pregnancies, although pregnancy may have special risk for both the transplant patient and the baby. Women should avoid pregnancy for at least 1 year after transplant surgery. You should

discuss birth control and any other questions related to pregnancy with your transplant team. Men with kidney transplants have been able to father children. Because of the medications that you take, it is important to discuss the possible risks to the baby with your transplant team.

VACATIONS AND TRAVEL

If you are planning a trip to a foreign country that requires vaccinations for smallpox, measles, German measles, or certain other diseases, ask your transplant team to decide what you cannot have and to send a letter to your local passport bureau indicating that you cannot receive these vaccines. Because you cannot receive these vaccines, travel to these countries may not be safe for you. As you travel to places that have time differences you will need to take this into account when you take your medications. You may find that you will be taking your medications at times that you don't normally take your medications at home. It is important to adjust to the new time change but remember to space your medication times as you had at home. For example, if you take your immunosuppressants every 12 hours at home, you will need to take your immunosuppressants in a new time zone every 12 hours.



Communication With Your Healthcare Team

Having a transplanted kidney and taking the medication needed to prevent rejection put you at risk for a number of problems. It is important for you to follow the instructions that will help prevent or lessen these problems. One of your most important jobs is to make sure that all members of your healthcare team - your family doctor, dentist, local pharmacist, and any other healthcare professionals you see - are aware of your transplant, the medications you take each day, and the precautions you must follow to stay healthy. Give each of your local healthcare providers the telephone number of your transplant team; ask them to call for specific information.

SIGNS TO WATCH FOR

While the main things for you to avoid are infection and rejection, many other problems, such as colds or flu, changes in other medication, and minor infections, can be handled by your doctor. You need to take precautions yourself, however, and learn to watch for signs of infection and rejection so you can call your doctor or transplant team right away.

These include:

- Decreased urine output
- A fever that continues for more than 2 days
- Fluid retention - a bloated feeling
- Pain over the kidney transplant
- A cough that produces a yellowish or greenish substance
- A dry cough that continues for more than 1 week

- Nausea, vomiting, or diarrhea for a long time
- An inability to take prescribed medication
- Bleeding, bruising, black stools, or red or rusty-brown urine
- A rash or other skin change
- Vaginal discharge or itching
- Burning discomfort when you urinate
- Exposure to mumps, measles, chicken pox, or shingles
- Unusual weakness or light-headedness
- Emergency-room treatment or hospitalization

DENTAL CARE

Precautions for dental care - If you have dental pain, call your dentist immediately. Before you have dental work done (including cleaning and polishing), check with your transplant team to see if you need to take antibiotics.

Cyclosporine has been known to cause gum hyperplasia (overgrowth) in some patients. Make sure your dentist knows you are a transplant recipient and which medications you are taking.

ROUTINE HEALTHCARE

Immunization with non-live vaccines, call your transplant team for advice. Medical and dental checkups are necessary for your continued well being.

NOTES



Glossary

A

ACUTE TUBULAR NECROSIS (ATN)

Reversible tissue damage of the kidney that results in delayed graft function. Prolonged long organ storage or certain anti-rejection medications can cause ATN. It might be referred to as a sleepy kidney.

ANESTHETIC

A medication that reduces pain by dulling sensation or can cause the patient to be in a sleep.

ANTACID

A medication that works to relieve heartburn and digestive discomfort.

ALLOGRAFT

An organ or tissue transplanted from one person to another person of the same species. Commonly referred to as a graft.

AMYLASE

A digestive enzyme that is produced by the pancreas.

ANTIBIOTIC

A medication that is used in the treatment of bacterial infections.

ANTIBODY

A protein substance made by the body's immune system in response to a foreign substance, for example a previous transplant, blood transfusion, virus or pregnancy. Because the antibodies attack the transplanted organ, transplant patients must take powerful anti - rejection medications.

ANTIFUNGAL

Medications that are used in the treatment of fungal infections.

ANTIGEN

A foreign substance, such as a transplant, that triggers an immune system response. This response may be the production of antibodies, which try to inactivate or destroy the antigen (the transplanted organ).

ARTERIOGRAM/ ANGIOGRAM

A x-ray of the arteries taken following the injection of dye. An arteriogram allows the team to see (visualization of) the blood vessels to the kidneys.

B

BACTERIA

A small organism that can cause infection.

BLADDER

A saclike structure that receives urine from the kidneys and stores it until urination occurs

BLOOD UREA NITROGEN (BUN)

The waste product of protein metabolism that is excreted by the kidneys.

C

CATHETER

A small soft rubber tube that is placed into the bladder through the urethra allowing urine to drain freely from the bladder.

**CHOLESTEROL**

A form of fat that performs necessary functions in the body but can also cause heart disease.

CHRONIC RENAL FAILURE

Permanent irreversible damage to the kidneys that is treated with dialysis or transplantation. Also known as ~~End-Stage Renal Disease or ESRD~~.

COMPLIANCE

The act of following medical instructions and treatment regimen plans.

CREATININE

A waste product of muscle cell metabolism, which serves as an indicator of kidney function.

CROSSMATCH

A blood test between a donor and a recipient that indicates compatibility. A negative crossmatch means there is no reaction between a donor and recipient's blood; therefore a transplant can occur. A positive crossmatch means that the recipient's immune system has reacted to the donor's blood cells and this means the transplant cannot occur.

**CMV
(CYTOMEGALOVIRUS)**

A virus that is found in a large percentage of the population that generally causes no harm. This virus, however, can cause serious illness in a patient that is immunosuppressed.

D

DIABETES

An individual's inability to process carbohydrates, proteins, and fats as a result

of glucose accumulating in the blood stream. This occurs because your body is not using glucose properly or not enough Insulin is being produced.

DIASTOLIC

The bottom of the two blood pressure numbers that measures the force of the heart muscle at rest.

E

EDEMA

The presence of abnormally large amounts of fluids in the tissues of the body. Commonly seen in the feet and legs.

ELECTROCARDIOGRAM (ECG)

A recording of the electrical activity of the heart.

H

HEMATOCRIT (HCT)

A measurement of the red blood cell content in the blood.

HERPES

A group of viruses that can infect people. Herpes simplex can cause lip and genital sores. Herpes zoster can cause shingles. These viruses can be serious in immunosuppressed people.

**HUMAN LEUKOCYTE ANTIGEN
(HLA)**

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.



I**IMMUNE SYSTEM**

The body's defense against foreign objects or organisms such as bacteria, viruses, tissues, or transplanted organs.

IMMUNOSUPPRESSION

Artificial suppression of the immune system with medication. This is done to suppress the immune system so that a body will not reject a transplanted organ or tissue.

INTRAVENOUS (IV)

Refers to fluids or medications that are given through a vein.

O**ORALLY**

Refers to fluids or medications that are taken by mouth.

P**PANCREATITIS**

A potential complication following a pancreatic transplant resulting in the inflammation of the pancreas.

PANEL REACTIVE ANTIBODY (PRA)

The percentage of cells from a panel of donors with 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.

PLATELET

A small blood cell that is necessary for normal clotting of the blood.

POTASSIUM

A mineral found in the body that is necessary for body function and helps to regulate cardiac function. Disturbances in potassium levels may cause serious cardiac problems.

R**RECTALLY**

Refers to medication or treatment administered through your rectum (Kaexylate enema is an example)

REJECTION

An attempt by the immune system to reject or destroy what the body recognizes as foreign.

S**SHINGLES**

A virus caused by herpes zoster that usually affects a nerve or group of nerves. This condition can be very painful and take some time to improve.

SODIUM

A necessary electrolyte in your blood. Sodium is absorbed by the kidneys and affects body water distribution.

STENT

A slender rod or thread like device that is used to provide support to the transplanted ureter. The stent helps to maintain flow of urine through the ureter and to the bladder.

SYSTOLIC

The top number of the blood pressure reading which measures the force of the heart muscle during contraction.

**T**

THRUSH

A fungal infection of the mouth.

U

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

VIRUS

A small germ that causes infection.

W

WHITE BLOOD CELLS

This is the measurement of leukocytes in the blood stream.

(WBC's)

Leukocytes are very important as they help us fight infection. A low or high WBC count can be a sign of infection or disease.



Sources For More Information

American Heart Association (AHA)
National Center 7272 Greenville Avenue
Dallas, TX 75231-4596
1-800-242-8721
www.americanheart.org
(Local and national AHA and the AHA Cookbook are good sources of nutritional advice)

National Kidney Foundation
30 East 33rd Street, Suite 1100
New York, NY 10016
Phone: 1-800-622-9010
Local: 212-889-2210
Fax: 212-689-9261
Email: info@kidney.org

International Transplant Nurses Society
1739 E. Carson Street
Box 351
Pittsburgh, PA 15203
(412) 343-ITNS (4867)
(412) 343-3959 (fax)
Web page: <http://www.itns.org>
Email: itns@msn.com

Transplant Recipient International Organization (TRIO)
2117 L Street NW, #353
Washington, DC 20037
Phone: 1-800-TRIO-386
Fax: 703-820-3948
Email: triointl@aol.com

United Network for Organ Sharing (UNOS)
1100 Boulders Parkway, Suite 500
P.O. Box 13770
Richmond, VA 23225-8770
1-888-TXINFO1
Web page: <http://www.unos.org>

American Nephrology Nurses Association
East Holly Avenue, Box 56
Pitman, NJ 08071-0056
Phone: 888-600-ANNA
Fax: 856-589-7463
Email: anna@ajj.com
Web: www.anna.inurse.com

Blood Pressure Association
www.bpassoc.org.uk

Official gateway to NHS organizations on the Internet
www.nhs.uk

Health information for patients and Health care professionals
www.healthsites.co.uk

British Diabetic Association
www.diabetes.org.uk

Diabetes Federation of Ireland
www.diabetesireland.ie

National kidney research fund
www.nkrf.org.uk

Action on smoking and health
www.ash.org.uk

Australian kidney association
www.kidney.org.au

Irish Kidney Association
www.ika.ie

Irish Health information
www.irishhealth.com

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www.fujisawausa.com

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Useful Forms

You may want to make extra copies of some of these forms before you fill them in.

PHONE DIRECTORY OF YOUR HEALTHCARE TEAM

Transplant team office phone number: _____

	<u>Name</u>	<u>Phone Number</u>
Primary Nurse:	_____	_____
Clinical Nurse Specialist	_____	_____
Transplant Coordinator	_____	_____
Nurse-Practitioner	_____	_____
Transplant Doctor	_____	_____
Transplant Surgeon	_____	_____
Social Worker	_____	_____
Nutritionist	_____	_____
Hospital Pharmacist	_____	_____
Physical Therapist	_____	_____
Psychiatrist or Psychologist	_____	_____
Other (_____)	_____	_____
Other (_____)	_____	_____

OTHER MEMBERS OF YOUR HEALTHCARE TEAM

Family Doctor	_____	_____
Dentist	_____	_____
Local Pharmacist	_____	_____
Laboratory	_____	_____
Other (_____)	_____	_____
Other (_____)	_____	_____

Patient's name

Pharmacy

Allergies

Pharmacy phone number

Drug	Strength	Directions	Number of Tablets/Capsules					
			Morning	Midmorning	Afternoon	Evening	Bedtime	

NOTES ON ADDITIONAL MEDICATIONS

RECORD OF LAB VALUES

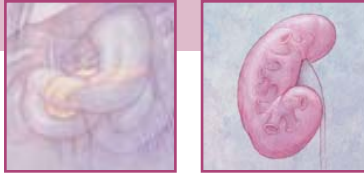
Patient's name _____

Normal Values

Date									
WBC (White Blood Cell)									
HCT (Hematocrit)									
PLT (Platelet)									
PT (Prothrombin Time)									
BUN (Blood Urea Nitrogen)									
CREAT (Creatinine)									
Ca (Calcium)									
PO4 (Phosphorus)									
Mg (Magnesium)									
Na (Sodium)									
K (Potassium)									
GLU (Glucose)									
Cholesterol									
Tacrolimus									
Cyclosporine									
Other (_____)									

QUESTIONS FOR YOUR TRANSPLANT TEAM

YOUR NOTES AND COMMENTS



Simultaneous Pancreas-Kidney Transplant (SPK)

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Congratulations!
You have a new kidney and
a new pancreas.
This section of the book is
just for you.

Many aspects of your care after a simultaneous pancreas-kidney (SPK) transplant are the same as they would be if you had had just a kidney transplant, but a few things are a little different. This section will cover just the things that are different after SPK transplantation. As a person with a new kidney and a new pancreas, you should read this section in addition to the rest of this book to learn everything you will need to know as you get ready to start this new part of your life. You may have had your pancreas transplant sometime after your kidney transplant. This section is still for you!

WHAT THE PANCREAS DOES

The pancreas, which lies below the stomach and above the intestines, performs many functions, (see Figure 1). In addition to producing digestive juices, it also produces insulin, which your body must have to be able to use sugar.

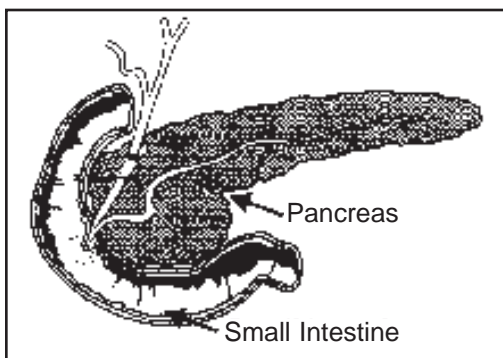


Figure 1. The pancreas

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.

When you eat, your pancreas is supposed to automatically send out the right amount of insulin to move glucose from your blood into your cells. In people with diabetes, however, the pancreas does not do this job right. As a result, glucose cannot get into the cells that need it to run, so it builds up in the blood, overflows into the urine, and passes out of the body, leaving the cells starving for fuel.

To make sure their cells get the energy they need, people with diabetes have to inject insulin that the pancreas does not make, and they must also control their diets, change their activities according to their doctors' advice, and test their blood sugar often.

WHAT YOUR SPK TRANSPLANT WILL DO

Your SPK transplant corrects two problems at the same time. Your native kidneys that were damaged by years of diabetes have been replaced by a new kidney that will filter the toxins out of your body; and your native pancreas has been replaced by a new pancreas that will produce insulin automatically, as your body needs it. SPK transplantation frees you from the two burdens of dialysis and daily insulin shots. That is why many patients' report that the quality of their lives is much improved after their SPK surgery.



THE LOCATION OF YOUR NEW KIDNEY AND PANCREAS

The new kidney and pancreas are usually placed next to each other in your body. The old pancreas is usually left in place, and the new pancreas is put a little to the right. The new kidney is placed to the left (See Figure 2).

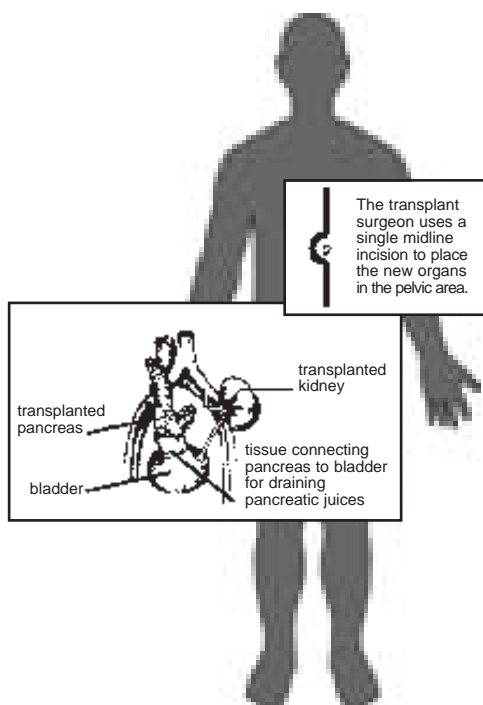


Figure 2. Location of your new kidney and pancreas.

DRAINAGE OF YOUR NEW PANCREAS

Besides making insulin, the pancreas makes proteins that help you digest. A new pancreas can be connected so that these proteins drain into either your intestines or your bladder.

These days, most SPK transplants are done so that the new pancreas drains into the bladder. With this technique, there is less risk of infection caused by bacteria in the intestines, and the digestive proteins can be

diluted safely by urine and removed from the body.

The digestive proteins draining into your urine may cause it to look a little unusual. It may look cloudy or contain little particles. It is important to watch for and tell your doctor about any change in the way your urine looks. Some things to look out for and report include:

- A change in the color of your urine
- A change in the smell of your urine
- Any sign of blood in your urine
- Any feeling of pressure or pain when you urinate
- **Inability to urinate**

NOTE: It is an emergency if you have a bladder-drained pancreas and cannot urinate. If this happens, contact your transplant team or doctor right away. He or she will be able to put a catheter into your bladder to drain your urine.

Your surgeon may decide to have your pancreas drain into your intestine. If so, your transplant team will give you more information about this.

WATCHING YOUR URINE AMYLASE LEVEL

One unique aspect of having a SPK transplant is the opportunity to use urine tests to keep track of your new pancreas' functioning. Having a bladder-drained pancreas gives you an early-warning system for pancreas rejection.

By measuring the levels of the digestive protein amylase in your urine, your doctor can check on how well your pancreas is working. After your pancreas transplant,



your urine will have higher-than-normal levels of amylase. If these decrease, it may be an early sign of rejection and when rejection is caught early, it is easier to treat. Therefore, you will probably be asked to collect urine samples for amylase measurements every time you go to the lab for tests. Your lab will tell you how to collect this urine sample at home.

WATCHING YOUR GLUCOSE LEVEL

Just as your new kidney should begin to make urine right away, your new pancreas will probably begin making insulin right away as well, and you will most likely have normal levels of blood sugar soon after your surgery. However, you may need to take insulin for a short time after your transplant.

To make sure your pancreas is working as it should, you will probably continue to monitor your blood sugar, though not as often as you used to. Your doctor may give you a glucose-monitoring program to follow.

If any of your blood-sugar readings are higher than _____, you should call your transplant team.

OTHER TESTS

Most of the other tests you will need will be pretty much the same as if you had had a kidney-only transplant. About once a year, you may be asked to return to your transplant center for an evaluation.

ANTI-REJECTION MEDICATION AFTER SPK TRANSPLANTATION

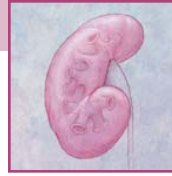
Taking your anti-rejection medications is as important after a SPK transplant as after a kidney-only transplant. The rules are the same; Your body sees your new kidney and pancreas as foreign objects and will try to reject them. To stop this rejection, you must take your anti-rejection medications every day, as prescribed, for the rest of your life.

It is common for transplant recipients to forget to take their medication or to skip a few doses after awhile. Don't do it. As long as you have your new kidney and pancreas, you will need to take the medication that come with them; not taking them will cause rejection.

It may seem hard to have to remember to take medications every day, but you are already used to it. You have already had dialysis and/or daily insulin, and most SPK recipients say that it is much easier to take their anti-rejection medications, side effects and all, than it was to take care of their diabetes.

The anti-rejection medications taken after a SPK transplant are the same as those taken after a kidney-only transplant. For more information about each of these medications, see the Information About Medications section of the handbook.

People who have had SPK transplants sometimes take slightly higher doses of some of these medications for a while because of the higher risk of early but reversible rejection. These higher doses may cause the risk of developing an infection to be slightly higher.



INFECTION AFTER SPK TRANSPLANTATION

Infection is always a risk for people who are taking anti-rejection medication. If you are taking higher doses of these medications to avoid rejection, you will just need to be a little extra careful about avoiding infection.

The infections that you need to watch out for are the same as the ones a kidney-only recipient has to watch for. You can read about these infections in the Complications section of the handbook. You should also read the advice about avoiding infections in the section titled Resuming Normal Activities.

As a reminder, here are the signs and symptoms of infection that you should watch for and report to your transplant team:

- Cold
- Flu-like symptoms
- Sore throat
- Skin rashes or sores
- Sores in or around the mouth
- Fever
- Unusual vaginal discharge

Although fever is a main sign of infection, you may not always run a fever when you have an infection. Therefore, if you have no fever but you have other signs of infection, call your transplant team or doctor right away.

REJECTION AFTER SPK TRANSPLANTATION

Rejection is always possible after a SPK transplant, just as it is after a kidney-only

transplant. The advantage you have is that you have an extra way of checking for signs of rejection that kidney-only recipients do not have. As we said earlier, a lower amount of amylase in your urine can be an early-warning sign of rejection of your pancreas.

Here are other signs of rejection you should be watching for:

- Fever
- Fatigue/weakness
- Less urine output
- Tenderness near your new kidney or pancreas
- Swelling of your hands and/or feet

SPK recipients can have rejection in the kidney or pancreas separately or in both at the same time. In general, however, rejection of the kidney usually comes before rejection of the pancreas, so the kidney is watched for signs of rejection. Treatment for rejection of either one usually prevents or treats rejection of the other as well.

As a SPK recipient, you may have a higher risk of early, reversible, rejection than a kidney-only recipient would have, and most people do have a few episodes of rejection. Generally, though, this stops happening after a while. Most SPK recipients are feeling much better within 3 months, and if you take your medications faithfully, there should be very few complications after the first year.

SPK transplantation is an operation that makes life better rather than saving your life.

Therefore, if either your pancreas or your kidney fail, you can return to your previous diabetes and kidney-failure treatments, and you may be able to have another transplant.



DIET AND NUTRITION

Eating right is as important to your health as it is after a kidney-only transplant, so be sure to read the information about diet and nutrition in the Resuming Normal Activities section of the handbook

One important difference is that, with a new pancreas, you will probably be able to be a little more relaxed about your diet and try some treats once in a while. Mainly, though, you will want to follow a low-fat, low-sugar diet. Healthful eating is important for preventing many diseases, not just for controlling diabetes, so follow your transplant team's instructions carefully.

Another difference for you, if your new pancreas drains into your bladder, is that you will experience a loss of bicarbonate. As a result, you may become dehydrated. To avoid this, make sure you drink 3 to 4 quarts (litres) of liquid every day. You may have to take bicarbonate supplements.

If you become dehydrated at home, you may have to go back into the hospital.

FOOT CARE

Even though your diabetes is "cured" by your new pancreas, studies show that you will still have some risk for foot complications that usually go with diabetes, including infection. Therefore, after your surgery, you will need to take these steps to care for your feet:

- 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 yourself. Have a doctor remove them.
- Wear comfortable, well-cushioned shoes. Do not wear high heels, and do not walk barefoot.
- Wear cotton socks, which absorb moisture. Change them every day.





Sources Of More Information

For more information on SPK transplantation, you may want to contact the following organizations:

American Diabetes Association

Attn: Customer Service
1701 N. Beauregard Street
Alexandria, VA 22311
Phone 1-800-DIABETES
Web: www.diabetes.org

British Diabetic Association

www.diabetes.org.uk

Federation of Ireland

www.diabetesireland.ie

**International Pancreas Transplant
Registry**

www.iptr.umn.edu

International Transplant Nurses Society

www.itns.org

**National Institute of Diabetes & Digestive
& Kidney Diseases (NIDDK)**

www.niddk.nih.gov

