

AFTER THE SURGERY

Congratulations!

Your transplant operation is over and you now have your new kidney and/or pancreas. As you are recovering, we will begin to prepare you to go home. This booklet will give extremely important information, including specific guidelines on how to take care of yourself for the rest of your life. It is very important that you learn this information. The transplant coordinators, doctors, nurses, and pharmacists will review the material with you.

It is necessary that you understand every detail of your care before you are released from the hospital. You must know what medications to take, at what time, what amount, and for what reason. You must also know the signs and symptoms that could indicate problems with your transplant, how to watch for them, and how to report them.

You will also be responsible for monitoring your health at home and for keeping daily records. You must bring these records with you each time you come to the Kidney Transplant Clinic for a follow-up appointment. This will allow us to monitor your condition with you, and to be on the lookout for any problems that may occur.

Surgery

Your kidney transplant surgery generally lasts for 3-4 hours while a pancreas transplant lasts for 6-8 hours. After surgery, you will either go to the Post Anesthesia Care Unit, Surgical Intensive Care Unit, or Patient Care Area 2300. Kidney transplants generally have an incision in the lower abdomen area on either the right or left side. In some people, the surgeon may choose to make the incision up and down the middle of your abdomen. You may have a drain to drain fluid from the wound. Pancreas patients have a midline incision with a drain in place. A catheter will be in place to drain urine from the bladder that will stay about 4 days.

Kidney transplant patients are usually up and moving around the next day. Once your diet progresses, you will start preparing to go home. Average hospital stay is about 4-6 days.

Pancreas patients normally stay in the hospital about 7-10 days. Your bowels take longer to wake up so your diet will not start for about 4 days. Again once you are taking fluids you will begin to learn how to take care of yourself.

Your education about how to care for yourself begins now. The transplant coordinator will speak with you and your family about monitoring for infection, when to call the transplant team and other common post-surgical topics. The transplant pharmacist will teach you about your medicines and you will begin to take your medicines with the help of the staff nurses prior to going home.

You can expect to be discharged from the hospital within 4-6 days for a kidney transplant and 7-10 days for a pancreas transplant. You will be required to have frequent clinic visits usually once a week for the first month then every couple of weeks and so forth. Remember that each person is different and your recovery depends on your progress or development of complications.

Your Long-Term Outlook

While a kidney transplant represents a great hope for people with end-stage renal disease, various complications can occur after kidney and pancreas transplantation. These may include rejection, infection, technical complications, and recurrence of original kidney disease.

During your hospitalization, we will teach you about your medicines, how to check your temperature, and monitor your incisions and drains daily. Often the first sign of rejection is seen in your lab work. That is why we ask you to come to clinic and to have your labs checked frequently. Any change in your renal or pancreatic function will be evaluated thoroughly. It is important that we carefully decide the cause of your symptoms so that we can treat you appropriately.

While complications are always a possibility, it is important to remember that the single most important factor in the outcome of your transplant is **YOU**. **You** must follow doctor's orders, **you** must monitor yourself for signs of rejection and infection, **and you** must take your medications. Kidney and pancreas transplantation is a lengthy commitment that will affect every aspect of your life. So take your responsibility seriously - and take good care of yourself.

The Duke Kidney Transplant Team knows that going through a kidney and/or pancreas transplant can be a trying time, and we want to help you through this process. Please let us know any way we can help ease your confusion and anxiety. We look forward to working closely with you.

MEDICATIONS

You will take many medications after your surgery. They will be used for different reasons but all are important to your recovery and health. The transplant pharmacist will help you understand the purpose of each medicine. You will take the most number of medications during the first year after transplant. You will take some of the medicines for the rest of your life.

Please contact a pharmacist for other questions. The information below is a reference.

Safety Information About Medications

Please observe the following precautions when taking your medications. Remember that medicines can be dangerous, even fatal, if taken accidentally by a child. Make sure your pharmacy has put your prescription medications in childproof containers, and store all your medications out of the reach of small children. In addition:

- ◆ Keep a list of medicines and doses in your wallet or purse.
- ◆ Bring a list of your medicines to each clinic visit along with medicines for the day.
- ◆ Take each medication exactly as prescribed.
- ◆ Keep all medications in their original containers with labeling that shows the name, dosage, and expiration date. Keep your medications in a dry place away from heat and direct sunlight.
- ◆ Report any side effects of medications to the transplant team.
- ◆ Never change or skip a dose of medication. Remember that if you stop taking your immunosuppressive medications, your body will reject the transplanted organ. If you ever forget to take your medications, call your transplant coordinator as soon as you realize your mistake.
- ◆ Should you experience any vomiting that prevents you from taking your medications, or if you vomit immediately after taking medications, call your transplant coordinator.
- ◆ Do not allow yourself to run out of your anti-rejection medication. Always keep at least an extra two weeks' supply on hand.
- ◆ When traveling, do not pack your anti-rejection medication and other medications in luggage that will be checked. Keep it with you in a carry-

on bag or your handbag. Always have your anti-rejection medication with you!

Other Medications

Do not take medication prescribed by other physicians until you check with us first. Because of your kidney and/or pancreas transplant and the medications you are taking, we prefer that you do not take some other medications. Medications like Ketoconazole, Biaxin, Erythromycin, and Dilantin should be avoided if possible. Please call your transplant coordinator about any new medication prescribed for you before you get the prescription filled.

Be cautious about over-the-counter medications, too. You may take Tylenol as needed for minor pains, and you may take a laxative of choice as long as your kidney is functioning. In general, we ask you to avoid using Non-Steroidal Anti-Inflammatory Agents or NSAIDs for pain. Examples of NSAIDs are Advil or Motrin (ibuprofen), Anaprox, and Naprosyn (Naproxyn) these medications can make your kidneys fail. Please do not take any other over-the-counter medications without checking with your transplant doctor or coordinator.

Immunosuppressants

Immunosuppression is a concept you need to understand in order to understand your care. Your immune system is a part of you that is able to recognize when foreign substances enter the body. Your immune system fights infection by recognizing and destroying foreign matter such as bacteria, viruses, and fungi.

Your transplanted organ is new and foreign to your body, and your immune system can recognize this. If something is not done to stop this process, your body's immune system will "see" your kidney and/or pancreas and soon begin to destroy it. Preventing this natural response of the body's immune system is called **immunosuppression**.

Prograf, Cellcept, Rapamune, Cyclosporin, and Prednisone are known as immunosuppressive drugs. They are given to transplant patients in order to

decrease the body's ability to recognize and destroy foreign substances. Essentially, the body is "tricked" into thinking your new kidney or pancreas is not different from your old kidney or pancreas. Without these medications, rejection of the transplanted organs would certainly occur. It is therefore very, very important that you take these drugs exactly as prescribed for as long as you have the transplant. **If you stop taking these medications, your body will reject the kidney or pancreas. There are no ifs, ands, or buts about it, if you stop taking these medications you will lose this kidney or pancreas.**

Being on immunosuppressive drugs does mean that you will be at greater risk for developing infections. It is important, therefore, to take some sensible precautions to avoid infection whenever possible. We will discuss these precautions later.

Information about 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. This section is a general overview. Always follow the instructions given to you by your transplant team. Your transplant doctor will not prescribe all of the medications described in this handbook.

Tacrolimus (also known as Prograf or FK-506)

Tacrolimus is an anti-rejection medication that specifically stops the action of certain immune cells called T-cells. We commonly call it Prograf. Prograf is the most common immunosuppressant medication started after kidney or pancreas transplant. In some cases we may use Cyclosporin or Sirolimus (see information below).

It is very important that you take Prograf twice a day at regular intervals twelve hours apart. These capsules should be swallowed whole, do not bite or chew the capsules.

You will probably have frequent lab tests during the first few months to keep watch on the effectiveness and side effects of Prograf.

On a day when your Prograf level is measured, do not take your morning dose until your blood has been drawn.

The benefits of taking this drug if you are pregnant or breastfeeding must be weighed against the possible danger to you, your unborn child, or infant.

Call your transplant team immediately if you think you are pregnant.

Prograf Side Effects

Unfortunately, there are side effects to any medication. Not all of the side effects are listed and everyone does not get all these side effects. This document is simply to help you become more familiar with this medication. Please report to your transplant doctor if you experience these or any other unusual symptoms.

- ✓ **Altered Kidney function:** If the level of Prograf in your blood is too high, it can be harmful to your kidneys. You will not usually experience any symptoms, but your creatinine level, which is a measure of kidney function, may become elevated. The transplant team will follow your lab work closely and will adjust your dose accordingly.
- ✓ **Headaches:** Notify your transplant team if headaches are severe and bothersome.
- ✓ **High Blood sugar:** You may experience high blood sugar (diabetes) as a side effect (especially early after transplant) and have to watch your diet or even need to take insulin injections as part of your post-transplant care.
- ✓ **Numbness, tingling, burning sensation and/or increased sensitivity in hands and feet:** These symptoms can be annoying, but are usually not uncomfortable.
- ✓ **Fine hand tremor:** Some patients experience a trembling of the hands, especially in the first month and if the blood level is too high. If this problem continues, please notify your transplant doctor.
- ✓ **Hair loss:** Loss of hair in specific areas, most commonly the head (or when brushing your hair and the hair comes in wads), may occur.
- ✓ **High Potassium levels:** You will need to restrict the amount in your diet. The transplant doctor will let you know if you experience this side effect.

Cyclosporine (also know as a Sandimmune, Neoral, or Gengraf)

* Please NOTE: these products (although all are Cyclosporine products) are NOT interchangeable! Let your transplant doctor know if you are taking a

different Cyclosporine product than the product you were originally prescribed.

Cyclosporine is an anti-rejection medication that specifically stops the action of certain immune cells that are involved in the rejection process known as T-cells.

It is very important that you take Cyclosporine twice a day at regular intervals twelve hours apart. These capsules should be swallowed whole, do not bite or chew the capsules.

You will probably have frequent lab tests during the first few months to keep watch on the effectiveness and side effects of Cyclosporine.

*Do not remove the capsules from the foil package in which they are wrapped more than a week before you take them. Longer exposure to air may damage the capsule and reduce the effectiveness of the medication.

Cyclosporine Side effects

- ✓ **Altered Kidney function:** If the level of Cyclosporine in your blood is too high, it can be harmful to your kidneys. You will not usually experience any symptoms, but your creatinine level, which is a measure of kidney function, may become elevated. The transplant team will follow your lab work closely and will adjust your dose accordingly.
- ✓ **Headaches:** Notify your transplant team if headaches are severe and bothersome.
- ✓ **Flushing:** A brief period of warmth in your face for one to two hours after Cyclosporine. The feeling usually disappears on its own.
- ✓ **Numbness, tingling, burning sensation and/or increased sensitivity in hands and feet:** These symptoms can be annoying, but are usually not uncomfortable.
- ✓ **Fine hand tremor:** Some patients experience a trembling of the hands, especially in the first month and if the blood level is too high. If this problem continues, please notify your transplant doctor.
- ✓ **Hair growth:** Increased hair on the face, arms and body is common, but usually not a problem.
- ✓ **Gum swelling:** Good dental hygiene is necessary to keep gums healthy. You should brush at least twice daily with a soft toothbrush and use

dental floss daily. We recommend that you see your dentist every six months. Please let your transplant doctor know if you experience swelling of the gums.

- ✓ **High blood pressure:** If this becomes a problem it will be treated with appropriate medication. We will ask you to monitor your blood pressure at home.
- ✓ **High Potassium levels:** You will need to restrict the amount in your diet. The transplant doctor will let you know if you experience this side effect.

Sirolimus (also known as Rapamune)

Sirolimus or Rapamune is another medication that suppresses the activity of the immune system (blocking T-cell responses) but in a different way than Prograf or Cyclosporine. Since it works differently than the previous anti-rejection medications, sometimes it may be used in combination with either Prograf or Cyclosporine. Sirolimus is a good choice as an immunosuppressant drug when a patient has decreased kidney function or severe chronic rejection.

Sirolimus is taken only once a day (usually in the morning) but should be taken at the same time each day as well. It should be taken at least 4 hours apart from your dose of Cyclosporine.

Sirolimus Side Effects

The following may be side effects of Sirolimus. Not all side effects are listed in this document. Please report to your transplant doctor if you experience these or any other unusual symptoms.

- ✓ **Upset Stomach:** You may experience nausea, vomiting, or diarrhea. Do not self-medicate more than a day without letting your transplant coordinator or doctor know of your symptoms. Try taking the medication with food (this may lessen the possibility of upset stomach).
- ✓ **Heartburn:** You may experience a feeling of burning in your stomach or burning in the throat area. You may try taking Mylanta or Tums to stop the heartburn but it's important not to take these medications at the same time as Sirolimus (Prograf or Cyclosporine). Mylanta or Tums may

bind the anti-rejection medications in the stomach and decrease their absorption from the stomach.

- ✓ **Low Blood Cell Counts:** Red Blood Cells (RBC), White Blood Cells (WBC), and platelets may be decreased while you are taking Sirolimus. The only way we can tell if this is occurring is if you are having your blood drawn regularly as directed by your doctor. Loss of RBC'S (anemia) may make you feel tired and weak and loss of WBC's (neutropenia) will make you at risk for serious infections. Loss of platelets increases your chance of bleeding (nose bleeds or gums bleed) or easy bruising. Meeting with the transplant team or your local doctors directed by the coordinator is essential to helping you avoid these problems with Sirolimus.
- ✓ **Headache:** Notify your transplant doctor if headaches are severe and bothersome.
- ✓ **High Cholesterol:** You may experience high cholesterol as a side effect of Sirolimus. If cholesterol is not controlled, it can increase your risk for a heart attack. It is important to have your blood cholesterol checked regularly as directed by your doctor. High cholesterol levels require you to eat a healthy diet rich in fiber, vegetables, fruits, and limited amounts of meats and fats. High cholesterol often means that you will need to take medications such as Zocor, Lipitor, or Pravachol to reduce your cholesterol level.

Regardless of which anti-rejection medication you are prescribed (Cyclosporine, Prograf, or Sirolimus); you must follow these directions to optimize your anti-rejection regimen.

Determining How much Immunosuppressant is Right for you

It is important to determine the amount of anti-rejection medication in your blood stream so that your dose can be adjusted to your individual needs. This blood should be drawn in the morning before you take your first dose. Each time you come for a Kidney Transplant Clinic visit or have labs done at home, we will be drawing blood for a Cyclosporine, Prograf, or Sirolimus level. On these days, bring your morning dose of Cyclosporine, Prograf, or Sirolimus with you so that you can take it as soon as the blood sample has been drawn. You may take all other medicines prior to coming to clinic.

You will receive a letter to take to your local lab to have your blood drawn and where to send the results to the Transplant Office.

Grapefruit and grapefruit juice increase the concentration (or levels) of Cyclosporine, Prograf, and Sirolimus. We suggest you avoid these products.

Prednisone

Prednisone is another medication that helps to prevent rejection by suppressing body's immune system. Because of Prednisone's actions within the body, it belongs to a class of drugs known as steroids. After transplant, you will start taking a moderate dose of Prednisone, but this dose will be tapered (decreased) rapidly to a lower dose to avoid as many side effects as possible.

Prednisone Side Effects

Not every patient experiences all of these side effects, but they do occur frequently enough that we want you to be aware of them. Most of the time, the side effects are dose-related. In other words, as your dose is decreased the side effects should become less troublesome. Side effects of Prednisone include:

- ✓ **Increased Appetite:** It is very important that you watch your calories and maintain your ideal weight. Increased appetite does not have to mean increased weight!
- ✓ **High blood sugar:** Prednisone (like the other anti-rejection medications listed before) will increase blood sugar levels. Diabetics will have to take more insulin or if they take an oral agent may have to start insulin.
- ✓ **High blood pressure:** Prednisone (like the other anti-rejection medication listed before) may increase your blood pressure. We may ask you to monitor your blood pressure at home.
- ✓ **High Cholesterol:** Prednisone may increase your cholesterol level. It is important to have your cholesterol level checked regularly.
- ✓ **Change in appearance:** You may notice a rounded face, larger abdomen, and thin skin. You may bruise easily.
- ✓ **Increased sweating:** This often occurs at night.
- ✓ **Acne on the face, back, and chest:** Wash your skin two to three times a day and keep the area as clean and dry as possible. If acne becomes

problematic, an antiseptic wash followed by application of 10-percent benzoyl peroxide ointment is usually helpful.

- ✓ **Muscle weakness (particularly in the legs):** Exercise! Walking is one of the best ways to strengthen leg muscles.
- ✓ **Eye problems:** Inform the Transplant Team of any blurring or other changes in vision.
- ✓ **Bone/Joint problems:** Steroids may cause bone loss. Tell us if you have persistent bone or joint pains; you may need x-rays or a referral to bone specialist.
- ✓ **Delayed wound healing:** Surgical incisions do not heal as quickly when taking Prednisone. Inform the Transplant Team if you notice increased drainage or redness around your wound.
- ✓ **Emotional changes:** You may notice an increase in restlessness or moodiness while on high doses of Prednisone.

Cellcept (Mycophenolate Mofetil)

Mycophenolate is an anti-rejection medication that works by decreasing the T-cells in the body that cause rejection. You will have to take this drug as long your transplanted organs function.

The side effects with Cellcept are:

- ✓ **nausea, vomiting, diarrhea:** We will decrease the dose if the symptoms are persistent.
- ✓ **Decrease in white blood cell, platelet count, and red blood cell counts:** We will monitor your lab values and adjust the dose if need be.

Antibiotics or Anti-Infective Medications

Septra DS (Bactrim DS, TMP-SMZ or TMP-SMZ)

Septra is a combination of two different antibiotic compounds (trimethoprim and sulfamethoxazole) which is used to help prevent a specific bacterial infection known as Pneumocystis Carnii Pneumonia or PCP. This bacteria causes the type of pneumonia seen in patients who have a suppressed immune system.

If you are allergic to sulfa, you should not take this medication. We will prescribe a different antibiotic.

You take this medication three times a week for one year.

Side Effects:

- ✓ **Nausea, Vomiting, diarrhea, loss of appetite**
- ✓ **Headache**
- ✓ **Increased sensitivity to sunlight:** Increased chance of bad sunburn, You must wear protective gear: sunglasses, hats, long sleeve when outdoors. Transplant patients have a higher risk of developing skin cancer after transplant.

Cytovene (Ganciclovir) or Valcyte (Valganciclovir)

Ganciclovir is an anti-viral medication that treats infections and prevents infections caused by the Cytomegalovirus (CMV) virus. CMV is a disease that normally presents as a cold/flu in people with a normal immune system. But once your immune system is suppressed, this virus can trigger and cause a severe infection. It can be given intravenously (IV) or orally (by mouth).

When given intravenously (IV), usually once or twice daily, Ganciclovir is usually administered in the hospital. However after the initial dose, it may receive (IV) at home with the assistance of a home health agency. A usual IV course of Ganciclovir treatment is 14-21 days.

Ganciclovir is available in pill form (called Cytovene) and some patients will need to take these pills for 3 months after transplant in order to prevent infection with CMV. Taking Ganciclovir by mouth often means taking as many as 12 pills of Ganciclovir a day.

Side effects:

- ✓ **Abdominal pain**
- ✓ **Diarrhea**
- ✓ **Fever,**
- ✓ **Headache, tingling in the hands and or feet**
- ✓ **Decreased white blood counts**

Because Ganciclovir is a large pill and a patient may have to take up to as many as 12 pills a day, Valganciclovir was developed to treat CMV.

Valganciclovir can be used to treat CMV infection. It is given once a day and only requires usually 2 tablets.

Antacid Medication or Anti-Ulcer Medication

Axid

Zantac (Ranitidine), Pepcid (Famotidine), Prilosec (Omeprazole), Protonix (Pantoprazole)

These medicines are used to decrease the amount of acid in your acid. You are at risk for developing an ulcer because you are taking Prednisone. You will take one of these medicines after transplant to reduce the risk of ulcer.

Side effects of these medications include abdominal pain, nausea, and headache.

Antihypertensives or Blood Pressure Medications

Many kidney transplant patients already were taking antihypertensive medications to control their blood pressure. We may change the medication you are on an after a transplant. Some medications are better for your kidney after a transplant than the ones you may have been taking while on dialysis.

Colace or Bowel Stimulants

While you are taking pain medication and returning to you typical activity and diet, you may experience constipation. Prescription pain medication also contributes to constipation. You should drink plenty of fluid each day. Taking a stool softener such as Colace along with a bowel stimulant like Senokot will help you from being constipated. These may be prescribed while you are in the hospital. Please continue to take these while you are taking pain medications.

CARING FOR YOURSELF AFTER DISCHARGE

When you leave the hospital after your transplant, you most likely will go home. Clinic visits will be once a week. Caring for yourself requires the support of your family, good common sense, and following these instructions.

Daily Care and Activity

- ◆ Activity after discharge should be focused on increasing activity each day while incorporating some rest periods. Walking is an excellent activity.
- ◆ No driving, no lifting > 5 pounds for about 4 weeks.
- ◆ Do not return to work until cleared by your transplant physician (usually 8-12 weeks).
- ◆ Use pain medications prior to starting an activity. While taking pain medication, drink plenty of fluid and use a stool softener like Colace.
- ◆ Continue low salt diet.
- ◆ Staples from surgery will be in place for 3 weeks as steroids reduce tissue healing time.
- ◆ May shower with staples and tubes in place. Cleanse sites with antibacterial soap. Pat dry being careful not to pull. Do not use powder or lotion around incision or tube site.

Problems to Report to the Transplant Nurse on-call

- 1) Fever > 100.5°F, chills, nausea, vomiting (more than once), watery diarrhea
- 2) Inability to take medicines
- 3) New pain that is sudden or sharp
- 4) Drainage from wound that is cloudy, has an odd smell, or is very bloody. Pink-yellow fluid is OK.
- 5) Severe headaches not relieved with Tylenol or pain medicines
- 6) You are admitted to the hospital at home for any reason

Contacting the Kidney Transplant Nurse On-Call

- ◆ *Transplant Nurse Coordinators are available 24 hours a day, 7 days a week. We ask that you use judgment to decide the urgency of your call.*
- ◆ *If the call can wait until normal business hours: Call the Renal Transplant Office at 919-684-5859. The office is open from 8:00 am – 4:30 pm. If the post-op coordinator is not available when you call, leave a message and your call will be returned. We ask that you call the office for non-urgent questions or anything that can wait for a response. We also ask that you call a day in advance for prescription refills and appointments to allow us time to do those requests.*
- ◆ *If it is the evening, nighttime or the weekend and the call is urgent call 919-684-8111 and ask the operator to page 5153. Do not ask for the surgery intern on-call.*
- ◆ *Stay on the line while the operator places the page. The call will be returned immediately and the operator will connect you with the coordinator.*
- ◆ *Please recognize that the nurses are not at the hospital during non-business hours. We are available for urgent needs. We want to attend to your needs in the most efficient manner possible.*

Preventing Infection

- ◆ Handwashing, handwashing, and handwashing are the keys to preventing infection, especially during the first year.
- ◆ Many people will want to visit when you return home. Be sure to ask people to visit at a later time if they have been sick or if members of their family have been sick recently. Avoid large crowds.

Resources

We want to help you and your family deal with concerns that may arise after your transplant. Your social worker, transplant coordinator, and physician can give you resources for your particular needs. The following list of resources may be useful.

Information and Resources

Duke University Health System
www.dukehealth.org
www.organtransplant.duke.edu

Organ Donation
United Network for Organ Sharing
1-888-894-6361
www.unos.org

Carolina Donor Services
1-800-200-2672
www.carolinadonorservices.org

Kidney Disease
American Kidney Fund
1-800-729-6682
www.kidneyfund.org

National Kidney Foundation
1-800-622-9010
www.kidney.org

Diabetes
American Diabetes Association
1-800-DIABETES
www.diabetes.org

Insulin Free World
www.insulin-free.org

Transplant Information
www.transplanthealth.com
www.transweb.org
www.unos.org

National Foundation for Transplant
1-800-489-3863
www.nft.org

Social Security Disability Hotline

1-800-638-6810

N.C. statewide information and assistance related to Social Security, Disability, or SSI

Medicare

1-800-672-3071

Information on Medicare coverage

County Department of Social Services (DSS): Medicaid persons with low income and few assets may apply in the county in which they reside for assistance with medical expenses. DSS also manages food stamps, AID to Families with Dependent Children, Fuel Assistance, and other emergency funds.

Social Security Administration

1-800-772-1213

Assists with applications for retirement, survivorship, disability, and supplemental security income and Medicare benefits.

Veteran's Administration Benefits Office

1-800-827-1000

Veteran's Affairs Medical Center (Durham)

(919) 286-0411

N.C. Division of Veteran's Affairs

(919) 733-3851

N.C. Division of Vocational Rehabilitation

(919) 733-3364

A state-sponsored program that provides services to help disabled persons obtain jobs. Services include evaluation, special training, job counseling, and funding for services to help you.

MANAGING AND AVOIDING COMPLICATIONS

Rejection

Rejection of your transplanted kidney or pancreas can occur at any time following your surgery. Episodes of rejection most commonly occur during the first few months after transplant. Try not to become too alarmed if you are told that you are experiencing rejection. Episodes of rejection are expected, and other than taking your immunosuppression medications correctly and following doctor's orders, there is nothing you can do to prevent them from happening.

Rejection can be reversed if it is detected early. For this reason, it is important for you to be able to recognize signs and symptoms of rejection. This include:

- ◆ **Fever(greater than 100.5)**
- ◆ **Decreased urine output**
- ◆ **Weight gain or swollen feet and ankles**
- ◆ **Pain, swelling, and tenderness around the kidney**
- ◆ **General flu-like symptoms**

Rejection may occur without any symptoms that you can detect. *The best sign of rejection is a rising creatinine.* That is why you need to get your blood tested frequently.

Treatment of rejection usually consists of three to five daily doses of intravenous Methylprednisolone. This drug is also known as Solu-Medrol, and is an intravenous form of Prednisone. You will usually be admitted to the hospital for this treatment.

If the Solu-Medrol doesn't turn the rejection around, we have other medications to use. We can use Thymoglobulin or OKT3. These drugs destroy cells responsible for rejection. Treatment can vary from 5-10 days. Both drugs are given intravenously in the hospital.

If the rejection is thought to be mild, the way to reverse it may be by increasing your oral prednisone dose, then rapidly decreasing back to baseline. If this method is chosen, your transplant physician will give you

specific instructions. You probably will not have to be in the hospital for this treatment.

As advances are made in the treatment of rejection and new medications are developed, you may be offered newer treatment options. The new medications and how they work will be explained to you when the treatment is offered. As always, we encourage you to ask questions. We are a team and we have to work together.

Almost always, rejection can be reversed. There is a type of rejection known as chronic rejection that is progressive deterioration of the transplanted organ. There is no treatment for this type of rejection. Occasionally, severe rejection cannot be reversed and dialysis will need to be started again. The rejected kidney will be removed only if it causes you to be ill.

Biopsies

After your transplant, you may need to have a ***biopsy*** of your transplanted kidney. A ***biopsy*** is a piece of kidney tissue that is removed from your body with a needle and studied under a microscope. Biopsies are usually done when the creatinine is rising for unclear reasons. Biopsies can tell the transplant team just what is going on inside the kidney.

A biopsy of your transplanted kidney will be done in the hospital. You will be taken to the x-ray department, where a small amount of jelly will be placed on your abdomen over the kidney transplant. A small box-like instrument called a transducer is then rubbed over the jelly, and a picture of transplanted kidney is shown on a nearby screen. This is an ultrasound picture. Your transplant physician will clean the skin over your kidney with an antiseptic solution, and numb a small area with Xylocaine. When the area of skin is numb, a tiny incision is made, and then a needle is inserted into the kidney, using the picture on the screen as a guide. You will feel a sensation of pressure as the needle goes into the kidney. Once the needle is in the proper place in the kidney, it only takes a few seconds to withdraw the piece of tissue. The biopsy needle makes a loud noise when it takes the tissue out. Often two separate needle sticks for samples will be done. Pressure will be held over the needle site for a few minutes to stop any bleeding that may occur.

After the biopsy is finished, you will return to your room on a stretcher. You will be instructed to remain in bed for the next 4-6 hours, and the nurses will check your pulse and blood pressure frequently. Some transplant patients pass a small amount of blood in their urine after a biopsy. This is usually nothing to worry about and clears up quickly. Always let the nurses check the urine after a biopsy.

Preliminary results of the biopsy may be ready in a few hours, but the final results take about 24 to 36 hours.

Infection

Your immune system is the part of your body that is responsible for fighting infection. When the immunosuppression drugs weaken this system in order to prevent rejection of the transplanted kidney, you become more susceptible to infections. Your susceptibility to infection is directly related to the amount of immunosuppression that you are receiving at any given time. Therefore you need to be most careful in the first couple of months following transplant and for the first month after rejection treatment.

Bacteria, viruses, or fungi may cause these infections, and can be quite serious and even life threatening. It is therefore very important that you try to prevent infections by avoiding large crowds, especially in closed-in places, and people with contagious illnesses. It is very important that you learn to recognize signs and symptoms of infection and report them to transplant physician immediately so that the proper therapy can be started as soon as possible.

The highest level of immunosuppression is immediately after the transplant operation. One of the best methods to prevent infection is good handwashing. Everyone who comes into your room will be required to wash their hands thoroughly to prevent transfer of bacteria, viruses, and other microorganisms to you.

Symptoms of Infection

If you experience any of the following symptoms of infection, you should notify your transplant doctor or coordinator immediately. As always, if there is ever a question, please call and ask!

- ◆ Temperature greater than 100.5°F or 38°
- ◆ Productive cough, change in color of sputum, or shortness of breath
- ◆ Sores, blisters, or lumps
- ◆ Chills or shaking episodes
- ◆ Flu-like symptoms or severe cold symptoms
- ◆ Drainage or swelling from a cut or wound
- ◆ Nausea, vomiting, or diarrhea that is severe and prolonged (lasting more than 24 hours)
- ◆ Increase in fatigue and decrease in exercise tolerance
- ◆ Burning on urination, or very frequent urination
- ◆ Weight gain or loss of more than 5 pounds in a week

Common-Sense Precautions

Infection in a transplant patient can be quite serious, even life-threatening. It is therefore very important that you take some precautions to prevent infection whenever you can.

Especially during the first three months following your transplant, we urge you to practice frequent handwashing. We do not recommend wearing a mask, but encourage you to avoid crowded spaces with coughing and sneezing people. This is most important in the flu season. If you wash your hands frequently and avoid close contact with potentially sick people you will escape most common germs. We recommend that you and your family get a flu shot every year, early in the fall, unless your transplant was within the last six months.

It is important that you avoid large crowds, where someone with a contagious illness could be present. This does not mean that you must always stay at home; it just means using common sense. For example, plan to eat out when restaurants are not crowded, for an early lunch or dinner. Matinee showings of movies are rarely crowded, but later shows often are.

It is also important to avoid a crowd in your own home. If you are staying in a small apartment after transplant, do not invite guests and family members to come out and see you right away. It is best not to have a large number of houseguests at any one time for at least two months after your transplant. For those people who do visit, please be sure they have not had recent infections, colds or exposures to childhood illnesses like the measles.

West Nile Virus

West Nile virus is a disease caused by a virus that is transmitted by mosquito bite. With the introduction of West Nile Virus, immunosuppressed patients are at higher risk for this disease. Prevention of West Nile Virus:

◆ **Decrease number of mosquitoes by eliminating sources of standing water:**

- Flower pots
- pet water bowls
- birdbaths
- swimming pool covers
- clogged rain gutters

◆ **Decrease number of mosquito bites**

- wear protective clothing
- stay inside at dawn and dusk
- repair torn window and door screens
- Use insect repellent: 10-50% DEET is sufficient

Around the House

Light housekeeping will not harm you and is a very good way to get back into shape. It is important, however, to observe the following precautions.

- ◆ Do not lift more than *five* pounds for the first six weeks after your surgery.
- ◆ Please wear gardening gloves if you enjoy gardening or working with plants and flowers, since many infectious organisms live in the soil.
- ◆ Remember to wash all fresh fruits and vegetables before eating.
- ◆ Make sure meats are cooked at least medium (no pink).
- ◆ No raw seafood.

Avoiding Colds and the Flu

Now that you have a transplant, you will probably get the same number of colds and flu-like illnesses that you always did, but, understandably, these will cause you more concern than they did before. For both your physical and emotional health, therefore, you should do all you can to prevent colds and flu. This is largely a matter of careful hygiene and common sense.

- ❖ You and all your family members should get a flu shot as soon as they are available each year. This is usually in October. If you have small children, discuss the flu shot with their pediatrician.
- ❖ It is very important to wash your hands very frequently, since most infections travel hand-to-hand rather than through the air.
- ❖ Do not get into the habit of eating after people (out of bags or bowls of popcorn, for example), drinking after people, or reusing a bathroom glass.

Despite your best efforts, you will catch a cold or flu from time to time. When you do, you should call the transplant physician to see if you need antibiotics. Should symptoms of a cold linger, or if you develop a fever, symptoms of chest congestion, or a productive cough, be sure to call the transplant physician right away.

Pets

If you have always enjoyed having a pet or pets in the house, there is no reason for that to change. Here, too, you should take care to avoid contact with infection-causing organisms.

- ❖ Keep your overall number of pets to a minimum. Just as having too many people in one house is unhealthful, so is having too many pets.
- ❖ You should wear gloves when changing cat litter boxes, cleaning after birds, or cleaning pets' ears. Better yet, get someone else to do these tasks.
- ❖ Be sure to take the pets to your veterinarian for their shots and check ups.
- ❖ Pets should not be allowed to sleep on your bed.

First Aid and Hygiene

The natural ability of your body to heal wounds will be slowed down because of the immunosuppressive medication.

- ◆ Clean any cut or injury with soap and water and keep a clean, dry dressing on the wound.
- ◆ If healing is prolonged or if you experience pain, swelling, redness, or other signs of infection, see your healthcare provider.
- ◆ Notify the transplant physician if you notice any unusual rashes, blisters, or other lesions on your skin.
- ◆ ***Good care of your teeth and gums is also very important since your mouth can be a major source of infection. Visit your dentist every six months to avoid tooth and gum disease.***
- ◆ Contact your dentist prior to your appointment in order to obtain an antibiotic before having any dental work done. Remember to check with your transplant physician to make sure that the antibiotic prescribed by your dentist is compatible with your immunosuppressant medications.
- ◆ Notify your transplant physician if you notice sores, ulcers, or white patches in you mouth.

Exercise and Nutrition

Exercise

While you in the hospital, a major part of your recovery will include physical therapy. For all but a very few patients, we will expect you to be out of bed within the first 24 hours after you return from the operating room. We will insist that you begin walking in the hall the day after surgery. Inactivity after your transplant will make you weak and increase the chances of medical problems.

After you have recovered from your transplant, you should continue to exercise. During the first few months we recommend moderate exercise such as gentle walking, because strenuous exercise could cause problems with your recovery. If you have specific questions about the type of exercise that

is preferable, your doctor or transplant coordinator would be happy to talk with you about this. As time passes after your transplant, you may gradually increase your exercise tolerance as tolerated. In our program, we have many patients who participate in strenuous activities after their transplant such as marathon running, barefoot skiing, golfing, and deer bow hunting.

Staying in shape is not easy, but exercise can prevent some of the side effects of your medications and is one of the best things you can do to help yourself live a longer and healthier life.

Nutrition

Diet and nutrition are very important aspects of everyday care after a kidney transplant. Some of the medications that you are taking can cause an increase in your appetite, high blood sugar and fluid retention. Now that you have had your transplant and your condition has improved, it is important to begin a diet that promotes a healthy lifestyle.

The basic principles for a healthful diet are discussed below. A dietician will talk with you in detail about how to follow a low-salt, low-fat, low-cholesterol diet beneficial for everyone, but especially essential for you.

Limit Sodium

Too much sodium, or salt in your diet in your diet can contribute to high blood pressure and fluid retention. Reducing the amount of sodium in your diet will help prevent these problems.

1. Never add salt to food. Keep the salt shaker off the table.
2. Do not cook with salt. Do not use salt containing seasonings. Use herbs and spices in cooking to replace salt.
3. Avoid foods with visible salt like crackers, chips, pretzels, salted nuts, salted popcorn, and salted french fries.

4. Limit highly processed foods. Canned, processed and preserved foods contain high amounts of sodium. Watch out for processed meats and cheeses, canned soups, frozen dinners, and pickles.
5. Limit dinner and side dish mixes that come with sauce or seasoning packages (like Hamburger Helper, Rice-a-Roni, and au gratin potato mixes).
6. Limit high sodium sauces (like soy sauce, canned spaghetti sauce, and packaged sauce, gravy and seasoning mixes).
7. Do not use Potassium Chloride salt substitutes (Lite Salt, No salt, Salt Sense).

Modify Fat and Cholesterol

Some of your anti-rejection medications can increase your cholesterol level. High Cholesterol levels cause fatty deposits to build up in the walls of the blood vessels and are associated with heart disease and blood vessel disease. Reducing the amount of saturated fat and cholesterol in the diet can lower cholesterol levels. Cholesterol levels can also be lowered if polyunsaturated fats are substituted for saturated fats and cholesterol in your diet. Even if your cholesterol level is normal, it is recommended that you decrease the fat and cholesterol content in your diet. Excess amounts of fat in the diet can also contribute to undesirable weight gain. Follow these guidelines:

1. Choose high protein foods which are lower in fat such as skim or 1% milk, low fat cheese, lean cuts of red meats (center cut loin chops, chuck or round and flank steak), chicken and turkey without the skin, and fish. Avoid organ meats (liver, brain, and kidney).
2. Trim all visible fat and skin from meats.
3. Limit fried foods. Bake, broil, roast, grill or boil more frequently than frying.
4. Try using low cholesterol egg products or egg whites.

5. When using fats to cook with or to add to food, use fats from vegetable sources (corn oil, safflower oil, canola oil, and margarine). Avoid fats from animal sources (i.e. butter, lard, and bacon grease).

Reduce Concentrated Sweets and Sugars

Prednisone and other anti-rejection medications can increase the level of sugar in your blood. High blood sugars can cause many health problems. Therefore, it is recommended that you decrease the amount of sweets and sugars in your diet to limit this effect.

Prednisone can also increase your appetite. Limiting your concentrated sweets intake will help you prevent excess weight gain. Examples include cakes, cookies, pies, ice cream, donuts, and regular soda. Healthier dessert choices include angel food cake, graham crackers, sugar free Jell-O or pudding, and vanilla wafers.

Reach and Maintain Your Ideal Weight

Your dietician will help you determine your ideal body weight. Being overweight increases your risk for developing heart disease, diabetes, high blood pressure, and complications from surgery. Being underweight also has its risks. Your dietician will help you develop a plan to either lose or gain weight as needed. Following a healthy nutrition and exercise plan will help you reach and maintain an ideal body weight.

Limit Alcohol Intake

Alcohol intake should be limited to a rare cocktail or glass of wine on special occasions. The medication you are taking will not react well with a large amount of alcohol over time.

Sexual Activity

Sexual Activity may be resumed after your incision heals, which is usually about six weeks after surgery. You should be careful at first to minimize the

weight or strain that is put on your incision. Pain is the best indicator that too much weight is being put on the incision.

In today's world, sex is sometimes a life-and-death matter, and everyone who is sexually active should take precautions to make sex as safe as possible. This is especially true for you, as the immunosuppressive medications that you are taking make you more susceptible to sexually transmitted diseases as well as other infections.

The use of a latex condom is essential to safe sex. Using a condom does not guarantee that you will not get a sexually transmitted disease, but it is your best preventive measure. Some diseases that can be acquired sexually are hepatitis, CMV (cytomegalovirus), AIDS, herpes, and candida (yeast infection).

If you are certain that your partner is faithful, use of a condom may not be necessary. But since something as simple as women's common vaginal infection could cause serious infection in a male transplant patient, complete, candid communication with your partner is essential. In such a situation, even faithful partners should use a condom or abstain from sexual intercourse.

Single people must insist on using a condom when a relationship becomes sexual. This is not always an easy or comfortable thing to do, but you have come too far to make what could be a very dangerous mistake. Finally, do not forget about **birth control**. Generally, you need to wait at least one year after transplant before attempting to become pregnant. You should also discuss this completely with your transplant physician before stopping birth control. Your transplant coordinator and doctor are available to discuss these matters with you if so desire, so please don't be afraid to ask about your concerns.

Monitoring and Follow-Up

Lab Studies

Periodically, you will need to have blood chemistries and other lab studies done. This is a way to monitor for rejection but we will also be monitoring drug levels. We will give you a letter to take to the local laboratory instructing them about lab studies. Your transplant coordinator or transplant physician will give specific instruction when to get obtain blood work.

We will be checking either Prograf or other drug levels. Please remember that when blood is drawn, it should be done first thing in the morning, before you take your morning dose of Prograf, Cyclosporine, or Rapamune. Your local laboratory will mail this sample to their reference lab. They should not mail the blood sample to Duke. When the results come back, then they will fax us the results. The results of other lab studies will be available the same day and will be faxed to the Transplant Office and to the Renal Office.

Self Monitoring

You will be asked to measure your temperature, weight, blood pressure, and intake and output on a daily basis for a few weeks once you are home.

➤ **Temperature**

Your temperature should be taken at the same time each day, and whenever you feel feverish. If your temperature is above 100°F or 38°C, call your transplant physician. Fever may indicate that you have an infection or rejection episode. Do not take any medications that can lower your temperature, such as aspirin or Tylenol, unless instructed to do so by your transplant physician.

➤ **Weight**

Weigh yourself at the same time each day, preferably in the morning. Weigh yourself with the same type of clothing on and on the same scale each day. A weight gain of two pounds a day for two days is significant, and needs to be reported to the transplant physician.

➤ **Blood Pressure**

Your blood pressure may need to be measured and recorded daily. You may need to purchase a blood pressure cuff if you do not already

have one or go to your local pharmacy/supermarket if they have a blood pressure machine. We generally recommend the digital read-out cuff because it is more convenient. Please keep your blood pressure records and bring them to clinic with you.

➤ **Intake and Output**

For the first few weeks after transplant, you should keep track of how much fluid you take in and how much urine you make each day. The transplant coordinator or physician will tell you if there is a minimum or maximum amount you should drink. It is important to let us know if your urine output drops dramatically from one day to the next.

➤ **Blood Sugar**

If you are diabetic, expect your blood sugars to be elevated. You will need to take your blood sugars 4 times a day for the first month or so until the Prednisone dose is reduced. Be sure to keep a record of your blood sugars and call the transplant coordinator if your blood sugar is over 400 or less than 70.

RESUMING LIFE AFTER TRANSPLANT

Clinic Visits

You will be seen frequently in the Post-Op Transplant Clinic during the first six months after your discharge from the hospital. In this clinic you will see different doctors and will not be assigned to a particular doctor. After six months, you will return to your nephrologist whom you saw while you were waiting for a transplant. As time passes and your condition improves, we will see you less often.

At each clinic visit, you will have blood drawn before seeing your doctor. A Prograf, Cyclosporine, or Rapamune blood level will be drawn each time you come to the clinic. Do not take your Prograf, Cyclosporine, or Rapamune until after your blood has been drawn. You can take your medications as they are not affected by blood levels.

In addition, please remember to:

- ❖ Bring a list of your medications including dose and how often you take it.
- ❖ Bring a day's supply of all your medications with you in case you are delayed.
- ❖ Bring your home records with you to each clinic visit.
- ❖ Organize your questions for the doctor.
- ❖ Review your prescriptions so you may ask for new prescriptions if needed.

Preventive Medicine

All of the members of our team feel very strongly that you should continue to follow the common health prevention recommendations that apply to all patients. Your local doctor can arrange these studies.

- ❖ Women over age 40 should have yearly mammogram and pap smear.
- ❖ Everyone over age 50 should have their stool checked for trace blood and a flexible sigmoidoscopy.
- ❖ Men over age 45 should have a yearly prostate exam and blood test for prostate cancer.
- ❖ Wear a hat and sunscreen on exposed skin areas whenever going into the sun.

In addition to these common recommendations, being on powerful immunosuppressive drugs may increase your risk for cancer-especially skin cancer.

We also routinely check all patients who are six months or more out from their transplant for high blood cholesterol. Prograf, Cyclosporine, Rapamune, and Prednisone can elevate cholesterol. Therefore if we discover that your cholesterol is elevated, we will recommend dietary changes or in some cases advise you to start taking a drug to help lower your cholesterol.

Medical Condition Alert Bracelet

We strongly recommend that each transplant patient wear an identifying tag on either a bracelet or necklace after transplant. The following information should be included:

- Your name
- Transplant Recipient
- Immunosuppressed
- Other serious conditions, such as diabetes, epilepsy, should be included on the tag

Going Back to Work

It is our goal to make it possible for patients who have been employed to return to work after the transplant. Most patients can go back to work about three months after their transplant. Depending on the type of work you do and your financial situation, you may need to return to work as a soon as possible.

It may be best to start back to work part-time and eventually move toward full-time work. We will assist you in dealing with your employer and insurance company by providing them with any information they require to help you get back to work again.

A Final Word

Please remember that it will always be important for you to practice good health habits and to take good care of yourself. A balanced life, one that includes good nutrition, rest, exercise, work, and play will do wonders for your health.

Remember that we are only a phone call away at any time. The transplant coordinator on call can be reached 24 hours a day by calling 919-684-8111 and asking for the Kidney Transplant Coordinator On Call.

It is hard to believe now, but in several months you will not think about your transplant every day. All that you have been through, and all the work you have done to make your transplant a success, is toward the ultimate goal to give you a fresh chance to enjoy life.