

Kovler Organ Transplantation Center

Kidney/Pancreas Discharge

A Patient Handbook

Welcome to Northwestern Memorial Hospital.

This is an exciting and challenging time. A kidney/pancreas transplant can make a positive change in your life. This booklet will help you to manage your own health after receiving a new kidney and pancreas. When you know what to expect and how to take good care of yourself, you can make the most of the opportunity these new organs give you.

This handbook describes:

- Your hospital stay
- Follow-up care after your surgery
- Returning to the routines of daily life

Please review this handbook as often as you need. Keep it as a reference. It is important that you go home with the confidence to care for yourself. The transplant nurse coordinator will review these care guidelines in detail and answer your questions and concerns.

The entire multidisciplinary Transplant Team (referred to as ‘Transplant Team’ in this handbook) is here to help you with both your decisions and your care. We will provide the best care possible for you before and after your kidney/pancreas transplant. This team is a group of health care professionals who have special training and experience in transplantation and includes:

- Nephrologists
- Transplant Surgeons
- Transplant Nurse Coordinators
- Nurse Practitioners
- Physician Assistants
- Staff Nurses
- Registered Dietitians
- Licensed Social Workers (LSWs)
- Licensed Clinical Social Workers (LCSWs)
- Clinical Coordinators
- Patient Financial Liaisons
- Physical Therapists
- Occupational Therapists
- Pharmacists

During and after your hospital stay, the Transplant Team welcomes any questions you may have. Please contact us at 312-695-8900.*

A transplant surgeon and doctor are “on call” for you for any daily or urgent needs. If this changes for any reason, we will let you know right away. The *phone numbers to call* and *reasons that you should call* are talked about in this handbook.

Transplant Physician and Surgeon on Call

On-Call means
Available to you...

- 365 days a year
- 24 hours a day
- 7 days a week
- No more than 1 hour away from the hospital

* To arrange for TDD/TTY, auxiliary aids and foreign language interpretation services, call the Patient Representative department at 312-926-3112, TDD number 312-926-6363. Issues related to the Rehabilitation Act of 1973 should be directed to the director of Employee Relations or designee at 312-926-7297.

Opportunities for Your Feedback

At Northwestern Memorial Hospital, our belief and commitment is *Patients First*. We want every patient to receive the best care and service. To do this, your feedback during the transplant process is very important to us.

There are several ways for you to provide feedback.

- Please feel free to take one of the Patient Comment Cards found in the waiting area in our outpatient clinic

- A Patient Satisfaction Survey will be mailed to your home after you leave the hospital

- You can share your feedback by calling the Patient Representative department at 312-926-3112.

- Feel free to call any member of the Kovler Organ Transplantation Leadership Team:
 - Lead transplant nurse coordinator or Clinical Manager: 312-695-8900
 - Director: 312-695-4383

If needed, you can contact the United Network for Organ Sharing (UNOS) grievance line at 1-888-894-6361.

KOVLER ORGAN TRANSPLANTATION CENTER

**KIDNEY/PANCREAS TRANSPLANTATION:
DISCHARGE PLANNING**

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Chapter 1: General Information

During your surgery, the transplant surgeon made an incision in the middle of your abdomen (Figure 1).

Figure 1

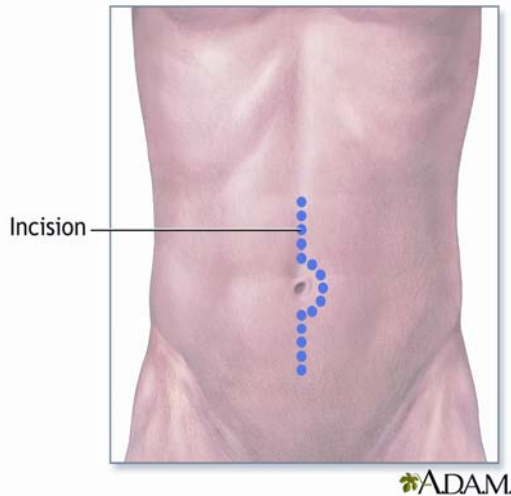
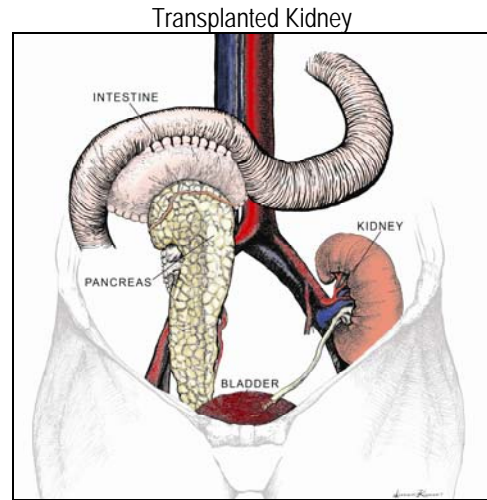


Figure 2



Your "old" pancreas and kidneys were not taken out. The new kidney and pancreas were sutured in place (See Figure 2).

Transplant Unit

After surgery you will spend a day in the Cardiothoracic Intensive Care Unit (CTICU) and then complete your recovery on the 11 East Feinberg Transplant Unit. You still will have your urine catheter in your bladder otherwise known as a "foley," an IV and possibly a Jackson-Pratt (JP) drain. To keep your lungs expanded and to prevent pneumonia, the nurse will have you begin coughing and deep breathing exercises right away. This includes using a hand-held device called an incentive spirometer. The spirometer allows you to see how deeply you are breathing. Deep breathing is important to:

- Keep your lungs clear of fluid and mucus build-up
- Guard against pneumonia

In the hospital, all patients are at risk for Deep vein Thrombosis (DVT). Steps will be taken to help prevent blood clots from forming. These may include:

- Elastic stockings
- DVT prevention boots

DVT prevention boots gently squeeze your calves to promote blood flow to the heart.

Figure 1 – Provided by ADAM Inc 2008

Figure 2 – Illustration provided by Simon Kimm, MD

When your stomach starts working, you can have small amounts of fluids to drink. As you are able, you gradually will be able to eat a normal diet. Often time patients are afraid to drink large amounts of water due to fluid restrictions before transplant, but it is very important to drink a lot of water.

The nurses also will get you out of bed and into a chair or walking as soon as possible. (This helps prevent blood clots.) As you grow stronger, you will be able to walk in the hallways. Each day you will be able to increase your activities.

Continue to take your pain medicine. To help prevent pain before it starts, many people find it helpful to take pain medicine before walking or before other activities that may trigger pain. Be sure to let your nurse know how well your pain medicine is working. Rate your pain on a scale of 0 to 10.

You will begin to learn about your new medicines. These medicines lower your body's normal immune response and help your body accept the new organs and prevent rejection. The donated kidney and pancreas always retain their original identity. You will need to take anti-rejection medicines *for the rest of your life*. Failure to do so *always will* lead to rejection and organ failure.

Your stay on the Transplant Unit will be about 3 to 4 days. The goal is to have you out of the hospital by the fifth day after surgery, depending on your progress.

Keep in mind that there are times when the kidney and/or pancreas do not work at all or do not work well enough to keep you well right after surgery. In those cases you still may need dialysis and/or insulin.

Preparing for Home

Before you go home the nurse will show you how to take care of yourself. You will have written instructions and your nurse will go over them with you in detail.

These might include:

- Care of wounds and foley
- Medicine instructions
- Signs of infection and rejection
- Activity and diet guidelines
- Follow-up doctor visits
- Lifestyle changes
- Whom to call with questions
- Important contact numbers

Arrangements for a home health nurse can be made if needed (example: removal of foley catheter).

You will meet with a pharmacist before you go home (and again at one of your first clinic visits) for more detailed information about your medicines. We have to be sure you understand how to take them and how to change doses as needed. It is important that you bring your pill box to your first clinic appointment.

We will arrange for you to receive IV fluids during your first week after transplant either at home or in the clinic.

Before you go home, the staff nurse or pharmacist will give you a pill sheet to help you keep track of your medicines. You can write your blood pressure, temperature, and weight on your pill sheet as well. Always **keep this** for your records and **bring it with you** to all of your Transplant Clinic visits.

You will be given an appointment calendar and clinic appointment instruction sheet which lists your transplant clinic appointments. For the first week after discharge you are seen at least once in the clinic. Over time, your visits will be less often. It is important that you arrange for transportation to these clinic visits until you can start driving again.

Lodging

If you live far from the hospital, rooms may be available at a nearby Residence Inn by Marriott. It is at 201 East Walton Place, about 6 blocks from the hospital. The Residence Inn offers a free place to stay after transplant for patients and a caregiver, until they are ready to go home. Any parking or telephone expense incurred at the hotel will be the responsibility of the patient/family.

Rooms are limited, and they are only available to newly transplanted patients. If other family members need a hotel room, discounts at other hotels can be arranged by calling (312)-926-ROOM.

There is a free shuttle from the Residence Inn to the hospital and back, but it is not wheelchair accessible. If you need wheelchair-accessible transportation, other arrangements can be made.

Transplant Clinic Visits

The Outpatient Office is located:
Northwestern Memorial Hospital
Kovler Organ Transplantation Center
676 N. St. Clair, Suite 1900
Chicago, IL 60611

Telephone number: (312) 695-8900
Fax for Labs: (312) 695-7752
Fax for Prescriptions: (312) 926-5489

Parking is available for patients and visitors in the garage at 222 E. Huron, across from the Feinberg and Galter pavilions. For discounted rates, please bring your parking ticket with you. Tickets can be validated at the Customer Services Desks on the 1st and 2nd floor of the Feinberg and Galter pavilions; 1st floor of Prentice (including the Prentice 24 hour desk near the Superior entrance).

You will be seen in the Transplant Clinic a day or two after your hospital discharge and often during the first few months. During your Clinic appointments you can expect the following to be removed:

- The JP drain(s) - a few days after the transplant
- Urine catheter - about 3-7 days post-surgery (unless already removed by a home health nurse)
- Incision staples - about 2-3 weeks post-surgery

It is important to **keep your appointments and to be on time**. If you are more than 20 minutes late for your appointment, you might have to wait until after the other scheduled patients are seen. Please make travel plans so that you are able to get to your appointments. Office visits last about 2 to 3 hours. They may be longer if a procedure is done or IV medicine given.

If you have a clinic visit scheduled *before 12 noon*, (common during the first 6 months) **do not take your cyclosporine, Prograf®, or Rapamune®. Instead, be sure to:**

- Bring these medicines to your appointment
- Wait until your blood is drawn, then take your cyclosporine, Prograf®, or Rapamune®

If your clinic appointment is *after 12 noon*, take your **cyclosporine, Prograf®, or Rapamune®** at your usual time.

Bring your pill sheet and discharge instructions to your office visits. If you cannot find your pill sheet, bring all of your medicines with you. Medicine changes and prescription refills will be made at these visits.

As you leave the clinic office, please schedule your next appointment at the receptionist desk. If you do not already have a standing order for your routine lab tests, it will be given to you at that time.

Lab Tests

You may choose to have these blood tests done at a local lab. When you are scheduled to have your labs drawn, please arrange to have the results faxed to the office **that same day** at (312) 695-7752. Ask your local lab to give you the results as well. It is important that you obtain your own lab results and know your own lab values. **Please call the outpatient clinic and leave a message on the “lab voice mail” to let us know when and where you had lab work done.** This will allow your Transplant Team to obtain your results if they are not faxed to us. Remember that the transplant nurse coordinator will *only* call you if there is a problem with your labs.

The schedule for your post-transplant lab work is as follows:

- For the **1st month** you need to have your labs drawn at least 3 times a week (Monday, Wednesday and Friday) in the morning
- During the **2nd month**, have your labs drawn twice a week (on Monday and Thursday)
- During the **3rd month**, your blood work will need to be drawn once a week, on Monday

Depending on how you are doing, other tests may be needed (e.g. kidney or pancreas biopsy, scans, special blood work, etc.). A member of the Transplant Team will explain each test or procedure.

About 6 weeks after your transplant, the stent (the small plastic tube in the ureter of your new kidney) will need to be taken out. This is done in the urologist’s office as an outpatient procedure. Your appointment with the urologist will be made before you leave the hospital. Be sure to keep this appointment. If the stent remains in place too long, it may cause serious problems, such as severe infection.

The Transplant Team works closely with all your referring doctors. You will be followed for at least 3 months after surgery in the Transplant Clinic, or more often if you are having any problems. After about 3 months, most patients are doing well and go back to the care of their referring doctor. If you have diabetes, be sure to continue to follow-up with your endocrinologist (diabetes doctor). We will work closely with your doctors to provide any help they may need to give you the best care possible.

Your doctor will manage your office visits, lab work, prescriptions and any other medical issues. We will continue to monitor and manage your anti-rejection medicines and see you in the Transplant Clinic once a year.

At your 3-month and once a year visits you will need to have special blood work drawn. We need to get the results of this test *before* your appointment. Please call the Transplant Team for the order sheet you will need for this special blood work. Get your labs drawn a few days before your appointment so we can have your results. At these visits, you will see a nephrologist (kidney doctor) or nurse practitioner.

After a transplant, most patients will have a better quality of life and manage well, but it can be a difficult course. Some patients feel depressed and worry about their health. They may feel anxious and even guilty about depending on others for help. It is important to have support systems at home – people to:

- Help you understand what is happening and what you need to do
- Share what you are feeling
- Get any treatment you might need

Your Transplant Team members are good resources for help. Please refer to Appendix A, *Stress, Emotions and the Transplant Process*, for more information.

Chapter 2: Rejection, Infection and Cancer

Rejection: What is it?

A major concern after transplant surgery is the risk of organ rejection. Rejection happens when your body stops accepting your new organ. When this occurs, your immune system attacks your new kidney and/or pancreas, as if they do not belong in your body. This triggers your body to make *white blood cells* (WBCs) and *antibodies* which:

- Reduce the blood flow to the kidney and pancreas
- Can damage the new kidney and pancreas
- Limit how well the kidney and pancreas work

Acute rejection often happens in the 1st several months after transplant. But rejection can occur at **any time**. You must *always* take your medicines to prevent rejection.

Most acute rejections can be reversed by giving you higher doses of anti-rejection or other medicines. In some cases, you need hospital care.

Signs of Rejection

It is important to watch for signs of rejection:

- A temperature above 100.5⁰ F
- Pain or tenderness over the transplant site
- Feeling like you have the flu
- Abdominal pain
- Blood in your urine
- Increased blood pressure (BP) noted over 2 or more readings
- Increased blood sugar (this is a *late* sign of rejection)

If you notice any of these signs, you must call the Transplant Clinic right away. This allows treatment to begin quickly to help you have the best outcome. Rejection is confirmed with blood work and a needle biopsy of the kidney/and or pancreas. This biopsy is usually done outpatient, either in the Transplant Clinic or in the Radiology Department.

Many times:

- Rejection can be detected only by lab tests
- Patients will not have symptoms at all

So, it is *very important* that you have routine blood tests *as directed by the Transplant Team*. We want to detect rejection *before* you have any symptoms. This allows needed tests and treatment to begin right away.

Infection

Anti-rejection medicines limit the action of your white blood cells (WBCs). WBCs help your body fight infection. When you take anti-rejection medicines you have an increased risk for infection. **It is very important that you try to prevent infection and watch for signs of infection.**

Call the transplant nurse coordinator **right away** (day or night) if you have:

- A temperature above 100.5°F
- Nausea, vomiting or diarrhea (more than 4 watery or very loose stools) for more than 24 hours
- Redness or tenderness around your incision
- Anything other than red-tinged clear drainage from your incision

Call the transplant nurse coordinator during clinical hours if you have:

- A productive cough that lasts more than 2 days
- A sore throat or mouth sores
- Pain or burning while urinating
- Cloudy urine or a feeling of urgency to urinate

There are some important but simple steps you need to take to help prevent infection.

- Avoid contact with persons who have a cold or flu or other illness
- Keep your vaccines up to date. Remember that you **cannot** have vaccines with **live viruses**. Ask your transplant doctor or nurse coordinator to make sure any vaccine is okay to get
- Get a flu shot every year and a pneumovax shot every five years
- Practice good hand washing, which means:
 - Wash your hands for 30 to 60 seconds using soap and warm water. Scrub all areas, including between the fingers, under the fingernails, and around the nail beds
 - You can also use alcohol-based hand rubs and wash for 20 seconds
 - Use plain soap and water for visibly dirty hands
 - Use alcohol-based hand-rubs when your hands are not visibly dirty
 - Always wash your hands when visibly soiled, after you use the bathroom, and before and after you eat

Cytomegalovirus (CMV) is a specific virus in the herpes family. You can get it from the donor (primary infection) or it may be a virus you already have in your body that causes infection (reactivates). Symptoms of CMV can range from feeling like you have the flu to a life-threatening illness. You may need anti-viral medications to either prevent or treat CMV.

BK is another virus many people have had. It causes an illness like a cold in very young children. After you have the BK virus, it stays in your kidneys and bladder (dormant or ‘asleep’) for the rest of your life. After your transplant, and because of the anti-rejection medicines, the virus may “wake up.” This happens in about 5 to 10% of transplant patients. The virus damages the new kidney and could even cause the new kidney to fail. After your transplant, we check your blood

and/or urine for this virus 2 weeks after your transplant and then:

- Three months after your transplant
- Every month for one year after your transplant
- Every 3 months for year two after your transplant
- Every year after that

We will also screen for BK virus:

- If you have signs of rejection or other kidney problems
- Each time you have a kidney biopsy

If you have the BK virus we might lower your doses of anti-rejection medicines or might give you an anti-viral medicine. Most of the time, if we catch it *before you have any symptoms*, we can treat the virus before it harms your new kidney.

Just like everyone else, you will get colds and the flu. Your immune system should be able to fight these common infections and you should recover normally. Also, the risk of infection becomes less as your anti-rejection medicines are decreased over time.

Cancer

Anti-rejection medicines that weaken your immune system increase your risk of cancer. Anti-rejection medicines increase your risk for skin cancer and some other cancers. It is important that you:

- Use sunscreen lotion or spray **every** day. Use sunscreen with SPF 60 on your face and at least SPF 30 on the rest of your body to protect your skin. Avoid sunburn. Try to keep out of the sun as much as possible, especially between 10 am and 2 pm. If you do go out in the sun, wear a hat
- Know and follow guidelines for monitoring for cancer. Be sure to have routine medical and dental check-ups. See Appendix B to learn how to help watch for any signs of cancer

Chapter 3 – Medications

Overview

You will take a combination of different anti-rejection medicines. These drugs work together to help your body accept your new kidney and pancreas. They lower your body's normal immune response to the new organs. **Without these medicines, your body will reject your transplanted kidney and/or pancreas.**

- Tacrolimus (Prograf®)
- Cyclosporine (Neoral®, Sandimmune®, Gengraf™)
- Mycophenolate (Myfortic®, CellCept®)
- Sirolimus (Rapamune®)
- Prednisone (Deltasone®)
- Thymoglobulin®
- Alemtuzumab (Campath®)
- Rituximab (Rituxin®)
- Basiliximab (Simulect®)
- Daclizumab (Zenapax®)
- Methylprednisolone (Solu-medrol®)

The doses of these medicines may change over time. Changes are made based on your blood test results. For example, if your WBC level goes too low, the dose of Myfortic®, CellCept® or Rapamune® may be lowered. At other times, you may be given medicine to help your body make more WBCs.

Prograf®, Neoral®, Rapamune® and sometimes Myfortic® or CellCept® doses are adjusted to maintain a certain drug level in your blood. For example, if the drug blood levels are too high, the dose of medicine may go down. If the blood levels are too low, the medicine dose may go up.

Other prescribed **and** over-the-counter medicines can also affect your blood levels, as can illness. For all of these reasons it is important to monitor drug blood levels for *as long as you have* your transplant.

Some important facts about your medicines:

- Most medicines are taken 1 to 2 times a day. A few medicines may need to be taken 3 or 4 times a day
- **Never stop taking your anti-rejection medicines.** If you do, you risk transplant rejection.
- **Never double the dose of any medicine.** If you forget to take a dose, follow these guidelines.

For medicines taken:

- **Once a day:** take it when you remember and then get back on schedule the next day
- **Twice a day:** if you are more than 5 hours late with one dose, skip it and take your dose at the next scheduled time. Then stay on schedule
- **Three or 4 times a day:** skip that dose and get back on schedule with the next one

But remember, taking the **right dose** of your medicines at the **right time** is very important!

Your Pill Sheet

Use your pill sheet to help you keep track of your medicines. We change the doses of some of your medications often, so *what is written on your prescription bottle may not be the most up-to-date dose/times*. Because of that it is critical that you:

- Keep track of the changes on your pill sheet
- Take the dose that is on your pill sheet

Write your blood pressure, temperature, and weight on your pill sheet as well. Always **keep this** for your records and **bring it with you** to all of your Transplant Clinic visits.

Prescription refills can be written for you at the Transplant Clinic. Or you may have your pharmacy send a fax to the clinic for a refill order. Please give the office at least 2 to 3 days notice when you are running low and need a prescription. Have your pharmacy fax the refill request to 312-926-5489.

Contact the Transplant Clinic before taking **any** new medicines or supplements (**either over-the-counter or prescribed by another doctor**). This will help avoid possible drug reactions or injury to your new organs.

It is also important to carry a list of all your current medicines with you, wherever you go.

Note: Generic drugs can be substituted for some medicines. This may help lower the costs. Some of the medicines, however, do not have a generic, or your doctor may not want you to take the generic. For your immunosuppressive (anti-rejection) medications, we generally prefer brand name products. Please call the transplant center **before** switching to any generic medication. Ask your transplant pharmacist if you have any questions.

Some of the medications can be expensive, but are necessary and extremely important for you to take to prevent rejection of your organ. It is important that you understand your insurance benefits and what part of the cost of the medicines will be covered with your policy. If you have problems with this, or other insurance or financial issues, please contact the transplant social worker immediately.

Note: Northwestern Memorial Hospital policy, as well as state and federal laws, states that we cannot, under any circumstances, take back any unused medications or supplies.

It is important to learn about your medicines including:

- The name
- The dose/strength
- When and how to take each one
- Possible side effects

More information about your medicines and side effects are on the following pages.

- The medicines you are most likely to take are described first
- Medicines used early in your transplant or when rejection episodes happen are described next
- Finally, there is a list of other medicines that you may or may not need, depending on how your body responds to your medication or if you develop any other health problems

Keep in mind, **every patient is different:**

- **Most patients do** have some medicine side effects but not all of them
- Some effects may bother you more than others
- You may have side effects that are not listed here
- Some of the side effects lessen or go away as your medicine doses are lowered

Talk to your transplant nurse coordinator if:

- You note any new changes in the way you feel
- The side effects persist and are bothersome

If any side effects are severe enough that you cannot wait for your next appointment, please do not just stop taking or adjusting your medications without calling your transplant nurse coordinator for advice.

Anti-Rejection Medicines

Mycophenolate sodium (Myfortic®) and Mycophenolate mofetil (CellCept®)

Myfortic® and CellCept® help prevent rejection. Myfortic® comes in 180 mg and 360 mg tablets and CellCept® comes in 250 mg capsules and 500 mg tablets.

How to Take

Doses are taken in the morning and evening, about 12 hours apart. Your doses should be taken at the same times each day (e.g. 9:00 a.m. and 9:00 p.m.). Take this medicine on an empty stomach. If your stomach becomes upset, you can take it with a small, low-fat meal or snack. But it is important to take every dose the same way, either with or without food.

Possible Side Effects

Diarrhea

If you have diarrhea be sure to drink plenty of fluids (8 to 10 glasses of fluid per day). This will help prevent you from becoming dehydrated. Tell the nurse if the diarrhea lasts more than 24 hours or if you have more than 4 watery stools in a day.

Decreased White Blood Cell (WBC) Count

Your dose is adjusted to keep your WBC within the normal range. If your count is too low, you may receive an injected medicine (Neupogen™) to increase your WBCs. It is important to wash your hands often and avoid anyone who is sick to help prevent you from getting an infection.

Nausea/Vomiting

If vomiting lasts more than 24 hours, call the Transplant Clinic. To avoid becoming dehydrated, you may need IV fluids.

Anemia

Your blood count will be checked closely for any decrease in your red blood cell (RBC) count. If you feel more tired or fatigued talk to a member of your Transplant Team at a clinic visit.

Sirolimus (Rapamune®)

Rapamune® is another drug that helps prevent rejection in transplant patients. It comes in 1 and 2 mg tablets. A blood test is done to check the drug level. On the day of the test or on your outpatient clinic visit, you must *wait to take your Rapamune®* until after you have your blood drawn.

How to take: Take at the same time every morning, without food. If your stomach becomes upset, you can take it with a small, low fat meal or snack.
Exception: On those days you when your blood tests are done, take this medicine **right after** your blood is drawn.

Possible side effects:
Increased Cholesterol/Triglycerides Cholesterol levels may rise above normal. You will need to follow a diet low in fat and cholesterol. You may also need medications to treat high cholesterol or high triglyceride levels.

High Blood Pressure You will be checking your blood pressure (BP) at home. It is important to report any increases in your BP to the Transplant Clinic.

Diarrhea If you have diarrhea, drink plenty of fluid (8 to 10 glasses of fluid per day). This will help prevent you from becoming dehydrated. Tell your Transplant Team if the diarrhea lasts more than 24 hours or you have more than 4 watery stools in a day.

Rash If you develop a rash, notify your Transplant Team.

Acne If you develop acne, take these steps

- Keep the area free of excess skin oil
- Wash twice a day with a mild soap such as Ivory®, Neutrogena® or Basis®, using a washcloth or loufa sponge. Avoid lotions or moisturizers.
- Try 5-10% benzoyl peroxide on the blemishes.
- Call the transplant dermatologist if none of these suggestions work. The Dermatology Clinic phone number is (312) 695-6647.

Anemia Your blood count is checked closely for a decreased RBC count. If you feel more tired or fatigued, talk to a member of the Transplant Team at your next clinic visit.

Mouth Ulcers or Sores If you develop sores in your mouth, tell a member of the Transplant Team at your clinic visit or by phone during clinic hours. A special mouthwash may be prescribed.

Delayed Wound Healing Your incision may not heal as well when you are on this medicine. If healing is a problem or if your wound opens, we may need to change your medicine.

Cyclosporine (Neoral®, Sandimmune® Gengraf™)

Cyclosporine helps prevent rejection. It comes in 25 and 100mg capsules. A blood test is done to check the drug level. On the day of the test or on your outpatient clinic visit, you must *wait to take your cyclosporine* until right after you have your blood drawn.

How to take:	Doses are taken at the same time each day, in the morning and evening about 12 hours apart (e.g. 9:00 a.m. and 9:00 p.m.). Take this medicine the same way, with or without food, for every dose. Exception: On those days you when your blood tests are done, take this medicine right after your blood is drawn.
Possible Side Effects:	
Increased Blood Creatinine	Cyclosporine may cause an increase in your blood creatinine (a sign of kidney problems). If your creatinine level is high, your cyclosporine dose may need to be lowered.
High Blood Pressure	As you check your BP, it is important to report any increases to a member of the Transplant Team.
Increased cholesterol/triglycerides	Cholesterol and triglyceride levels may rise above normal. You need to follow a diet that is low in fat and cholesterol. You may need medicine to help lower your high cholesterol and triglyceride levels.
Increased hair growth	A special cream (such as Nair®) or wax treatments may be used to remove unwanted facial or body hair.
Swollen gums	Maintain good oral hygiene that includes brushing and flossing. Ask your dentist if you need to have your teeth cleaned more than every 6 months. Remember that you will need to take antibiotics before and after a teeth cleaning. Your dentist must prescribe the antibiotics. Please call the clinic if your dentist needs to know what to prescribe.
Hand Tremors	You may notice slight hand tremors, often when you are writing. It may be due to high levels of cyclosporine. If you have tremors, tell the Transplant Team during a clinic visit. If the tremors are bothersome, please call the Transplant Clinic during regular clinic hours.
Increased potassium	Your potassium level may rise above normal. If this occurs, you will be placed on a low potassium diet. If your potassium is very high, you may be given medicine to help bring it down.
Decreased magnesium	If your blood magnesium level goes down you will need to take a magnesium supplement.

Tacrolimus (Prograf®)

Prograf® helps prevent rejection. It comes in 0.5, 1 and 5mg capsules. A blood test is done to check the drug level. On the day of the test or on your outpatient clinic visit, you must *wait to take your Prograf®* until after you have your blood drawn.

How to Take: Doses are taken at the same time each day, in the morning and evening about 12 hours apart (e.g. 9:00 a.m. and 9:00 p.m.). Take this medicine the same way, with or without food, for every dose. **Exception:** On those days you when your blood tests are done, take this medicine **right** after your blood is drawn.

Possible Side Effects:

Increased Blood Creatinine Prograf® may cause an increase in your blood creatinine to rise (a sign of kidney problems). If your creatinine levels become high, your Prograf® dose may need to be lowered.

High Blood Pressure As you check your BP, it is important to report any increases to a member of the Transplant Team.

Hand Tremors You may notice slight hand tremors, often when you are writing. It may be due to high levels of Prograf®. If you have tremors, tell the Transplant Team during a clinic visit. If the tremors are bothersome, please call the transplant center during regular clinic hours.

Thinning of Hair You may notice a thinning of your hair.

Elevated Blood Sugar Your blood sugar may become elevated and you may develop diabetes. We will be checking your glucose levels with your blood work. If you do develop diabetes, you may need a special diet, medicine or insulin to control your blood sugar.

Nausea/Vomiting If vomiting lasts more than 24 hours, call the Transplant Team right away. To avoid becoming dehydrated, you may need IV fluids.

Seizures This side effect rarely happens, but your family should know to call 911 if a seizure occurs. Notify the transplant office as soon as you can.

Increased Potassium Your potassium level may rise above normal. If it does, you need to eat a low potassium diet. If your potassium is very high, you may be given medicine to help lower it.

Decreased Magnesium If your blood magnesium level goes down, you will need to take a magnesium supplement.

Basiliximab (Simulect®) and daclizumab (Zenapax®)

Simulect® and Zenapax® are drugs used to prevent rejection. They are given IV in either the hospital or the clinic.

Possible Side Effects:

**Shortness of Breath
Trouble Breathing**

Call your transplant nurse coordinator right away - day or night.
If the breathing problem is severe, call 911.

Rash, Itching, Hives

You may have itching and/or a rash. If you do, tell a Transplant Team member at your next clinic visit or call during clinic hours.

Rituximab (Rituxan®)

One dose of rituximab may be given before your transplant and/or when you have a rejection episode. It is given over 6 hours in the hospital or Transplant Clinic through an IV. The dose depends on your weight.

Possible Side Effects:

Infusion Reaction	A serious but rare side effect is a reaction during or within 2 hours after this medicine is given (infused). You might feel flushed or experience shortness of breath, dizziness, or swelling of your lips or throat. You will be given medication before the IV infusion to lessen this reaction. The infusion may need to be stopped but can usually be restarted at a lower rate once the symptoms lessen.
Fever, chills, aching	Take 2 Tylenol® tablets (regular strength, 650 mg) and one 25 mg Benadryl® tablet just before the medicine is given to help prevent these common symptoms. Report any new fever greater than 100.5°F to the transplant nurse coordinator right away.
Rash, Itching, Hives	You may have itching and/or a rash. If you do, tell a Transplant Team member at your next clinic visit or by phone during clinic hours.
Headache	You may have a headache after your dose. This often improves with time. You may take 2 Tylenol® tablets for headache pain but do not take more than 4,000 mg of acetaminophen or Tylenol® in a 24-hour period . Tell a member of the Transplant Team if the Tylenol® does not work for you.
Cough, runny nose, sinusitis	You may have cold symptoms. If you do, tell a Transplant Team member at your next clinic visit or by phone during clinic hours.
Joint pain	You may develop sore joints. If you do, tell a Transplant Team member at your next clinic visit or by phone during clinic hours.
Drowsiness or dizziness	You may develop dizziness or drowsiness. Call the Transplant Team if this occurs. Use care when changing positions to prevent falls. Do not drive or handle dangerous equipment while you are feeling dizzy or drowsy.
Kidney problems	It is important to drink 2 to 3 quarts of fluid over the 2 days after your dose, unless you are told to limit the amount of fluids you drink.

Thymoglobulin®

Thymoglobulin® is used to treat rejection. The first 3 doses are given in the hospital. The rest of the daily doses may be given by a home health nurse or in the Transplant Clinic. The dose is based on your weight and is given daily for 5 to 10 days. All doses are given IV over 4 to 6 hours. Depending on how your blood tests turn out, you may be told to skip a day or two.

Possible Side Effects:

Fever, chills, aching	You may have these side effects with the first 2 to 3 doses. Take 2 Tylenol® tablets and one 25 mg Benadryl® tablet just before the medicine is given to help prevent these common symptoms. Report any new fever greater than 100.5°F to the transplant nurse coordinator right away.
Decreased WBC	Your WBC is checked every day while you are taking this medicine. Your dose is adjusted if the WBC begins to go down. It is important to wash your hands often and avoid anyone who is sick to help prevent you from getting an infection.
Rash, Itching	You may have itching and/or a rash. If you do, tell a Transplant Team member at your next clinic visit or call during clinic hours.
Headache	You may have a headache after the 1 st few doses. This often improves with time. You may take two Tylenol® tablets for headache pain but do not take more than 4,000 mg of acetaminophen or Tylenol® in a 24-hour period . Tell your transplant nurse coordinator if the Tylenol® does not work for you.
Nausea/Vomiting	If vomiting lasts more than 24 hours, call the transplant nurse right away. To avoid becoming dehydrated, you may need IV fluids.
Anemia	Your blood count will be checked closely for any decrease in your red blood cell (RBC) count. If you feel more tired or fatigued, talk to a member of the Transplant Team at your next clinic visit.

Prednisone

Prednisone is a steroid that helps prevent rejection. It comes in 1, 2.5, 5, 10, 20 and 50 mg. tablets. The 5 and 20 mg tablets are used most often. Check the mg marked *on the tablet* to make sure you are taking right dose of your prednisone.

How to Take: One dose is usually taken each morning with breakfast. If your doses are high, we may ask you to take several smaller doses over the day.

Possible Side Effects:

Increased Appetite Most people feel hungry, even after they have eaten. Eat 3 well-balanced meals a day to help make sure you take in enough calories. The dietitian can help you plan meals.

Fluid Retention/high blood pressure Prednisone can cause you to retain salt and fluid. This may result in increased weight and BP. Monitor your salt intake carefully and limit how much you use. Report a weight gain of 5 lbs. overnight or 10 lbs. in a week to your transplant nurse coordinator during clinic hours.

Stomach Ulcers Prednisone may increase stomach acid, which could lead to ulcers. A medicine called Pepcid® or a similar drug may used to block excess stomach acid until your prednisone dose is lowered. Report any stomach discomfort or burning to your transplant nurse coordinator or doctor at your clinic visit or by telephone during regular clinic hours. Immediately report any blood in your stool or if you start to vomit blood.

Joint pain/muscle wasting Regular exercise can help prevent the feeling of “weakness” in your legs and arms. You should not feel joint pain while doing exercises. During your clinic visit, tell the Transplant Team about any mild to moderate joint pain. Severe joint pain should always be reported right away.

Sweating Profuse sweating (often at night) may occur. This sweating will lessen with time.

Skin Changes Your skin may become thin and bruise easily. You may also be prone to acne or sunburn. Cuts and scratches may heal more slowly. Wear gloves to protect your hands when working (i.e. carpentry or yard work). Remember, skin cancer is real risk, so you need to apply sunscreen every day. Use a sunscreen with SPF 60 on your face and at least SPF 30 on the rest of your body to protect your skin and avoid sunburn. See Appendix B.

Acne	<p>If you develop acne, take these steps:</p> <ul style="list-style-type: none">▪ Keep the area free of excess skin oil▪ Wash twice a day with a mild soap such as Ivory®, Neutrogena® or Basis®, using a washcloth or loufa sponge. Avoid lotions or moisturizers▪ Try 5-10% benzoyl peroxide on the blemishes▪ Call the transplant dermatologist if none of these suggestions work. The Dermatology Clinic phone number is (312) 695-6647
Changes in appearance	<p>Prednisone changes the way your body burns calories. Your cheeks may become fuller and you might gain weight. Regular exercise and a low fat diet can help.</p>
Candida, Thrush (yeast infection of the mouth)	<p>Inspect your tongue and the inside of your mouth for white patches or sores. You will be on medicine to help prevent this yeast infection.</p>
Mood Swings	<p>Be aware of mood changes. Tell your family members that this is a possible side effect of your prednisone. The mood swings will lessen as your dose is lowered.</p>
Steroid-induced diabetes (SIDM)	<p>Prednisone may cause SIDM in some post-transplant patients. We will be checking your glucose levels with your blood work. If you do develop SIDM, you may need a special diet, medicine or insulin to control your blood sugar.</p>
Osteoporosis	<p>Bone loss is another possible side effect. You will need a bone scan every year or so and may need calcium supplements or other medicines to help prevent bone loss.</p>
Cataracts	<p>Another risk with prednisone is cataracts. Remember to see your <i>ophthalmologist</i> every year and if you have any problems with your vision.</p>

Solumedrol®

Solumedrol® is a steroid used to treat a rejection episode. It is given IV.

How to Take: Usually 500 mg daily for three days, either in the hospital or at home.

Possible Side Effects: Possible side effects are like those seen with prednisone. These side effects include increased blood sugar and blood pressure. We will monitor your blood sugar and blood pressure closely. If you are diabetic, make sure you make the transplant team aware. You may need temporary increased dose of insulin.

Other Medicines

Based on your own needs, other medicines may be needed. For example:

Medication	Use/Action
<ul style="list-style-type: none">▪ Ganciclovir (Cytovene®)▪ Valganciclovir (Valcyte™)▪ Acyclovir (Zovirax®)▪ Valacyclovir (Valtrex®)	<ul style="list-style-type: none">▪ Treat or prevent CMV (cytomegalovirus) infection or other viral infections
<ul style="list-style-type: none">▪ Lansoprazole (Prevacid®), esomeprazole (Nexium®) or famotidine (Pepcid®)	<ul style="list-style-type: none">▪ Reduce stomach acid and help prevent ulcers
<ul style="list-style-type: none">▪ Nystatin or clotrimazole (Mycelex® troche)	<ul style="list-style-type: none">▪ Prevent or treat fungus infection (candida, also called thrush) in your mouth
<ul style="list-style-type: none">▪ SMX-TMP, (Bactrim SS®) or another antibiotic if you are allergic to sulfa	<ul style="list-style-type: none">▪ Prevent urinary tract infections
<ul style="list-style-type: none">▪ Dapsone (Atovaquone or Aczone®) (Mepron®) or SMX-TMP, (Bactrim SS®)	<ul style="list-style-type: none">▪ Prevent a certain type of pneumonia called pneumocystitis pneumonia
<ul style="list-style-type: none">▪ Magnesium oxide	<ul style="list-style-type: none">▪ Help keep your blood magnesium level normal
<ul style="list-style-type: none">▪ Hepatitis B immunoglobulin (H-BIG) [if you had hepatitis B before the transplant] and lamuvidine (Epivir®)	<ul style="list-style-type: none">▪ Prevent re-infection with hepatitis B
<ul style="list-style-type: none">▪ Cidofivir	<ul style="list-style-type: none">▪ Treat BK virus

Your Transplant Team will explain these and other medicines in more detail as they are prescribed to you. If you have any questions, please ask.

Chapter 4 - Laboratory and Other Tests

Blood Tests

Each time you come for your office appointment, your blood is tested to:

- See how well your kidney and pancreas are working
- Check the blood levels of some of your anti-rejection medications

Other labs may also be drawn at your local hospital or lab as often as 2 to 3 times per week. (The number of tests and how often you have blood drawn is based on when you had your transplant and how you are doing.)

It is important that you know your own lab values. Keep in mind that *your* lab results may not *ever* be in the “normal” range. Patients have their own normal lab values and these vary with each patient. The doctors and nurses look for *changes* in *your* labs, not just normal ranges. The Transplant Team will discuss the test results with you. Below are some of the blood tests that are done most often. For more details about these tests, refer to Appendix C.

Complete Blood Count (CBC) with Platelets (Plts)

- Hematocrit (Hct)
- Hemoglobin (Hgb)
- Red Blood Cells (RBCs)
- White blood cells (WBCs)

Chemistry Panel

- Blood urea nitrogen (BUN):
- Calcium (Ca)
- Carbon dioxide (CO₂)
- Chloride (Cl)
- Creatinine (Cr)
- Glucose or blood sugar
- Magnesium (Mg)
- Phosphorous (P)
- Potassium (K)
- Sodium (NA)
- Total Protein (TP)
- Uric Acid (UA)

Chemistry values need to be in balance for the body to stay healthy and do its work.

We also look at the level of some of your drugs in your blood. Based on the results, and your side effects, the doses of some of your medicines may be changed. **Be sure to track all changes on your pill sheet!**

Getting Your Labs Drawn

You need to get your labs drawn as described earlier in this handbook. You must choose a local lab where you will have your labs drawn or, on non-clinic days, come into the Diagnostic Testing Center (DTC) – on the 2nd floor in the Arkes Family Pavilion at 676 N. St. Clair Street or on the 5th floor of Prentice Women’s Hospital at 250 E. Superior Street. We are not able to offer “lab only” visits in the Transplant Clinic.

Diagnostic Tests

Other tests may be done as needed to see if there are problems with your new kidney or pancreas. The transplant nurse coordinator will talk to you about any tests that you might need. Based on how you are feeling and your test results, 2 other tests that are done most often are:

Kidney Ultrasound with Color Doppler Blood Flow

Ultrasound with color doppler uses sound waves to detect a blockage in the arteries or veins to the transplanted kidney. This test may be done to check for extra fluid in or around the kidney. It may also be used prior to a kidney biopsy.

Before the Ultrasound

There is no preparation for this test. You can eat and take your usual medicines.

During the Ultrasound

The technician (tech) helps you lie on your back on an exam table. A warm, clear gel is applied to the area. Then the tech or doctor moves a small hand-held device (transducer) on the skin over your transplanted kidney. The transducer transmits sound waves to a monitor, where images can be seen and saved for later review. During the test, you may be asked to take a deep breath and hold for about 30 seconds. You may see the images on the monitor and hear some sounds as the tech records the blood flow.

After the Ultrasound

You may resume your normal activities. The Transplant Team will discuss the results with you. Please feel free to ask any questions.

Kidney Biopsy

A kidney biopsy can often help find the cause of kidney function problems. The biopsy results provide a “road map” to help the transplant doctor decide how to treat any problems with your new kidney.

A biopsy also helps us check on the health of your kidney. You will have a biopsy:

- 3 months after your transplant
- One year after your transplant
- If you are having a rejection or other kidney problems

This biopsy can be done as an outpatient (in clinic or in Interventional Radiology) or in your hospital room. We will contact you with detailed instructions before the appointment.

Before the Biopsy

Do not take aspirin for 7 days before your biopsy. If you take other medicines that affect blood clotting, like warfarin (Coumadin®) or clopidogrel (Plavix®), talk to the Transplant Team to find out if you should take them before your biopsy. Your transplant nurse coordinator will let you know if there are any medications you should not take before your biopsy and when you can start taking them again. You may eat and take most of your usual medicines.

A family member or friend should come with you to the test. An ultrasound of the kidney may be done first to select the biopsy site.

During the Biopsy

While you are lying down, your abdomen is cleaned with a special soap. Numbing medicine is injected into the skin. You will feel some slight burning. The doctor then makes a small incision and inserts a needle through this site into the kidney. A tiny piece of kidney tissue is removed. You may feel slight pressure at the site. The needle is then withdrawn. Firm hand pressure is applied to the area for about 15 minutes. The procedure takes only a few minutes.

After the Biopsy

After the biopsy, you will need to lay flat in bed for 1 hour. Before going home, your urine must be checked to make sure that it is clear. If you were told to hold any medications before the biopsy, we will let you know when you can resume taking them.

You must have a responsible adult to assist you in getting home safely.

At Home

No heavy lifting (greater than 15 lbs.) or strenuous activity for 24 hours. If your urine is pink-tinged, be sure to drink extra fluids.

When to Call the Nurse:

Call the transplant nurse coordinator right away (no matter what time it is) at (312) 695-8900 if you notice any of the following:

- A blood clot or bright red color in your urine
- An inability to urinate
- New, severe pain in your abdomen
- A fever greater than 100.5°F

If your fever continues to be greater than or equal to 100.5°F after speaking with the transplant nurse coordinator or being evaluated in the clinic, please call the transplant nurse coordinator.

The Transplant Team will let you know when your biopsy results will be ready and will talk about the findings with you.

Pancreas Biopsy

A pancreas biopsy is rarely done. If you need a biopsy of your pancreas it will be done in Interventional Radiology. Your transplant nurse coordinator will talk to you about this test.

Chapter 5 - Health Matters: At Home

Guidelines

The following guidelines will assist you in the weeks following your transplant surgery.

Activity

During the first weeks of recovery, it is common to tire easily. Vary your activities and allow for rest periods during the day.

Rest when you get tired but do not lie down for long periods. Get up and walk every hour while you are awake. Gradually increase the distance you walk daily. One to two miles each day is a good goal. Do not resume strenuous exercise until after you discuss this with your doctor or nurse at your follow-up visit.

It is important that you do not do any heavy lifting for 8 weeks. Do not lift more than 15 pounds.

Bathing/ Incision Care

You may shower, but **do not take a tub bath** until all of your drains and staples are removed. Do not soak your incision or drain site. Support the drainage tube and bulb while taking a shower. Use a mild soap to gently clean your incision and carefully pat it dry.

It is best to leave your incision uncovered. If the staples are bothering you or you have a *small* amount of drainage from your incision, you may put a light, dry gauze dressing - it should not be airtight. Staples are removed by your nurse at your 2 to 3 week follow-up clinic visit.

Small Steri-Strips™ (little white pieces of tape) may be placed on your incision. Do not remove these strips. They offer extra support while your incision heals. Steri-Strips™ should remain in place for about 7 to 10 days. Over time, these strips curl up and fall off, or they will be taken off at a follow-up visit. Let them fall off; do not try to remove these strips yourself.

If there is any change in the amount, color, or smell of the drainage, be sure to tell your transplant nurse during office hours. **Call the transplant nurse coordinator right away if you notice:**

- **The incision is opening up**
- **New or sudden bright red blood**
- **A great increase in the amount of drainage**

JP Drain

If you have a JP drain, your nurse will show you how to care for it at home. Be sure to:

- “Milk” the tube 2 to 3 times per day
- Empty the drainage bag 2 to 3 times a day and record the color and amount
- Bring drainage record to your clinic appointment

Urine Output/Catheter

Be sure to measure and record all your urine output on your pill sheet. You will most likely go home with a catheter. The nurse will tell you on how to take care of it. There are bags that can be strapped to your leg during daytime hours so that you can maintain your mobility. You will see an instructional video before discharge and the nurse will instruct you how to change the bag. Follow the guidelines in the *Urinary Indwelling Catheter* booklet. After the catheter is removed, call the transplant nurse coordinator right away at 312-695-8900 if you:

- Have pain over your bladder
- Have increased swelling in the scrotum (men), or in the labia (genital) area (women) or swelling in your legs
- Are unable to urinate

Medicine

Be sure to take all medicine as directed. Use your pill sheet to keep track of your medicines. If you have any questions, please contact your transplant nurse coordinator.

Incision pain and tenderness should lessen over the next 2 weeks. Pain and discomfort can usually be relieved with your prescribed pain medicine or acetaminophen (Tylenol®). Take pain medicine as directed. Remember that many pain medicines contain acetaminophen. It is important to check the labels or ask the pharmacist. If your medicine has acetaminophen or Tylenol® in it, **do not take more than 4,000 mg of acetaminophen in any 24-hour period**. Do not take ibuprofen or any ibuprofen containing products unless you have talked about this with your doctor. To help prevent nausea it is best to take your pain medicine with food. Contact your transplant nurse coordinator if your medicine does not control your pain or if your pain becomes severe.

Driving

Check with your transplant nurse coordinator before you resume driving. Patients often begin driving about 2 weeks after surgery. Do not drive while you are taking any pain medicine other than acetaminophen or Tylenol®.

Work and School

We encourage most transplant patients to get back to their normal life, including work or school. It may take a while until you are fully ready to return to these activities. In some cases, patients may need to change the type of work they do. As you get stronger, the Transplant Team will talk to you about this.

About Sex

Many people have questions about resuming sexual activity after surgery. If you feel good and are well-rested, sexual activity may be resumed. But during the first month, avoid positions that strain the incision sites. For the first 2 years after surgery, it is important for women to use effective birth control to avoid pregnancy.

Kidney disease, diabetes, the surgery, medications, depression, high blood pressure, etc., can affect a person's sexual function. If you are having problems, know that you are not alone. There are medications, treatments and counseling that may help you. Please feel free to talk about this with the Transplant Team.

Women

Regular menstrual periods may not resume for several months after your transplant. We advise you to wait 2 years before becoming pregnant. This will allow your body to recover from surgery. All women of childbearing age need to consider some form of birth control (even if you are not having regular periods.) Women who want to become pregnant should talk with their gynecologists and transplant doctors. We recommend that you see a high-risk obstetrician (OB).

Men

Dialysis or diabetes may cause impotence in men. After a transplant, **some** men will find that their sexual function does not return. If impotence persists, talk to your doctor or transplant nurse coordinator.

Your New Diet

Now that you have a new kidney and pancreas, you will have more freedom with what you can eat. However, there are some important things you should know and do.

- For the first 6 weeks after surgery, eat foods high in protein, such as lean meats, fish, and skim milk. This helps your body heal after surgery. Proper calorie intake helps prevent loss of muscle mass. Be sure to eat 3 meals a day and be sure that your diet includes starches, fruits and vegetables, dairy products, meats and small amounts of healthy fats (e.g. canola oil, olive oil, or peanut oil)
- Food Safety: Some of your anti-rejection medicines can increase your risk for food borne illnesses. If there is a food recall, and you are unsure whether a certain product has been recalled, it is best to avoid eating that food. For specific information, call the manufacturer, or visit www.fda.gov/safety/recalls/default.htm and enter the product's name or brand
- Always drink pasteurized dairy products
- Wash all fresh fruits and vegetables carefully before eating
- Always cook your food well. When eating out ask for your food to be "well done"
- Drink at least 8 to 10 eight-ounce glasses of fluid every day. Water is best. This is very important to help clear waste products from your body
- To help prevent constipation, increase the amount of fruit, raw vegetables and whole grains in your diet. Drinking enough fluids should help with this as well
- Do not eat grapefruit or drink grapefruit juice since they can increase blood levels of Prograf®, cyclosporine, and/or Rapamune®

Your medicine may cause an increase in appetite. Be careful not to over-eat or you **will** gain weight. Try to stay at the target weight suggested by your doctor or dietitian. Eat well-balanced meals. Avoid foods high in fat and sugar such as candy or potato chips. A better option would be fresh fruit or carrots. You might also try eating 3 small meals with planned healthy snacks in between. You may notice a weight gain while in the hospital. This is related to the IV fluids that you receive to keep your new kidney hydrated. Within a few days to weeks, you should return to your normal weight.

Some of your medicines might cause you to have a high potassium level. If that happens, the Transplant Team may ask you to limit how much potassium you take in. Some foods that are high in potassium include:

- Potatoes (any kind)
- Cantaloupe and honeydew melons
- Orange or prune juice
- Tomato products and milk (if your potassium is high you may be told not to drink more than one glass of milk per day)
- Bananas

Some diet supplements are also high in potassium, so check with your team before you take these.

Two months after surgery begin to follow a heart healthy diet. The heart healthy diet includes low sodium (salt) intake. Choose foods with less than 200 mg sodium per serving or less than 600-700 mg per meal, for a total of no more than 2300 mg /day. Use seasonings to add flavor. Avoid sauces, gravies, breaded foods. Many fast, tasty, easy recipes are available online and at your local library for heart healthy meals. Transplant patients tend to have high cholesterol and triglyceride levels. The following tips will help control your intake of cholesterol.

- Use lean cuts of beef, chicken, turkey, fish, pork or veal for most of your meals
- Trim all the fat you can see and do not use the fat drippings
- Limit use of organ meats (brains, kidneys, sweetbreads) to once a month
- Eat only 2 to 3 egg *yolks* per week. This includes eggs used in baking. You can eat as much egg *white* or egg substitute as you want
- Use *monosaturated* fats, such as canola, olive or peanut oils
- Use soft or pourable margarine made from polyunsaturated oil instead of butter. Make sure the label reads “*no trans fat*”
- Limit margarine, salad dressings, and oils to no more than five teaspoons total per day
- Use skim or 1% milk and low fat cheese instead of whole milk and whole milk cheese
- Eat sherbet or flavored ice instead of ice cream
- If your medicines are causing high blood sugars, high potassium levels, weight gain from an increased appetite or fluid retention, talk with the dietitian or nurse to get ideas for some changes in your diet

A dietitian can meet with you for specific nutritional needs or concerns.

Alcohol

Alcohol can affect how your medicines work. Talk to your doctor about drinking alcohol.

Special Instructions

When your kidney is working well, it is important that you drink at least 8 to 10 eight-ounce glasses of fluid each day. If you drink enough fluid your urine will be light yellow or clear. When you have a fever or diarrhea, drink more liquids to avoid becoming dehydrated.

When you have a fever, increase your fluids to avoid becoming dehydrated. Contact the Transplant Team right away if you:

- Feel dizzy or cannot drink enough fluid
- Are unable to tolerate your medicines

It is very important to check and record your blood pressure (BP) at the same time each day. Some patients will need to do this twice a day - while sitting **and** standing. Your transplant, your body position and activity can all affect your BP so it is helpful to sit quietly for about 5 to 10 minutes before taking your BP. Be sure to bring your BP record to the transplant center at every clinic appointment. You should check your BP before taking any BP medications. If you do not have a BP cuff, please let the transplant coordinator know and we will arrange for you to get one before discharge.

If you have either higher or lower than “normal” BP (noted on 2 or more readings), treatment may be needed. It is important to call the transplant center if:

- The top number, or systolic blood pressure, is greater than 190 or less than 100
- The bottom number, or diastolic pressure, is greater than 105

If you have high blood pressure or are retaining extra fluid, talk with your doctor and the transplant dietitian about the need for a diet low in salt.

Weigh yourself (without clothes) every morning on the same scale. Record your weight on your pill sheet. This will alert you to early weight or fluid gain. Report a gain of 5 pounds or more in a day, or 10 pounds or more in a week. If needed, the transplant dietitian can help you plan a weight loss program.

Immunizations: It is important to keep current with vaccinations, including yearly flu shots and a pneumovax shot every 5 years. But **never get any shots containing live viruses**, such as smallpox, measles, or rubella. Since your body's response to infection is somewhat limited, you could get the actual infection or disease from the live virus shot itself. Call your transplant nurse coordinator during clinic hours if you have questions about this.

Before you travel overseas, talk with Northwestern's Travel Clinic at (312) 926-8282. You may need diphtheria-tetanus or other immunizations.

Before you take **any** new medicines, either prescribed by another doctor or purchased over-the-counter (OTC) – this includes herbals or supplements – talk to your transplant doctor or nurse.

You should **not** take the following medications *unless* ordered or okayed by the transplant doctor:

- Erythromycin (Ery-tab®)
- Clarithromycin (Biaxin®)
- Diltiazem (Cardizem®, Cartia XT®, Tiazac®, Dilacor XR®)
- Verapamil (Calan®, Isoptin®, Verelan®)
- Cimetidine (Tagamet®)
- Fluconazole (Diflucan®)
- Ketoconazole
- Voriconazole (Vfend®)
- Itraconazole (Soprano®)

You are more sensitive to the sun and likely to sunburn more quickly than others. You are at a higher risk for skin cancer. It is very important that you protect yourself from the sun and from sunburn. Use a sunscreen lotion or spray with SPF-60 for your face and at least SPF 30 on the rest of your body. Put the sunscreen on at least 30 minutes before you go outside. It is best to put sunscreen on *every day*, whether you are in the sun or not. If you can, wear a hat and long sleeves while in the sun. It is also **very important** that you see a dermatologist **every year** for skin cancer screening. You can call the Dermatology Clinic at (312) 695-6647. See Appendix B.

Since smoking can increase your risk for high blood pressure, lung infections and cancer, *stop smoking* to avoid its harmful effects. Stay away from second hand smoke as well.

Talk with your Transplant Team about an exercise program that is right for you.

Chapter 6 - Follow-up Care

Doctor Visits

Urologist

During your transplant surgery, the new ureter (the tube that drains urine from the new kidney) is connected to your bladder. A stent (tiny tube) is placed in the ureter. The stent helps to relieve any pressure in the ureter and allows the site to heal.

About 6 weeks after your transplant, the stent will need to be taken out. To do this, the urologist inserts a small scope into your urethra (urine opening). The scope helps locate the stent so it can be gently removed. This takes only a few minutes and is done in the urologist's office. Be sure to keep this appointment. If the stent remains in place too long, it may cause serious problems, such as severe infection.

Nephrologist, Endocrinologist or Primary Care Doctor

About 3 months post-transplant, if your condition is stable, your routine care will be transferred to your nephrologist, endocrinologist and primary-care doctor. By this time the kidney and pancreas are usually working well and anti-rejection drug doses are stable. You will still be followed by the Transplant Clinic 12 months after your transplant and then every year or as needed.

Early changes in your kidney and pancreas function can only be detected by checking your blood, **so it is very important that you have your labs checked regularly:**

- **Even though you feel fine**
- **Every month for the rest of your life**

It is helpful to have your lab reports and general comments about how you are doing sent to the Transplant Clinic. Please ask your doctor's office or the lab where your blood is drawn to do this.

Also, please remember that any serious viral illness such as the flu can trigger a rejection of your kidney/pancreas transplant. **It is very important to have your labs checked once a week for 6 weeks after the flu (with a fever/cough).** Please call your primary care doctor or the Transplant Clinic to arrange for this blood work and **please make sure we get the results.**

If for any reason you go to another hospital, we will need a discharge summary from that hospital stay as well.

Routine Health Appointments

It is important to have routine health exams every 6 months. Be sure to tell all members of the health care team about your transplant and all the medicines you are taking.

Dental

Good brushing and **daily flossing** of your teeth help prevent infection in your mouth. Since our mouths contain a lot of bacteria, you will need antibiotics before **any** visit to the dentist, even for dental cleaning. Call your dentist before you go in so antibiotics can be prescribed ahead of time. We recommend following the American Heart Association guidelines. Your dentist can always call the Transplant Clinic with any questions.

Eye

Both prednisone and Prograf® increase your risk of cataracts. If cataract surgery is ever needed, it can be done without any harm to your new kidney or pancreas. Eye exams from an *ophthalmologist* should detect cataracts and you need to have an exam every year. Of course, be sure to tell your ophthalmologist about any changes in your vision.

Gynecologic

Since the risk of cervical cancer may be slightly higher after a transplant, it is important that every woman have a pelvic exam and Pap smear every year. If detected early, cancer of the cervix can almost always be cured.

Skin

The Dermatology Clinic at Northwestern Memorial Hospital works with the Transplant Clinic to see and treat transplant patients with skin problems. Please call the Dermatology Clinic at (312) 695-6647 to schedule an appointment if you have any skin problems. Since your transplant medicines increase your risk for skin cancer, it is also **very important** that you see a dermatologist **every year** for skin cancer screening. Always remember to use sunscreen.

Important Transplant Clinic Numbers

Telephone:	(312) 695-8900
Fax for Labs	(312) 695-7752
Fax for Prescriptions	(312) 926-5489
Location:	Northwestern Memorial Hospital 676 N. Saint Clair Street, Suite 1900 Chicago, Illinois 60611
Office Hours:	Monday thru Friday 8:30 a.m. – 5:30 p.m.

If you need to contact a transplant nurse coordinator or nurse practitioner during office hours, call (312) 695-8900.

For urgent issues after hours, call (312) 695-8900. The answering service will page the transplant nurse coordinator on call. Identify yourself as a transplant patient; briefly describe why you are calling. Provide a phone number where you can be reached. The nurse will call you back within 20 minutes.

For life-threatening emergencies, call 911.

Social Workers	(312) 695-0828
Dietitian	(312) 695-8900
Patient Assistance for medicines	(312) 695-0828
Dermatology Department	(312) 695-6647
Infectious Disease (ID)	(312) 926-8358

Chapter 7 – Additional Information

APPENDIX A: Stress, Emotions, and the Transplant Process

Having a medical illness can be emotionally challenging. It is common, normal and even healthy for transplant candidates and their loved ones to experience many different emotions throughout the transplant process. These feelings are different for everyone. They might range from positive to negative, often within a very short period of time. It is important to understand some of the causes of your stress and how to successfully manage them.

During the evaluation period, transplant candidates often express feelings ranging from hope and resolve to guilt or anxiety. The waiting period can be long and stressful for the transplant patient. Sometimes there are serious setbacks during the waiting time — both medical and emotional. Emotional distress (e.g., sadness and frustration) often changes, depending on how well you feel.

After transplant surgery, you might have mood changes as you return to your daily routine. Some of this is caused by some medicines, but also by the medical ups and downs that often happen after a transplant. It is impossible for anyone to predict your emotions or feelings of stress throughout the transplant process. But we can share with you some common experiences to help you be ready for some of the changes and help you think of ways to deal with them. Remember, most patients adjust well to the different phases of the transplant journey – in their own way and on their own time.

Depression

Everyone has times when they feel sad or down. That is normal and most of the time this sadness gets better in a short time. When sadness lasts more than 2 weeks and affects the way a person functions, it may be a sign of a more serious illness such as *clinical depression*.

Clinical depression is not the same in everyone. But it often includes feeling sad and/ or a loss of interest in most activities. One person may have a hard time concentrating, feel irritable, sleep poorly, and have no appetite or energy. Another may feel tearful and hopeless, guilty and ashamed; and feel no joy in anything. No matter what the sign, depression is distressing and it makes it difficult to live a normal life.

Having some or all of the symptoms that are listed in this chart, when felt for 2 weeks or longer, may be a sign of depression.

- | | |
|--|---|
| ▪ Sadness, tearfulness or crying spells | ▪ Irritability or anger |
| ▪ Loss of interest in activities that you used to like | ▪ Decreased sexual desire |
| ▪ Feeling tired and having a lack of motivation | ▪ Changes in appetite or weight |
| ▪ Feelings of guilt, helplessness and hopelessness | ▪ Increased or decreased sleep patterns |
| ▪ Forgetfulness or changes in concentration | ▪ Decreased self-esteem level |
| ▪ Body aches and pains, such as headaches or upset stomach | ▪ Withdrawing from others |
| | ▪ Altered perceptions |
| | ▪ Recurrent thoughts of death or wanting to harm self |

Depression is more common in transplant patients than in the general population. Depression can occur before surgery, soon after surgery or even a long time after your transplant. Depression can cause a slower recovery and can have an effect on your social relationships, your desire and ability to be productive, your ability to follow medical recommendations and even your will to live.

If you have signs of depression, or if your loved ones notice them in you, call your Transplant Team. It is important to look at your specific symptoms and feelings and work with the transplant psychiatrist, social worker, or Transplant Nurse Coordinator. Treatment depends on what you need, but may focus on:

- Improving your mood
- Helping you cope with stress
- Adjust to what is happening to you

Treatment can help teach you how to relax and ways to help your sleep and mood. Sometimes you will need medicine to treat your depression. By monitoring your symptoms, talking with your Transplant Team, and possibly receiving individual counseling and/or medication, your depression can often be managed and short lived.

Anxiety

You may also experience anxiety, worry and fear during your transplant journey.

Remember, emotions that come and go quickly and do not cause significant distress are normal, healthy and appropriate. Many transplant patients express fear, anxiety, and worry about rejection, physical symptoms and medication side effects. They may be worried about their quality of life and wonder how long or how well they will live. These are normal emotions that allow people to think ahead, plan for future setbacks and solve problems.

When anxiety, worry and fear become overwhelming then worry is no longer helpful. Patients may then have a hard time sleeping, trouble concentrating, increased irritability and excitability, muscle tension and sometimes even panic attacks. Anxiety is treatable and can often be helped by talking to a professional. Our transplant psychiatrist and social workers are available to help you name your anxiety, develop problem-solving skills, become more comfortable with your medical situation, learn relaxation techniques and find helpful ways to cope with stress. You may also be referred for individual counseling.

Fear and anxiety are often the result of the fear of the “unknown” or when:

- The worst-case scenario is assumed
- People feel they have little or no control

As a transplant patient, there are many aspects of your health and recovery that you cannot control. But there are also many things that you can and need to control. To ward off anxiety, try to remain focused on those things that you can control.

- Keep your follow-up appointments
- Follow medication guidelines
- Exercise and eat a healthy diet
- Keep a positive outlook
- Be an active partner in your care

Another way to have control is by having the information you need to understand:

- What is happening and why
- What is the best thing you can do to help

It is important to talk to the Transplant Team. Ask questions, so that you have accurate information.

Find comfort in knowing that you are doing everything in your power to make the situation better.

Stress

Stress is a natural part of our daily lives and it is healthy and necessary for our existence. Stress helps us manage many different situations. Too much stress, however, can be harmful. Everyone experiences stress differently, but most respond to stress with some emotional, physical and behavioral changes. The emotions that are brought on by stress might include sadness, frustration, anger or depression.

Physically you might feel tense muscles, stomach upsets, headaches and/or changes in sleep or appetite. People often feel “butterflies” in their stomach, a fast heartbeat, sweating, or tingling in their fingers during a stressful event. Some may cry, shout, walk away or abuse drugs or alcohol. Everyone responds differently to stress, even to the same stressful situation. For example, what causes anxiety and insomnia in one person might cause diarrhea and an upset stomach in another. One person may become angry when under stress, while another tends to be tearful and sad. People also vary in how they view a situation. If you believe that you can cope with or overcome the challenges that face you, then you are likely to feel less stressed.

Chronic stress can greatly strain body systems and damage them over time. It is especially important for those with weakened immune systems to limit the amount of stress experienced in their daily lives so that the physical effects of stress will not harm their new organ.

It is important, then, to take a good look at your ability to cope with difficult situations. You will likely realize that you can cope with almost anything. The transplant process might not be easy, but know that you have many resources to help you through the tough times. While you probably will have a roller coaster of physical changes and emotions with your transplant, including stress, believe in yourself and believe in your ability to keep going and you will be less likely to trigger the stress response.

There are positive ways to respond to and ease your stress. One of the best things you can do, of course, is to take care of yourself, both mentally and physically. Some ideas are listed in the table to the right.

Ideas to Help Reduce Stress

- Make sure you get adequate sleep and have time to relax
- Avoid nicotine, alcohol and illicit drugs
- Find activities that relax your body such as:
 - Meditation
 - Prayer
 - Yoga
 - Laughter
 - Baths
 - Music
 - Writing
 - Deep breathing

Coping

Coping refers to the way people react in the face of a challenge, the things they do to comfort themselves in the face of stress. Not all coping strategies are healthy. For example, some people use nicotine, alcohol or drugs to help them cope with stress. These behaviors might seem to bring some immediate relief, but they can eventually be harmful. It is important that you use healthy coping strategies to help you get through difficult situations.

There is no “right way” to cope. The best way is for you to identify coping strategies that work for you, that help you feel more comfortable and at peace with the events you face. It can be hard, especially when you may have had so much to cope with already with your illness, but think about what works for you. Some ideas are described in greater detail here and your Transplant Team can also help you learn new ways to cope.

Gathering information: it often helps to gather as much information as you can about your medical condition, what to expect during the transplant process and what your responsibilities are throughout that process. Knowledge helps you establish more realistic expectations, which can often help lessen stress. Since stress, depression, and anxiety can make it harder to concentrate and remember things, it often helps if you bring someone with you to your appointments. You may also bring a small notebook for note taking. You should write down your questions before your appointments and then write what you learned during that appointment. Also, feel free to visit Northwestern Memorial’s Health Learning Center, a state-of-the-art health information library on the third floor of the Galter Pavilion. Health educators are available in the Center to help you gather information about medical topics - at no charge. For more information, contact the Health Learning Center at 312-926-LINK (5465) or by e-mail at HLC@nmh.org. The Alberto Culver Women’s Health Learning Center also is available in Prentice Women’s Hospital.

Spirituality and prayer: Religious faith and spirituality can be powerful coping tools, especially in response to events that are beyond your control. If you consider faith to be an important part of coping, consider talking with someone at your religious institution or at Northwestern Memorial, who can offer support or guidance, or working with a prayer group, for example. To speak with someone at Northwestern Memorial Pastoral Services, please call 312-926-2028.

Distraction: While some people like to actively confront a situation, others prefer to distract themselves. Distraction can be particularly helpful during a hospital stay when you often have a lot of time to dwell on stress and worries. You can keep yourself busy in the hospital or while recovering at home by being creative. You can do things like watching television or movies, reading, playing games such as cards or checkers, talking with others, knitting, doing crossword puzzles, walking, inviting visitors, writing about your experience, drawing, using the computer or writing to friends, etc. Ask for help to make sure the things that you would like to do are available to you.

Relaxation: Relaxation techniques can often help counter the physical and emotional effects of stress. Learning new ways to breathe, meditate or use guided imagery to help you feel more relaxed, energized and calm. Relaxation training can be a positive way to minimize stress, decrease pain, improve sleep, reduce anxiety, and improve energy. The transplant social worker can work with you on these techniques, either while you are in the hospital or on an outpatient basis. Engaging in leisure activities that you like to do and that make you feel relaxed can have similar physical and emotional benefits. Some of our patients relax with such activities as yoga, cooking, fishing or taking bubble baths.

Humor: Laughter and a sense of humor are related to a better quality of life and better physical health. Laughter can improve sleep and mood and even reduce pain. It can help you relax your breathing and improve your heart rate and blood pressure. You can help improve your spirits by looking for the humor in your situation whenever possible or by making time to read funny things or watch television shows that make you laugh.

Communicating with Family and Friends About Your Transplant: You should not travel this journey by yourself. Sharing your concerns, questions, feelings and emotions with others, telling them what you need, asking for help when you need it. For example, let family and friends know whether you want them to visit you in the hospital, to call more often or less often, to bring your favorite foods or magazines to the hospital, to let others know about your condition or just to be there for support. Loved ones usually feel more comfortable if you give them some direction.

Sharing your fears and concerns with your family and friends can also be important. Your loved ones may well be experiencing some of the same thoughts and emotions as you and it often helps to talk about them with each other.

How Should I Feel?

There is no particular way that you *should* feel. There is much that is happening before and after a transplant. Both your physical and emotional health can roller-coaster, independent of your plans or behaviors. Resources are available to help you deal with your reactions.

Advice for Family Members and Caregivers

It is hard to watch a loved one suffer. The transplant process can be exhausting, emotionally draining and physically and financially demanding for everyone involved. It is inevitable that you will feel helpless at times. Although the patient is the focus of medical attention, the Transplant Team realizes that family and friends will also have emotional ups and downs. While caring for and supporting your loved one, be sure to take care of yourself. It is easy for caregivers to feel worn out. The same ideas about coping and reducing stress apply to them as well.

The Transplant Team is available to help family members cope with the emotions, stresses and responsibilities associated with care giving, or refer you to other professionals if that is what you need. Always feel free to ask for help.

Summary

The transplant process, while exciting and full of hope, can trigger emotions such as depression, anxiety and increased stress. Patients and their loved ones learn that life changes after a transplant. Patients will probably have some physical limitations, at least temporarily, and might not be able to do all their household chores, errands and other things they used to do. Family members are likely to be pulled in many directions and may not be able to do it all on their own. Everyone will need to learn to adjust their expectations to meet these challenges. Priorities need to shift to reflect your capabilities in a new situation.

There are many ways to lessen your stress such as:

- Practicing healthy coping strategies
- Surrounding yourself with family and friends
- Focusing on the parts of the situation that you can control
- Establishing realistic expectations and priorities
- Planning ahead
- Communicating effectively with your family, friends and Transplant Team

Notice your emotional symptoms, talk about them with your Transplant Team and ask for help from the psychological, behavioral and educational resources that are available to you.

For most individuals, receiving a new organ is a joyous time filled with celebration, hope and a renewed appreciation for life. We wish you all the best throughout your transplant journey.

Appendix B: Guidelines for the Early Detection of Cancer

Adapted from the American Cancer Society Guidelines for the Early Detection of Cancer

Guidelines revised March 28, 2007

General guidelines for prevention and early detection of cancer, from the American Cancer Society, are listed here.

For patients at greater risk for cancer, including transplant patients, cancer-screening guidelines may be different. You may need to start screening earlier or be screened more often. No matter what, it is important that you follow these cancer-screening guidelines (or those suggested by your doctor) and see your doctor right away if you have any symptoms that could be cancer.

Cancer-related Checkup

For people aged 20 or older it is important to have a routine health exam. Your doctor can:

- Look for any signs of cancer
- Talk to you about your cancer risk
- Discuss ways to prevent cancer

Skin Cancer

- Stay out of the sun as much as possible, especially between 10:00am and 2:00 pm. when the sun is usually its strongest
- Wear a hat when you are in the sun
- Apply sunscreen *every* day, whether you will be in the sun or not. It is important to apply the sunscreen at least 30 minutes before you go outside. Use sunscreen with SPF 60 on your face, SPF 30 on the rest of your body
- See a dermatologist every year to check for signs of cancer, including any skin changes that might look suspicious

Breast Cancer

- Yearly mammograms are recommended starting at age 40 and continuing for as long as a woman is in good health
- Clinical breast exam (CBE) about every 3 years for women in their 20s and 30s and every year for women 40 and over
- Women should know how their breasts normally look and feel and report any breast change promptly to their health care provider. Breast self-exam (BSE) is an option for women starting in their 20s

The American Cancer Society recommends that some women – because of their family history, a genetic tendency, or certain other factors - be screened with MRI in addition to mammograms. Talk with your doctor about your history and whether you should have additional tests at an earlier age. For more information, call the American Cancer Society and ask for their document *Breast Cancer: Early Detection*.

Colon and Rectal Cancer

Starting at age 50, talk with your doctor about:

- Yearly fecal occult blood test (FOBT) or fecal immunochemical test (FIT). These tests look for blood in your stool and can often be done with a home-test kit
- Flexible sigmoidoscopy every 5 years
- Both a yearly FOBT or FIT, and a flexible sigmoidoscopy every 5 years. (This is usually preferred over either the FOBT or FIT or sigmoidoscopy alone)
- Double-contrast barium enema every 5 years
- Colonoscopy every 10 years. **For transplant patients, we recommend a colonoscopy every 5 years**

Also, people who have higher risks of getting colon cancer should talk to their doctor about starting colorectal cancer screening earlier and/or getting screened more often. Some of the higher risks include a strong *family* history of colorectal cancer or polyps or a personal history of:

- Colorectal cancer or adenomatous polyps
- Chronic inflammatory bowel disease (IBD)

Cervical Cancer

- All women should start getting a Pap smear either at age 21 years old or about 3 years after they start having intercourse, whichever comes first. You need a regular Pap test every year, or can go every two years if your doctor uses the newer liquid-based Pap test
- If you are 30 or older *and* have had 3 normal Pap test results in a row, you might be able to change to screening every 2 to 3 years. Or you can get a Pap test **and** the HPV DNA test every 3 years. It is important to have a Pap smear every year if
 - Your mother took diethylstilbestrol (DES) before you were born
 - You have HIV infection
 - You have a weakened immune system after transplant, chemotherapy, or chronic steroid use
- Women 70 and older may choose to stop having Pap tests **if** they had 3 or more normal Pap tests in a row and no abnormal Pap tests in the last 10 years
- Ask your doctor if you need to continue to get Pap smears after a hysterectomy

Endometrial (Uterine) Cancer

At the time of menopause, it is important to know about the risks and symptoms of endometrial cancer. If you have any unexpected bleeding or spotting, report it to your doctor right away. If you have or are at high risk for a certain kind of cancer called hereditary non-polyposis colon cancer (HNPCC), you should have an endometrial biopsy every year starting at age 35.

Prostate Cancer

Starting at age 50, men should have a prostate-specific antigen (PSA) blood test and a digital rectal exam (DRE) every year. African-American men and men with a strong family history of prostate cancer should start being tested at age 45. If you have several close relatives who have had prostate cancer, you should start being tested at age 40. **Patients who had a transplant should also start being tested at age 40.** If that test is negative, most patient may wait until age 45 to repeat the test.

References

American Cancer Society. *Cancer Facts & Figures 2007*. Atlanta, GA: American Cancer Society; 2008.

Saslow D, Boetes C, Burke W, et al for the American Cancer Society Breast Cancer Advisory Group. American Cancer Society guidelines for breast screening with MRI as an adjunct to mammography. *CA Cancer J Clin*. 2007;57:75-89. [Free full text article available at: <http://caonline.amcancersoc.org/cgi/content/full/57/2/75>]. Accessed March 28, 2007.

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Appendix C: Blood Tests

A **CBC (Complete Blood Count) with platelets** tells if the body is “making” enough blood. It also gives important information about:

- Blood volume (**Hematocrit** or **Hct**)
- Blood count (**Red Blood Cells** or **RBCs**)
- The blood’s ability to carry needed oxygen to all parts of the body (**Hemoglobin** or **Hgb**)
- The blood’s ability to clot (**Platelets** or **Plt**)
- The body’s ability to fight or prevent infection (**White blood cells** or **WBCs**)

A **Chemistry Panel** measures the level of important chemicals in the body. It includes the following.

- **Blood urea nitrogen (BUN)** is a by-product of the breakdown of protein in the liver that is excreted by the kidneys. A BUN test helps to assess kidney function.
- **Calcium (Ca)** is important for muscle function, normal heart rhythm, blood clotting and for healthy bones and teeth.
- **Carbon dioxide (CO₂)** is a gas that is a natural waste product of the body. Changes in the CO₂ blood level may be caused by infections, respiratory complications, liver or kidney failure, severe diarrhea, or incorrect acid/base balance.
- **Chloride (Cl)** is an electrolyte that can affect the body’s balance of acids and bases.
- **Creatinine (Cr)** is another test to check how your kidneys are working.
- **Glucose** or blood sugar measures the amount of “sugar” in your blood. The liver helps make glucose.
- **Magnesium (Mg)** is important for normal muscle function and strength. If Mg levels are too high or too low, abnormal heart rhythms (cardiac arrhythmia) can occur.
- **Phosphorous (P)** calcium must be in balance for normal muscle activity.
- **Potassium (K)** is needed for normal cell, nerve, heart and muscle function.
- **Sodium (Na)** is needed by the body for a normal fluid balance and normal nerve and muscle function. High levels and low levels can result in mental changes.
- **Total Protein (TP)** level in the blood is affected by liver function and nutritional status.
- **Uric Acid (UA)** is another of the body’s waste products.

Creatinine Clearance is actually not a blood test. It is a urine collection (you collect and save your urine for 24 hours), but it helps tell how well your kidneys are removing creatinine from the blood.

CMV Antibody is a blood test to check for exposure to the cytomegalovirus (CMV) virus. This is done before you get your transplant to help us know your risk of CMV disease after transplant.

CMV PCR Quantitative is a blood test to look for and measure the CMV virus in your blood. It is very important to get this test and NOT the antibody test after transplant.

Hemoglobin A1-C is drawn if you have diabetes. It looks at how well your blood sugars have been controlled over the last 2 to 3 months.

Quantiferon TB Gold will detect any previous exposure to tuberculosis.

APPENDIX D: Diagnostic Tests

Your follow-up care may include some of the tests listed below. Your nurse will provide more detailed information about any of these tests if they are ordered for you.

A **bone mineral density** exam can detect early bone mineral loss, such as calcium. This mineral loss may lead to osteoporosis. The exam is done in the Nuclear Medicine Department and takes about 30 minutes.

A **bone scan** shows early bone disease. In many cases, the test can detect this condition before it is seen on standard x-rays. A bone scan uses a small amount of radioactive material (tracer) that is absorbed into the bones. The exam is done in the Nuclear Medicine department and takes about 2 hours.

A **cardiac catheterization (cath)** is an X-ray exam of the heart and its arteries. It looks at how well the heart works. The test helps detect the area and extent of any artery blockage or narrowing. During the exam, a thin catheter (tube) is inserted in the femoral artery (in the groin) and slowly passed to the heart. Dye (contrast) is injected and X-rays are taken. The contrast allows the blood vessels to be seen. The exam lasts 1 to 2 hours. You may need to lay flat for up to several hours after this procedure and will need a scheduled ride home.

A **colonoscopy** is an exam used to detect disease of the lower digestive tract for early signs of colon and rectal cancer. This includes polyps, which can, over time, develop into cancer. It also is helpful in finding the cause of diarrhea, bleeding or changes in bowel habits. The test takes about 30 minutes. You will be asked to do a colon cleanse before this procedure. Make sure you follow the directions carefully and complete the cleanse. If not properly done, the procedure may not be able to be completed. You will be given medication to relax you during this procedure and should not remember it when you wake up. You must have a scheduled ride home before undergoing this test. During the exam, a small flexible tube is inserted into the rectum and to the colon. At the end of the tube is a tiny video camera with a light. This test may be more helpful than X-rays alone since the doctor may:

- Actually view the area
- Remove polyps
- Take a small tissue sample (biopsy)

A **computed tomography (CT)** scan is a special way of looking inside your body. The images produced are cross-sectional planes taken from a part of your body, much like slices taken out of a loaf of bread. A CT of the kidney is done to check for disease, blood clots and cancer. Please tell the nurse if you:

- Are on dialysis
- Are diabetic
- Have had a problem with this exam (or other contrast exams) in the past
- Have any allergies to contrast dye or shellfish

This will allow us to take special steps both prior and after the scan.

A **dobutamine stress echocardiogram (DSE)**. See pharmacologic stress echo below.

A **2-D echocardiogram** uses high frequency sound waves (ultrasounds) to look at how the various parts of the heart work.

An **upper endoscopy (EGD, gastroscopy or esophagogastro-duodenoscopy)** is an exam that can detect diseases of the esophagus, stomach and duodenum (top part of the small intestine). An EGD is used to find the cause of:

- Persistent nausea, vomiting
- Heartburn or stomach pain
- Ulcers or bleeding
- Swallowing problems

The test takes about 15 to 30 minutes. You will need a scheduled ride home after this procedure. During the exam, a small flexible tube is inserted into the mouth, down the throat into the stomach and duodenum. At the end of the tube (endoscope) is a tiny video camera with a light. This exam may be more helpful than X-rays alone since the doctor:

- May actually view the area
- Can take a small tissue sample (biopsy)

Endoscopic Retrograde Cholangiopancreatography (ERCP) is a test used to study the ducts (drainage paths) of the liver, pancreas, and gallbladder. It uses a thin flexible tube (endoscope) with a tiny video camera with a light. The tube is inserted into the mouth and to the stomach. The doctor is able to see the small openings to the common bile duct and pancreatic duct. The exam lasts about one hour. ERCP is helpful in detecting diseases of the pancreas, bile ducts, liver and gallbladder. It can also allow the doctor to:

- Place a stent (tube) to open a blockage
- Repair narrowed ducts
- Obtain tissue biopsies
- Remove stones or sludge in the ducts
- Decide the need for surgery

A **flexible sigmoidoscopy (flex-sig)** is an exam of the rectum and lower 1/3 of the large intestine (descending colon). This test helps detect disease or early signs of cancer in the lower large intestine. A sigmoid exam is used to find the cause of:

- Diarrhea or constipation
- Bleeding
- Changes in bowel habits

The test takes about 15 minutes. During the exam, a small flexible tube (sigmoidoscope) is inserted into the rectum and to the descending colon. At the end of the tube is a tiny video camera with a light. This exam may be more helpful than x-rays alone since the doctor may:

- Actually view the area
- Take a small tissue sample (biopsy)

A **kidney or pancreas ultrasound** looks at the pancreas and the kidneys and bladder. The test uses sound waves to project an image. This allows the doctor to view organs and areas within the body. A small, hand-held device called a transducer is placed on the skin over the area to be examined. The sound waves from the transducer are reflected off the internal organs back to the transducer. The sound waves create an image on a video screen. The images are seen and captured in real time, showing movement. The exam, done in the Ultrasound department, takes about 30 minutes.

A **pharmacologic stress echocardiogram** (echo) test is used to detect coronary artery disease (CAD), a blockage of blood flow to the heart. This test provides a more complete picture of the workings of your heart during periods of rest and exercise. During the exam, a medicine, Dobutamine, is given to increase the rate and force of your heart beat (similar to what happens during exercise). The echocardiogram uses high frequency sound waves (ultrasounds) to look at how the various parts of the heart work. If CAD is present, the stress echo will often note changes in how the heart muscle contracts.

Although Dobutamine is the most common drug for this test, other drugs may be used instead. Thus, you may hear this test called a pharmacologic stress echocardiogram when the specific drug is not designated.

Pulmonary Function Tests (PFTs). A **Full PFT** is a group of tests that checks lung function such as:

- How easily the air moves in and out of the lungs
- The amount of air your lungs can hold
- How much oxygen (O₂) the lungs send to the heart

An **MRI exam** is a special way of looking inside of your body. It is different from an x-ray. An MRI uses a magnetic field and radio waves to create the pictures. During the test, a contrast agent (“dye”) may be given. It makes certain parts of your body appear brighter on the pictures. The exam time depends upon the area to be scanned and the information needed by your doctors. Most exams last about 45 to 60 minutes.

Every MRI patient needs to be screened to ensure that certain safeguards are in place. If you have any metal inside of your body, please tell your doctor before the exam. This may include:

- Pacemaker
- Aneurysm clip
- Ear or eye implant
- Joint or bone rods or clips
- Metal plate
- Bullets or shrapnel

It is also helpful to talk with your doctor if you:

- Cannot lie flat (for about an hour)
- Have claustrophobia (are uncomfortable with closed-in spaces)

There are specialized MRIs:

MRA (Magnetic Resonance Angiography): to look at your arteries

MRV (Magnetic Resonance Venogram): to look at your veins

A **pharmacologic (medication) cardiac perfusion test** checks the blood flow to your heart. This test can detect coronary artery disease (CAD), a blockage in the blood vessels to the heart. It also can show how severe the blockages are. This exam is done most often for patients who should not exercise or have difficulty with exercise.

The test consists of 2 separate sets of pictures. The 1st set is taken when you are at rest. The 2nd is done after a medicine is used to briefly change the blood flow to your heart, much the same way blood flow changes during exercise. The test uses a small amount of 2 radioactive tracers to show the blood flow (perfusion) to the heart muscle. The amount of radiation used in this test is small and well within limits that are not harmful. Your total test time is 3 to 3½ hours.

X-rays are done to show images of your bones, organs and tissues. There are a few specific x-rays:

- **KUB:** an x-ray of your abdomen with a focus on your kidneys, ureters and bladder.
- **CXR: a chest c-ray**
- **Panorex: an x-ray of your teeth and gums**

APPENDIX E: Glossary of Terms: Transplant Team Members

- *A nephrologist is* a doctor who is a specialist in the care of the kidneys
- *A transplant surgeon is* a doctor who specializes in transplant surgery
- *Nurse practitioners* are Registered Nurses (RNs) with special education and training. They work closely with the Transplant Team and often order tests and prescribe medicines
- *Physician assistants* are health care professionals licensed to practice medicine. They work closely with the Transplant Team in the clinic and the operating room
- *Transplant nurse coordinators* work closely with you in many ways throughout the transplant process
- *The clinic nurse* helps in the clinic with your visits and any procedures you might need (for example, if you need IV medications)
- *Clinical coordinators* assist the transplant nurse coordinator in your care
- *Customer Service Coordinators* work in the clinic, schedule appointments and tests for you, and help things run smoothly in the clinic
- *Phlebotomists and medical assistant:* draw blood for your tests, take your vital signs, and help with biopsies
- *Transplant pharmacists* teach you and your family about your medications
- *A registered dietitian* advises you on special diets to help you manage your diabetes and kidney disease
- *A psychiatrist is* a doctor who works with patients and families to help them cope with challenges that might come up after the transplant
- *A licensed clinical social worker or licensed social worker* assists with the emotional, family relationship and financial issues of pancreas and kidney failure and transplantation
- *A transplant financial liaison* helps you with any insurance issues related to your transplant

APPENDIX F: Going Home with Confidence Checklist

Fill in the answers to these questions and your nurse will review them with you.

Medicines

Name the 2 or 3 medicines that you take to prevent rejection of your new kidney and pancreas.

1. _____
2. _____
3. _____

What can happen to your kidney or pancreas if you do not take these medicines correctly?

Is it okay to miss just a couple of doses of your anti-rejection medicines?

- Yes _____
- No _____

Rejections/Infections

What is rejection?

What is the best way to detect rejection in its early stages?

- See how I feel
- Have my labs checked as I am instructed

Name two signs of infection.

1. _____
2. _____

Name two ways you can avoid infection.

1. _____
2. _____

How can I avoid kidney damage from BK virus?

What symptoms need to be reported to the transplant nurse coordinator right away, no matter what time of day or night?

When you have your lab work done:

- Where will you go to have your labs drawn? _____
- Who should receive the results? _____
- How will you make sure the Transplant Team will get the results? _____

Why do you have to see the urologist?

What if you miss this appointment?

Diet/Activity

What type of diet will you be on at home?

What activity/exercise plan will you be doing at home?

Outpatient Transplant Clinic

Before having dental work done, you will need to:

What can you do to protect yourself from the sun?

Not sure about the answers to these questions? Your staff nurse will review all of this information before you go home from the hospital?



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Northwestern Memorial Hospital is one of the country's premier academic medical centers and the primary teaching affiliate of Northwestern University's Feinberg School of Medicine. The hospital which is located near the medical school on the Northwestern Campus, serves as a regional and national referral center as well as a local hospital for the community.

Consistently rated by consumers as the most preferred hospital in Chicago, Northwestern Memorial is noted for its leadership in a number of clinical specialties. The hospital's clinical programs are closely integrated with the university's research initiatives.

The Transplant Program at Northwestern Memorial Hospital is recognized as one of the top programs in the country for patient care, innovation and research. More than 400 organs are transplanted each year at Northwestern Memorial, making the program a national leader both in terms of the number of transplants and for its superior results. Patients are supported by comprehensive and compassionate care from a variety of healthcare professionals throughout the transplant process.

Para asistencia en español, por favor llamar al Departamento de Representantes para Pacientes al 312-926-3112.

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