





Health Sciences Center, T19-040 Stony Brook, NY 11794-8192 Phone 631 444 2209; Fax 631 444 3831 Monday - Friday: 8:30 am - 5:00 pm

POST TRANSPLANT PATIENT HANDBOOK

If you need immediate help after hours, on weekends, or holidays, please call the Hospital operator at 631 444 1077 and have the Nephrology Fellow on call paged

Transplant Clinic Appointments: 631 444 9208 24 Research Way, Suite 500, East Setauket, NY 11733

Social Workers: 631 444 8141 or 631 638 4354 Financial Coordinator: 631 444 7406

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INTRODUCTION

Congratulations on your kidney transplant!

This booklet will provide you with information you need to take care of yourself. Your nurses and doctors will also give you information. This booklet is not a substitute for communication between you and the transplant team. It is important for you to understand and follow the instructions you receive. ASK QUESTIONS! Learn as much as you can about your kidney transplant. By knowing about your care, you can provide the nurses and doctors with valuable information. This will help them make the most appropriate decisions regarding your treatment. We want you to lead an active life, enjoying the people, places, and things that make you happy.

To help achieve that goal, you will participate in a transplant teaching program. We will help you every step of the way. Our objective is to teach you how to care for yourself at home. You will learn how to take your blood pressure and temperature, record your weight, note your blood test results, and take your medication correctly. Most of this is unfamiliar and may seem overwhelming at first. In time, however, the teaching you receive now will help you feel better about your new routine and caring for yourself. Demonstrating your understanding and practicing your new skills will make the change from the hospital to your home a little easier.

Safe Health Practices after Transplantation and Keeping your Kidney Healthy

Remember to always take your transplant medication as prescribed. You must call your pharmacy to refill your prescriptions at least one week in advance. Do not wait for the last minute to refill your medications!

- Wash hands frequently and thoroughly with antimicrobial soap; it is the most effective way to prevent the spread of infection
- Do not eat or drink from another person's plate or cup
- Avoid people with obvious signs of illness; do not visit with friends or relatives who are ill during the first few months after your kidney transplant; thereafter, use common sense in avoiding risky contact with people who have contagious diseases
- Avoid raw meats, shellfish, fish, poultry, or raw eggs
- Avoid unpasteurized products
- Avoid cleaning cat litter boxes, bird cages, aquariums, and any type of mold
- Avoid petting zoos
- Don't allow animals to scratch you or bite you, wash hands after petting animals
- No live virus vaccines; no vaccines for six months after transplant, you should then get the flu vaccine annually. You may NOT receive the following vaccines post-transplant: Varicella, (chicken pox), MMR, (measles, mumps or rubella), oral polio, or yellow fever. Injectable polio vaccine and the shingles vaccine are acceptable
- Avoid close contact with infants and others who have recently received live virus vaccines (*i.e.* MMR); this includes changing diapers of infants who have received the MMR vaccine within the past three months, as they can shed the organisms in the body fluids and transmit them to you
- Consult with transplant team about travel to areas requiring malaria prophylaxis and/or vaccinations
- Avoid intravenous drug use
- Follow safe sex guidelines
- Do not take NSAIDs other than aspirin. (*i.e.* Ibuprofen, Motrin, Advil, Aleve, Naproxen)
- No dental cleanings for four months
- Take antibiotic prophylaxis prior to any dental work

- Wear sunscreen SPF30 or greater when exposed to the sun for more than 20 minutes
- Have a dermatologist check your skin at least annually
- Keep up with screening exams (*i.e.* mammography, PAP smears, PSA's, colonoscopy, *etc.*)
- Use boiled water if drinking water safety is questionable
- Check with transplant professional before taking new medications or vitamins
- Do not use a tanning bed
- Wear heavy gardening gloves when working in the garden. It is also recommended that if there is a chance you may inhale some of the soil particles, that you wear a protective mask over your nose and mouth

Studies have shown one of the leading causes of transplant loss after the first year is patient non-compliance. You can prevent non-compliance by:

- Always taking your medication as prescribed
- Always keeping your clinic appointments
- Always following your blood work schedule
- Monitoring your vital signs and reporting any abnormalities such as fever
- Always following your specific treatment plan

Remember, you are the most important member of the transplant team. Please take an active role in assisting us to care for you. Being compliant increases your likelihood for the best possible outcome.

NEVER STOP TAKING OR CHANGE YOUR ANTI-REJECTION MEDICATIONS

If you are concerned about the dosage or cost of your anti-rejection medications, please contact the transplant team.

CLINIC APPOINTMENTS

Your first clinic appointment will be made for you. This is scheduled for

_____ at _____.

After discharge from the hospital, your clinic appointments will be approximately twice a week, depending on your condition. Please make all your follow-up appointments before you leave the clinic. Gradually, the number of clinic visits and lab tests will decrease.

CLINIC INSTRUCTIONS

It is important that you bring your _____, ____ medications, Transplant Handbook, and a snack with you to all clinic visits. You may take your medication and eat your snack after your blood is drawn.

For your first visit, you may go out after your blood is drawn, but must return to the clinic at 11:00 am. Plan on being at the clinic until 12:00 noon.

WHAT ABOUT MY DONOR?

The transplant team <u>will not</u> provide you with specific information regarding your donor.

The decision to write to your donor family is a very personal choice. However, we encourage recipients to write a letter, as it often provides solace to a grieving family to know their loved one's gift saved another's life. Here are some guidelines to help you write your letter should you choose to do so:

- Describe some of your interests or hobbies. Talk about your family and mention things that you are now looking forward to doing
- Be sure to include your first name only, in order to maintain confidentiality
- Mention only the state where you live, not the city or town
- Do not include your address, telephone number, or the hospital where you received your transplant
- Sign only your first name

Once your letter is complete, it should be given to a member of the transplant team. Please place your letter in an unsealed blank envelope, along with a separate sheet of paper that includes your name and date of transplant. We will then forward your letter to Donor Services at LiveOnNY. They will identify the donor and their family, and if the family is ready to receive a letter from a recipient, your letter will then be forwarded to them. Once you and the donor family have established written contact, either of you may wish to reveal more personal information or communicate with each other directly. LiveOnNY can also help you with that.

We cannot anticipate if or when the donor family will write back, as it is often a very emotional process for them. Please know, however, that any responses from donor families to you will follow the same path back through LiveOnNY, the transplant center team, and back to you.

*Excerpts from LiveOnNY Caring for New Yorkers through Organ Donation

TRANSPLANT MEDICATIONS

Name	9:00 AM	3:00 PM	9:00 PM	
ENVARSUS 4 MG (TACROLIMUS XL)				Prevents kidney rejection
ENVARSUS 1 MG (TACROLIMUS XL)				Prevents kidney rejection
MYFORTIC 180 MG (MYCOPHENOLIC ACID)				Prevents kidney rejection
VALCYTE 450 MG (VALGANCICLOVIR)				Antiviral
BACTRIM 80/400 (SULFAMETHOXAZOLE)				Antibiotic
PEPCID 20 MG (FAMOTIDINE)				Prevents acid in the stomach
NYSTATIN				Antifungal

ADDITIONAL MEDICATIONS

Name	9:00 AM	3:00 PM	9:00 PM	

VITAL SIGNS						
Date	Weight	Temperature		ght Temperature Blood Pressure		Other
		AM	РМ	AM	РМ	

DIABETIC FLOW SHEET

Date	Time	Glucose	Insulin	Comments

DRAIN OUTPUT LOG

Date	Time	Drain 1	Drain 2	Output

KIDNEY FUNCTION

The kidneys are two bean-shaped organs located above the waist near the spine beneath the lower ribs. Each kidney is a little bit bigger than your fist.



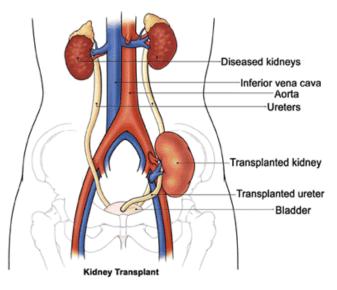
FUNCTIONS OF THE KIDNEYS

- 1. Control the amount of water and other substance in your body such as potassium, sodium, calcium, and phosphorus
- 2. Rid the body of waste products such as urea and creatinine
- 3. Help regulate blood pressure control
- 4. Stimulate red blood cell production
- 5. Help maintain your body's acid-base balance
- 6. Excrete many drugs

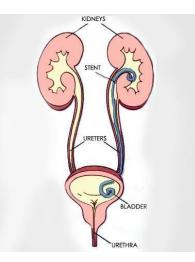
A person's kidneys can be severely damaged before he or she feels ill. A kidney specialist, called a nephrologist, uses medical therapy to help preserve kidney function as long as possible. When kidney function declines to about 10% - 15% of normal or less, however, a person will require renal replacement therapy in the form of dialysis or a kidney transplant to live.

KIDNEY TRANSPLANT SURGERY

The kidney transplant operation lasts about three to four hours. During surgery, the transplanted kidney is placed in the pelvis near one of your hipbones. The surgeon connects the blood vessels from the kidney transplant to blood vessels in the pelvis.



The ureter (urine drainage tube) from the transplanted kidney is connected to your bladder so urine can be excreted. Usually, a stent (a flexible, narrow tube) is inserted into the ureter going into your bladder to keep the connection open. This stent will be removed six weeks after surgery by a procedure called a cystoscopy, and is done as an outpatient procedure in the transplant clinic.



The surgical incision usually heals completely in six weeks. Fourteen to twentyone days after surgery, the staples are removed. Tape called "steri-strips" will then be applied. Do not peel these strips off; they will fall off gradually. Until the incision heals completely, examine it every day. **Call the transplant team if your incision is red, warm, draining, swollen, or more tender than usual.** You may shower as soon as you are discharged, but do not take tub baths until after your incision has completely healed.

DELAYED FUNCTION

After a transplant, most patients have immediate function of their new kidney. However, up to 25% of patients may experience "delayed function". Before your kidney is transplanted, it is preserved in a cold solution that keeps the kidney at a very low temperature. There is no blood flow, and it is, in effect, "asleep". The transplant team strives to keep this preservation period as short as possible. After surgery, the blood supply is restored. It may take your kidney several days, or even weeks, to "wake up" and start working. During this time, your creatinine may not decline, and you may not make much urine. If this is the case, dialysis is frequently resumed. Almost all of the time, delayed function resolves. In the meantime, lab tests, scans, ultrasounds, and/or biopsies may be performed to monitor for rejection or other causes of less than optimal function. If you have delayed function, this does not mean that your kidney will never work. Your kidney may just need extra time to heal and adjust.

TESTING YOUR NEW KIDNEY

After your kidney transplant, several tests are performed to determine how well your new kidney is functioning. Blood tests are performed frequently. If your creatinine rises, a renal ultrasound may be performed. This test is used to diagnose complications such as a leakage of urine or lymphatic fluid, fluid build-up in the kidney due to a blockage, or problems with blood flow into the kidney. If the ultrasound is normal, other tests such as a renal scan or renal biopsy may be done. The most reliable measure of your kidney function is the creatinine. It is a by-product of muscle use and is filtered out by the kidney. This tells the transplant team how well your kidney is excreting waste products.

YOUR IMMUNE SYSTEM

Each person is a "one of a kind" collection of cells, tissues, and organs. Each person inherits a unique combination of genes from his or her parents. The body system that recognizes a person's own cells from other cells and tissues is called the **immune system.** When the immune system finds "foreign" cells and tissues in the body, it attempts to destroy them to protect the body from harm. Bacteria and viruses are examples of foreign organisms that the immune system destroys. The immune system also removes the body's own defective, damaged, or worn-out cells.

When a person receives a kidney transplant, the immune system sees it as foreign, and attempts to reject it by producing cells and/or antibodies that invade and damage the kidney. To prevent the immune system from damaging the transplanted kidney, you will take immunosuppressive (anti-rejection) drugs. <u>It is</u> <u>very important to take your medications every day, exactly as prescribed.</u> A sudden decline in kidney transplant function due to injury caused by the immune system can occur in spite of taking these medications. These events, called "rejections" or "rejection episodes" and are discussed in the next section.

REJECTION

There are three types of rejection:

- 1. <u>Hyperacute rejection</u> is extremely rare today because it can almost always be prevented by tissue cross matching. Hyperacute rejection is caused by preformed antibodies directed against the donor kidney cells. It occurs within minutes to hours of transplantation and completely destroys the kidney transplant. If it occurs, the transplanted kidney must be immediately removed.
- 2. <u>Acute rejection</u> can occur at any time, but it is most common from one week to three months after transplant surgery. Fifteen percent or less of patients who receive a deceased donor kidney transplant will have an episode of acute rejection. When treated early, it is reversible in most cases. The likelihood of rejection decreases as the kidney continues to function well.

3. <u>Chronic rejection</u> happens over time and is due to scarring within the transplanted kidney. It may occur within months to years after your transplant. It is thought that controlling blood pressure, blood sugar, and cholesterol levels can help prevent chronic rejection. Because there usually are no symptoms, it is often diagnosed by changes in your laboratory tests and a kidney biopsy. To date, there is no medication used to reverse this type of rejection. Kidney function generally lasts for months or even years after the diagnosis is made. If the kidney transplant is rejected, you may be able to receive another transplant in the future. Sometimes the transplanted kidney must be surgically removed. Many patients choose a second transplant, which often functions well.

SIGNS AND SYMPTOMS OF ACUTE REJECTION

You may observe one, several, or all of the following during an episode of acute rejection:

- Tenderness or pain over the kidney transplant
- A general achy feeling
- Swelling in the hands and feet
- An elevated temperature
- A rapid weight gain
- An increase in blood pressure
- An increase in blood creatinine
- A decrease in urine output

The only way to diagnose acute rejection is to perform a renal biopsy. Under local anesthesia, a small fragment of your kidney is removed with a needle and examined under a microscope. A pathologist will determine whether rejection is present. There are several medications that can be used to reverse acute rejection, including intravenous steroids (Prednisone), antibodies, and other immunosuppressants.

INFECTION

After a kidney transplant, you will take immunosuppressive (anti-rejection) medications. These medications make you slightly more prone to infection. Infections are caused by germs such as bacteria and viruses. It is very important to recognize when you have an infection. **Infections must be treated promptly!** You may become ill and need to be admitted to the hospital. The signs of infection vary with the type of infection.

SIGNS AND SYMPTOMS OF INFECTION

- Sweating
- Pain
- Fever
- Chills
- Flu-like symptoms
- Nausea
- Vomiting
- Diarrhea
- Congestion or "stuffed up" feeling
- Productive cough
- Burning or pain when urinating
- Increased frequency or pressure when urinating
- Redness, pus, or drainage from your surgical wound
- Any sores or lesions on your skin

Your blood tests may show an increase or decrease in the white blood cell count when an infection is present. Often the doctor will order extra tests to evaluate how severe the infection is, and how best to treat it. If you become extremely ill with a severe infection, your physician may stop your anti-rejection medicines. At this stage, curing the infection is more important than saving your kidney. You must report symptoms of an infection to the transplant team promptly, so it can be treated. **Call the transplant team or Nephrology fellow immediately if your temperature is 101°F or higher.** Also, notify the transplant team if you have a low-grade temperature of more than 100°F for over 24 hours.

VACCINES AND EXPOSURE TO INFECTIOUS DISEASE

After receiving a kidney transplant, you should avoid *LIVE* vaccines including:

Varicella zoster Bacillus Calmette-Guerin (BCG) Smallpox Intranasal influenza Live oral typhoid Ty21a and other newer vaccines Measles (except during an outbreak) Mumps Rubella Oral polio

Avoid direct contact with anyone who has received a live vaccine:

- Children who have received oral polio vaccine for 3 weeks
- Children who have received measles or mumps vaccines
- Adults who have received attenuated varicella vaccine to prevent zoster
- Children or adults who have received the nasal influenza vaccine

You may receive a flu shot, a diphtheria-tetanus booster, or a Mantoux (TB) test. If you have been exposed to viruses such as chicken pox, herpes, or HIV, please notify the transplant team so that appropriate measures can be taken.

MEDICATIONS

In the early phase after a kidney transplant, your medications will change frequently. It is YOUR responsibility to learn the name, dose, and purpose of each medication and the time to take it. The staff nurses and transplant team will help you learn these medications. The medicines and a medication chart about them will be placed in your room to help you learn. Before you are discharged home, the transplant team will discuss pharmacy options with you and order all of your medications. Information about transplant specialty pharmacies may be obtained from your coordinator. Never stop or change your medications unless instructed by the Transplant Team. Please call the transplant team before taking any other medicines, even "over the counter" medications. Also, call before taking medicines or vaccines prescribed by another physician or dentist. Do not take non-steroidal anti-inflammatory drugs (NSAIDS) in the form of Ibuprofen, Aleve, Naprosyn, Midol, (Motrin/Advil) or large doses of Aspirin. These drugs can decrease blood flow to your kidney, causing your creatinine to rise. You may take Tylenol-based pain medication, Actifed and Robitussin for minor cold symptoms. It is important to plan ahead so you don't run out of medications. Even missing one dose can cause problems. Contact your pharmacist at least one week before you run out of medicine so that they can fill your prescription. Always call if you need a new prescription of if there is a problem obtaining your medication.



IMMUNOSUPPRESSIVE MEDICATIONS

Immunosuppressive medications are also called anti-rejection medication. They prevent rejection by decreasing the body's natural desire to destroy foreign cells. However, they also decrease the body's ability to fight infections.

It is extremely important that you take your medication every day exactly as prescribed. You will need to take your immunosuppressive medications every day. If you do not take your medications as instructed, you will lose your transplanted kidney!!!!

Prednisone (Deltasone) is taken to prevent rejection. Take prednisone with food because it can be irritating to the stomach. Some common side effects are an increased appetite, difficulty falling asleep, acne, a round "chubby" face, moodiness, night sweats, increased blood pressure, and edema (swelling). Prednisone can also cause joint pain, muscle weakness, high blood sugar, vision changes, and bone loss, which can result in osteoporosis. Your prednisone dose will be tapered down during the first year after your transplant. Most of the side effects of prednisone resolve or substantially improve as the dose is lowered.

You will be on prednisone if you have been taking it already. If you have not been on prednisone, then you will only receive three doses while you are in the hospital.

Prograf (Tacrolimus), or **Astagraf** (Tacrolimus Extended Release) is given to prevent rejection. Your Astagraf dose will be adjusted by checking a blood sample called a tacrolimus level that reveals how much of the drug is in your blood. The blood level of Tacrolimus must be drawn thirty minutes to one hour prior to taking this medication. It is a trough level which measures the lowest amount of drug in your body. Notify your coordinator if you are unable to have your blood drawn at the appropriate time so that your lab date can be rescheduled. Based on your Tacrolimus level, your dose may be adjusted.

Issues that may influence your Tacrolimus level are:

- Weight change
- Drug interaction
- Erratic absorption of tacrolimus
- Change in kidney function
- Diarrhea and/or vomiting
- Dehydration
- Incorrect timing of medication administration

Tacrolimus can cause hair loss, hand tremors, headaches, higher blood sugar, high blood pressure, fluid retention, elevated cholesterol levels, and high potassium. Many of these side effects also resolve or increase as the dose is decreased. If your tacrolimus level is too high, your kidney function may be affected, resulting in an elevated creatinine level. This is treated by lowering your Prograf or Astagraf dose. As time passes after your transplant, you will require less immunosuppression, and your Tacrolimus dose may be reduced.

GUIDELINES FOR ADMINISTRATION OF MEDICATIONS

Astagraf and Prograf capsules are available in two strengths: 1 mg and 5 mg. These strengths are different sizes. The capsules must be stored at room temperature. Do not cut or puncture the capsules. There are now generic forms of Prograf available. Please let the transplant team know if a generic drug is required by your insurance carrier.

OTHER ANTI-REJECTION MEDICATIONS

Myfortic (Mycophenolic Acid) or **CellCept** (mycophenolate mofetil) is another drug that is taken with Astagraf or Prograf to prevent rejection. It is taken twice a day. CellCept or Myfortic can cause diarrhea, vomiting, and a decrease in your white blood cell count. Blood tests will be obtained regularly to monitor the effects of this medicine.

ULCER PREVENTION

Zantac, Protonix, Nexium, Prevacid, and Prilosec help to decrease stomach acid secretion to prevent or treat stomach ulcers. Possible side effects include diarrhea, headache, muscle pains, and low white blood count. If you continue to experience heartburn while taking the medication, please notify the transplant team.

ANTIBIOTICS, ANTIFUNGALS, ANTIVIRALS

After your transplant, your ability to fight infections is reduced by your immunosuppressive medications (Astagraf, Prograf, Myfortic or CellCept). The following drugs help fight the germs that cause infection. They may be used to treat an active infection or help prevent one.

Bactrim (TMX-SMP) is an antibiotic. It is used to help prevent and/or treat bacterial infections, especially in your lungs or urinary tract. This can be taken daily or every other day (depending on the individual). Bactrim should be taken with a large glass of water to improve absorption. You should wear sunscreen while taking Bactrim because it increases your sensitivity to sunlight. **Dapsone** may also be used in place of Bactrim if you are allergic to Bactrim or sulfa drugs.

Nystatin is an antifungal drug that prevents oral yeast infections (or thrush). Swish one teaspoon of Nystatin in your mouth and swallow it after meals. Thrush appears as white spots in the mouth or a thick white coating on the tongue, which doesn't brush away. When you brush your teeth, check your mouth for white patches. If you notice any, notify the transplant team. Nystatin is usually given for 3-6 months after your transplant.

Valcyte (valgancyclovir) is an antiviral medicine that may be given either to help prevent or treat cytomegalovirus (CMV). This is a virus that can be harmful to immunosuppressed patients. Valcyte is taken once a day for six months following your transplant. It can also be prescribed at any time if CMV becomes apparent.

Acyclovir is an antiviral drug that may be used on some patients in place of Valcyte.

ANTIHYPERTENSIVES

Antihypertensives are commonly known as blood pressure pills. There are many types of blood pressure medications, and each one acts differently in your body. These medications are prescribed on an individual basis. Blood pressure medications and dosages may change frequently after your transplant. These medications can have side effects; the most common are dizziness, light-headedness, weakness, and fatigue. Other side effects may include dry mouth, nausea, diarrhea, constipation, or a change in sex drive or function. Swelling, shortness of breath, or a slow pulse can result from some antihypertensives as well. Inform the transplant team of any side effects. Often changes in medications or dosages can be made. It is important to find the right medication or combination of medications for you.

NUTRITION AND DIET



Following transplant, the diet prescribed for you will depend upon how quickly and effectively your new kidney begins to work. If your new kidney is functioning well, a no-added salt, low cholesterol diet is ordered. Usually, you may drink as much fluid as you like. Your anti-rejection medications may cause changes in the way your

body works. You may experience the following:

- A change in the way your body uses sugar and starches
- A breakdown of muscle tissue
- o Increased appetite, often causing weight gain
- Increased sodium (salt) retention, which may cause high blood pressure
- Altered lipid (fat) metabolism, which may cause high cholesterol and triglyceride levels

Decreasing your sodium and cholesterol will help you maintain a good nutritional status and decrease the side effects of the immunosuppressive medications. If you have diabetes, your diabetic nutritional guidelines should also be followed. The renal dietician will visit you during your hospitalization to discuss and explain your new diet. Please feel free to discuss any of your nutritional concerns.

FAMILY AND SOCIAL RELATIONSHIPS

Receiving a new kidney transplant can be a very emotional time for both you and your loved ones. While many of these emotions can be very positive, having a kidney transplant can also be a stressful and confusing time. Stress may arise from any number of areas such as financial problems, life-style changes, sexual concerns, medical problems, relationships, or self-image. It is also difficult to learn how to "be healthy" again. Our transplant social worker is available to you and your family to help you with stresses, problems, and/or concerns you may be experiencing.

• SEXUAL ACTIVITY

Sex drive and fertility may return after a kidney transplant. If you choose to be sexually active, you may begin having intercourse three to six weeks after the surgery. If you have pain or discomfort during sex, wait and discuss it with the transplant team. For women, it is very important to use birth control if you are of childbearing age. Your gynecologist and transplant team should be consulted

about the method that is best for you. Condoms and foam are highly recommended both as a birth control method and to prevent infection.

• PREGNANCY

Women of childbearing age should wait a minimum of one year after transplant before considering conceiving a child. Your kidney function and blood pressure must be stable. The transplant team and obstetrician must agree that your current health is adequate to safely complete a pregnancy. If you become pregnant, you will require very careful monitoring. This includes having Prograf levels drawn every week, and will require you to stop taking certain medications such as Myfortic. A substitute medication will be ordered.

• RETURNING TO WORK

Depending upon the type of job you have and how well things go, you may return to work 4 to 6 weeks after your operation. Some individuals who have been out of the work force for an extended period of time may need additional emotional support or physical therapy as they prepare to return to work or school. Keep in mind that we are here to help. The reason why we work very hard at making your transplant a success is so you can resume a normal life. This includes going back to work.

LONG-TERM CARE

After discharge from the hospital, you will be followed very closely in the transplant clinic. Typically, after six months, we will refer you back to your primary nephrologist for routine follow up care. We will continue to see you at the transplant clinic once or twice a year. Together, your transplant team and nephrologist will follow your kidney transplant progress indefinitely.

GENERAL HEALTH CARE

DENTAL CARE



Good dental care is essential after a kidney transplant. Infected teeth or gums could develop into a serious illness. You should brush your teeth, tongue, and gums twice a day with a soft toothbrush. It is also very important to floss your teeth twice a day. Regular flossing will help control gum swelling. You should see your dentist every 3 to 12 months depending upon your needs. For the first 6 months following your transplant, inform the transplant team of any dental work that needs attention. Do **NOT** have your teeth cleaned by the dentist for the first four months following your transplant. **Always inform your dentist that you received a kidney transplant. You will need antibiotics before any invasive dental work that may cause your gums to bleed**. Please call the transplant team prior to your dental visit so an appropriate antibiotic can be prescribed for you. Your dentist may also prescribe these antibiotics. We suggest Amoxicillin 2 g or Levaquin 500 mg taken one hour before the dental work is begun.

• HAIR AND NAILS

If you have been prescribed Prednisone, be aware that it can cause acne. To help control acne, wash your face and other affected areas frequently with soap and water. You may try 10% Benzyl Peroxide, a non-prescription solution available from

any pharmacy. You can be referred to a dermatologist (skin specialist) if acne remains troublesome. If you develop cold sores or fever blisters on your face, please notify the transplant team promptly. The ointment form of Acyclovir can help. It may decrease the discomfort you feel and speed the healing process. Growth of facial hair, especially for women, can be a concern after transplant. You may use half-strength hydrogen peroxide to bleach your hair, or hair removal cream (depilatory), which is available at most pharmacies. Please follow the directions on the bottle if you choose to use a hair removal or bleaching product. Some can be irritating to the skin. Hair waxing or wax removal is another option and should be done by a professional at a full service salon.

Please report bruising and hair loss, which are other side effects of your immunosuppressive medication. If your nails become ingrown or infected or you develop warts or growths on your skin, please notify the transplant team. You will need to take antibiotics if you have any procedures done, including having an ingrown toenail removed. If you cut yourself, wash the cut well with soap and water and watch it carefully for signs of infection. Go to the emergency room for treatment if the cut is deep. Don't forget to inform the transplant office.

Patients who take anti-rejection drugs are at a slightly increased risk for developing skin cancer. Whenever you will be in the sun for more than 20 minutes, you should use a sun block product rated 30 or greater. You may buy any brand you choose. Consider wearing a hat outdoors during the summer, especially when in the sun.

• EXERCISE AND ACTIVITY

A kidney transplant is major surgery. It takes approximately 6 weeks for your abdominal muscles to heal. You may notice discomfort as the nerves and muscles heal. Itching around the incision is also normal. Some patients notice the leg on the same side of the body as the kidney transplant swells a little. This is normal. Call us if the leg becomes tender or painful. Your activity should be limited while you heal.

<u>Tou should not drive until you are on or your pain medicine and your</u>
<u>surgeon clears you to drive.</u>
Expect to refrain from driving for two to four weeks after discharge from the
hospital.
Do not lift anything over 10 lbs. for six weeks after you are discharged from
the hospital.

You can exercise your arms and legs after surgery. Walking is an excellent form of exercise. You can climb stairs. Bike riding is allowed six weeks after transplant. You may want to participate in more passive sexual activity to avoid added stress on your wound for two months after surgery. After your incision is healed and you are cleared by your surgeon, you can do abdominal exercises such as sit-ups. Swimming is an excellent exercise because it does not put pressure on bones and joints. You can play golf, roller skate, ice skate, fish, garden (using gloves) and do similar things as often as you like. Please notify us before engaging in any rigorous physical activities. Renal disease and the immunosuppressive medications can make your bones weak. We may refer you to a bone specialist, who can tell you how much stress you can safely place on your bones and joints.

• ALCOHOL, DRUGS, AND TOBACCO

You may drink alcohol in small amounts. If you are taking blood pressure medicine however, alcohol may make you ill, and therefore you should not drink. Never drink and drive. Do not take any mind-altering or mood-altering drugs such as cocaine, marijuana, or PCP, as they can affect your blood pressure and heart and will damage your new kidney. You should not smoke or chew tobacco for the same reasons. In addition, smoking leads to other serious and life-threatening consequences. It can significantly increase your risk for cancer, infections, high blood pressure, and coronary artery disease. Smoking constricts blood flow to your kidney and reduces its oxygen supply and nourishment. We strongly encourage you not to smoke and to avoid exposure to second hand smoke as well. The social worker can refer you to programs to help you quit smoking. If drinking or drug abuse becomes a problem after transplant, please notify any transplant team member. This is a dangerous situation and you could lose your kidney transplant and become seriously ill.

CARING FOR YOURSELF AT HOME

After discharge from the hospital, you will continue to work closely with the transplant team as we follow your progress. Every morning you need to do a mini check-up on yourself:

- Weigh yourself before breakfast
- Measure your temperature and blood pressure once a day
- Double-check your calendar for lab/clinic visits and follow-up appointments
- Record this information on the data sheet in the back of this book and bring it to each clinic visit

DIABETES AND TRANSPLANT SURGERY

Newly diagnosed diabetes, increased insulin requirements or, previously diagnosed diabetes are potential complications of transplantation. Reasons for this include effects of drugs such as Prednisone and lower insulin levels due to increased metabolism of insulin by the normally functioning kidney. With diabetes, the pancreas does not produce as much of the hormone insulin as the body needs, or the cells of the body do not respond to the insulin properly. Without enough insulin, sugar cannot enter the cells so it builds up in the blood. Risk factors for the development of diabetes following kidney transplantation are obesity, older age, and a family history of diabetes. Treatment of diabetes includes a meal plan that controls the amount of sugar that enters the blood and a daily exercise program which lowers blood sugar. Rarely, insulin injections may be needed to increase the amount of insulin available to the body. There are several types of insulin. Each has a specific pattern for when it will begin to work and when it will work the strongest. If you need to learn to give yourself insulin, you will be instructed before you leave the hospital. You will also need to learn the symptoms of high blood sugar (hyperglycemia) and low blood sugar (hypoglycemia). You will be taught how to monitor your blood sugar levels at home. If you develop diabetes, your transplant surgeon will refer you to a specialist for diabetic management.

TEMPERATURE EQUIVALENT

Celsius	Fahrenheit
36.0	96.8
36.4	97.5
36.6	97.9
36.8	98.2
37.0	98.6
37.2	99.0
37.4	99.3
37.6	99.7
37.8	100.0
38.0	100.4
38.2	100.8
38.4	101.1
38.6	101.5
38.8	101.8
39.0	102.2
39.2	102.6
39.4	102.9
39.6	103.3
39.8	103.6
40.0	104.0
40.2	104.4
40.4	104.7
40.6	105.1
40.8	105.4
41.0	105.8

