



*In alliance with
The University of Vermont*

Kidney and Pancreas Transplantation Services

TRANSPLANT MANUAL

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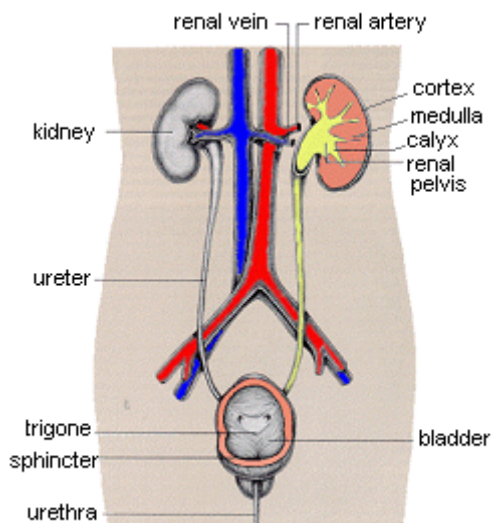
**Please contact Eileen DeLuca with
questions regarding this booklet.**

Before Transplant

KIDNEYS AND THEIR FUNCTION

WHAT IS A KIDNEY?

Your kidneys are located toward the back of your body, just above the waist on either side of your spine. Each kidney is about the size of a fist and together they weigh slightly more than a pound. They are made up of millions of tiny filters called nephrons that work continuously to filter out waste products, toxins, and excess fluid. Approximately 1% of the population is born with only one kidney.



WHAT DOES A KIDNEY DO?

The major function of the kidney is to cleanse the blood 24 hours a day. The entire blood supply circulates through the kidneys every two minutes. Urine is produced from the fluids and wastes removed by your kidneys. When the kidneys are not

working well, people often feel very tired and look puffy from the build up of excess waste material and fluids.

The Main Kidney Functions Are:

- to produce urine
- to eliminate waste materials and excess fluid from the blood
- to help regulate blood pressure
- to help produce red blood cells
- to help build bones
- to regulate chemicals needed by the body

WHAT IS DIALYSIS?

When kidneys are not performing these functions, dialysis can serve as a substitute for some of the things that kidneys normally do. For some people with kidney disease, dialysis is an adequate treatment, and many that are doing well on dialysis never consider transplantation.

Some patients, however, may have difficulty with dialysis. For example, dialysis may interfere with their daily activities and they may lack the freedom they once had. Others struggle with their access site for dialysis. Still others simply do not feel well on dialysis, experiencing a general lack of energy or feelings of nausea. Many individuals dread the needles that are required for dialysis. These are common reasons for

people to seek transplantation as a treatment for their renal disease. Considering whether to pursue a kidney transplant is a very personal matter that depends on your particular situation.

IS A KIDNEY TRANSPLANT A BETTER TREATMENT THEN DIALYSIS?



A kidney transplant, like dialysis, is a form of treatment for kidney failure. With a successful transplant you will not need dialysis. Most patients live longer with a transplant than they do on dialysis and report living a more normal lifestyle. Their diet and fluid intake are much less restricted and individuals report higher energy levels after a transplant. Still, it is important to keep in mind that a kidney transplant is a treatment- not a cure.

Transplanted organs only function for a limited time. Currently, more than 80% of all transplanted kidneys from deceased donors are still functioning after two years. The survival rate of kidneys from living donors is 90-95% after two years. You will be given more specific information on current national and FAHC outcomes at the time of your evaluation.

Although many people feel the gains far outweigh the negatives, there are several important questions to consider. Transplantation will no doubt affect you in many areas of your life: physically, socially,

financially, and emotionally. These topics will be discussed later in this booklet and if any of these areas are a concern for you be sure to speak with the social worker, transplant coordinator, and/or health care provider.

WHO IS ELIGIBLE FOR KIDNEY TRANSPLANT?

Kidney transplant recipients are those with kidney failure who are nearing the start of dialysis or are currently on dialysis. During your evaluation, your general health condition will be assessed through a variety of diagnostic tests. The testing required is described later in this booklet and will be discussed during your initial evaluation.

Is Transplant Right for You? Ask Yourself:

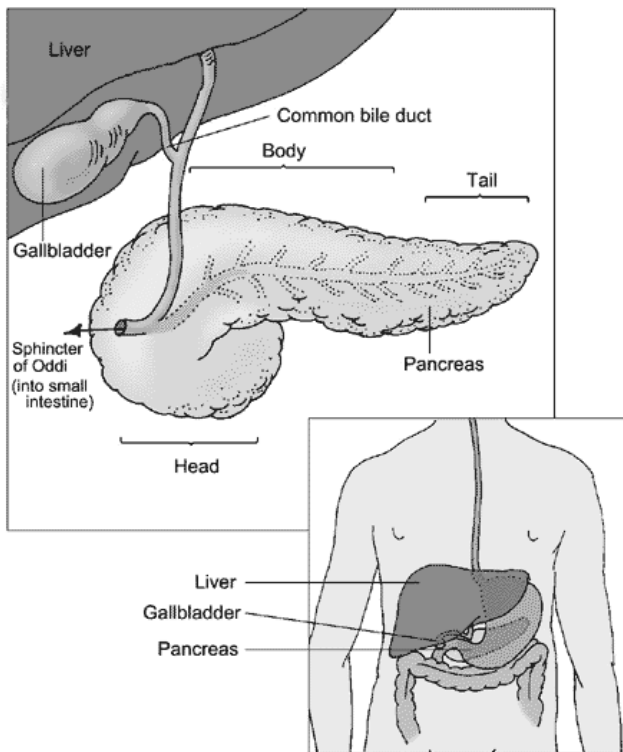
- What are the risks and benefits to transplantation?
- How will I manage the medication regimen after transplant?
- Who will provide personal support for me?
- What will the out-of-pocket expenses be?
- What transportation options are available during the course of my treatment?
- How often will I need to come back and forth to the hospital?
- What will my insurance cover? Is there a cap or maximum on my insurance coverage?

THE PANCREAS AND ITS FUNCTIONS

WHAT IS A PANCREAS?

The pancreas is a slender organ approximately six to nine inches long. It is located above your intestines and behind your stomach in the middle of your abdomen. The major functions of the pancreas are the production of hormones such as insulin and digestive juices called enzymes.

Pancreas and Middle Gastrointestinal Tract



Enzymes are made in the pancreas and travel through a small tube directly into the intestine to help digest food and break it down into molecules such as glucose. Glucose

is your body's main source of energy. It is used by all of your cells.

After food is broken down into glucose, it passes through the wall of the intestines into your bloodstream. Rising levels of blood sugar are sensed by special cells in the pancreas called islet cells. These cells then produce the hormone insulin. The insulin travels through your bloodstream and attaches itself to insulin receptors, which are special sites on the outside of cells. Insulin is what allows glucose to enter all body cells.

WHAT IS DIABETES?

You may develop diabetes if your pancreas does not produce or your body does not use insulin appropriately. There are two types of diabetes:

- Type I Diabetes – when the pancreas does not produce insulin
- Type II Diabetes – when the pancreas makes insulin but your body cannot use it properly.

Healthy islet cells (insulin producing cells of the pancreas) respond to the body's blood sugar level from moment to moment, releasing the right amount of insulin and preventing complications caused by blood sugar imbalance. Diabetic individuals do not have healthy islet cells in their pancreas, so insulin injections are taken at specific times during the day in an attempt to control blood sugar levels. Unfortunately, due to many variables, many diabetic individuals experience

erratic blood sugar levels (many “highs and lows”). Both types of diabetes result in the body not being able to use glucose properly. Glucose is needed by cells to produce energy. People with Type I or Type II diabetes require medical treatment to control blood glucose levels. Insulin injections, dietary restrictions, and visits to doctors allow many people with diabetes to live normal or near normal lives.

Even when diabetics control their blood glucose levels, many experience related health problems. Fifty percent of people who have diabetes develop problems such as kidney disease, heart disease, eye and nerve damage, and disease of the blood vessels of the arms and feet.

WHAT IS A PANCREAS TRANSPLANT?

Although insulin therapy is life saving for diabetic patients, a number of individuals on long-term insulin therapy will eventually develop additional health problems. Given the complications of diabetes, a pancreas transplant is an option to consider seriously. The complications of diabetes generally result from erratic blood sugars. While some individuals can control their diabetes reasonably well with insulin, others cannot. Only a functioning pancreas with healthy islet cells can effectively control blood sugars and prevent complications.

WHO IS ELIGIBLE FOR PANCREAS TRANSPLANT?

Candidates for pancreas transplantation are Type I Diabetics who take injected insulin to control their blood sugar levels. They may experience episodes of hypoglycemic unawareness. Diabetics who have kidney failure or are about to require dialysis should consider a combined kidney and pancreas transplant. Diabetic individuals who currently have excellent control of their disease with insulin therapy, and who do not yet have any complications from diabetes, are not considered appropriate candidates for pancreas transplantation at this time.



*Your
transplant
will
involve
lifetime
treatment.*

The Transplant Experience

THE EVALUATION PROCESS

The purpose of the evaluation is to make certain:

- that transplant is an appropriate treatment for you
- that the surgery itself will not pose undue risk for you.
- that you will be able to care for yourself and your new kidney and/or pancreas after transplant

You will be working closely with your transplant coordinator from the beginning to the end of this process.

YOUR FIRST VISIT:

You will be seen by a transplant coordinator, social worker, nephrologist (kidney doctor).

- The *transplant coordinators* will give you information about what you can expect before, during, and after surgery. They will be your contact when scheduling tests necessary for transplant work-up.
- The *nephrologist* will review your records, examine you briefly, and review the risks and benefits of transplantation.
- The *transplant social worker* will gather your social history, explore your feelings about transplantation, and review basic financial information.

YOUR SECOND VISIT:

You will be seen by a transplant surgeon and transplant nutritionist.

- The *transplant surgeon* will assess your ability to undergo an operation and determine if any further tests are required.
- The *transplant nutritionist* will perform a nutritional assessment and provide education.

In certain cases, you may benefit from additional evaluation by other members of the transplant team, such as:

- Psychiatrist/Psychologist
- Financial Counselor
- Nutritionist (Dietician)

The time that is required for evaluation for kidney and/or pancreas transplant varies from patient to patient but generally takes approximately 2-4 hours.

TESTS REQUIRED FOR TRANSPLANT EVALUATION:

BLOOD TESTS: Blood tests will be done to determine your blood type (A, B, AB, or O), immunization status, test for viruses like Hepatitis B and C, HIV, and CMV, and to screen for antibodies.



TISSUE TYPING: Your blood is tested to identify small proteins on your cells called antigens. Potential organ donors undergo the same blood test. This helps the transplant team to identify how closely any kidney matches you. However, we often perform a kidney or kidney/pancreas transplant with few or no antigen matches as long as the blood types are compatible. Advances in immunosuppression have made “matching” less important in achieving a successful outcome with a transplant.

Because antigens are inherited from parents, people who are related are often good “matches”. For example, a biological mother or father automatically will share one half of their antigens with their children. A brother or sister may have half, all, or none of the same antigens as his or her siblings. In fact, people who are not blood related but who are “emotionally related” such as a spouse or a friend, can be donors even if not well matched. The results following unrelated living donors are similar to transplants in which the donor is a parent, child, or sibling.

CHEST X-RAY: A chest x-ray will be taken to see if your lungs are healthy.

ELECTROCARDIOGRAM (EKG or ECG) HEART STRESS TEST: EKG/ECG and a heart stress test monitor the functioning of your heart and look for evidence of coronary artery disease.

MAMMOGRAM and /or PAP SMEAR: Mammogram and/or pap smear are part of the basic work-up for all women.

TESTS THAT MAY BE REQUIRED:

- People who are over age 50 will also need a *colonoscopy*, which is a screening tool for colon cancer. Men over 50 will also need a prostate-specific antigen (*PSA*) blood test to screen for prostate cancer.
- *Heart catheterization* if coronary artery disease is suspected based on your medical history or stress test results.
- *Vascular studies* such as Doppler study or angiogram to assess blood flow to your legs or head and neck.
- *Pulmonary Function Test (PFT)* to assess your breathing/lung function.
- *Voiding cystourethrogram (VCUG):* VCUG is used to assess how well your bladder empties.

After all testing is completed and the results are studied, the Transplant Selection Committee will analyze the information. Once a patient has completed their test evaluation and is approved by the committee, she/he will be placed on the list for receiving a transplant or their transplant will be scheduled. Circumstances may require that a patient be re-considered by the Transplant Selection Committee at a later date.

PREPARING FOR TRANSPLANT

Waiting for transplantation can be both an exciting and stressful time. Many details must be arranged prior to being listed to ensure the smoothest possible outcome for you and your family. It is essential to be prepared for transplant from the moment you are listed. The following will guide you in your preparation.

Identify your emotional and physical support. Managing your emotional and physical health during this stressful time is very important. Everyone's experience with transplantation is different, yet most identify the support of friends and family as a key component to a successful outcome. It is essential to communicate openly with the important people in your life about your feelings and your needs. If you feel you do not have emotional or physical supports in your life, speak with your social worker about different resources in the community.

Confirm your insurance coverage. You will need insurance coverage for both your transplant and the medications after transplant. Please let your social worker know if there are any changes in your insurance coverage while you are waiting. *It is important that you maintain your health insurance coverage.*

Arrange reliable communication (i.e. phone, beeper, etc) The transplant team must be able to contact you 24 hours/day/7 days a week. It is ideal to carry a beeper or cell phone. If this causes an economic hardship

speaking with your social worker. It is also important to inform the transplant team of any travel plans so we will know where to contact you at all times.

Arrange transportation to Fletcher Allen Health Care (FAHC). It is essential for you to arrange transportation to FAHC that will be accessible 24 hours/day/7 days a week and will get you to the hospital by the time prescribed by your team. If transportation is a concern, speak to your social worker about different possibilities.

Make sure your affairs are in order. It is important to plan for a sudden disruption in your life and to consider who will be taking care of your needs and those dependent on you. For example, who will look after your children, pets, or your home? Have legal issues been settled? Have you identified who will make your medical decisions should you become unable? Have you filled out paperwork regarding your wishes? Your social worker will review these issues with you and assist you in planning appropriately.



Every person who is considering transplant has a varied set of needs. Do not be afraid or embarrassed to discuss any topic with your social worker, transplant coordinator, or your health care provider.

SOURCES OF HEALTHY KIDNEYS

Kidneys can come from three sources:

- **a relative (called a living related donor)**
- **a spouse or friend (called a living unrelated donor)**
- **a person who has died whose family agrees to donate his/her organs for transplantation (called a cadaveric, cadaver donor, or deceased donor)**

LIVING DONORS:

Living related or unrelated donors are the best possible source of a kidney. Statistics show that 90-95% of kidneys received from living donors are still functioning one-year after transplant and are expected to continue working for many years. Also, it is a planned surgery, so you can know the exact date of the transplant, and both the donor and recipient can be in optimal health for the operation.

Any person who wishes to be a potential donor must undergo blood testing for compatibility. If the donor is found to be compatible, then additional testing is completed to ensure that donating a kidney will not jeopardize his or her health. This includes a thorough medical evaluation, cardiac testing, chest X-ray, analysis of urine and a

procedure to visualize the kidneys (MRI or CT scan). Each donor will meet with the transplant social worker to review the pros and cons of donation. In addition every donor will meet pre and post donation with a Living Donor Advocate to ensure the donor is well informed and his/her needs are being met. In certain cases donors may require further evaluation from the hospital psychiatrist or psychologist. After the surgery, donors can anticipate being in the hospital for three to five days, and most return to work in four to six weeks.

DECEASED DONOR:

Many people do not have living donors. In these cases, recipients go through the same testing as those with a living donor. When the testing is complete, their names are placed on a waitlist with the United Network for Organ Sharing (UNOS) so that a kidney will be found through this national organization.

Some donor organs have a higher risk of poor function. Because there is a serious shortage of deceased donor kidneys and the number of people waiting for a kidney increases every year, an organ from an “expanded criteria” donor may be offered to you. “Expanded criteria” donors are donors who are older or who have specific health problems, that might affect how well or how long their kidneys will work after they are transplanted. Kidneys from donors who meet the following criteria are considered “expanded criteria: organs:

- The donor is 50-59 years of age or older OR 2-3 of the of the following:
- The donor had a medical history of hypertension (high blood pressure)
- And/or the donor's most recent creatinine was 1.5 mg/dL or higher.
- The donor's cause of death was a stroke.

Many of these “expanded criteria” kidneys will work very well; some will not. A study done by the national kidney program showed that patients receiving these kidneys add about 5 extra years to their life compared to patients who do not receive a transplant and remain on dialysis.

Based on your age and/or overall health, you may be offered the option of an expanded criteria kidney. Agreeing to accept an “expanded criteria” kidney if one becomes available does not affect your status on the regular waiting list. You may accept or refuse the offer of an “expanded criteria” kidney at any time while you are waiting for an organ to become available.

THE WAITING LIST:

Waiting time begins from the day you are listed for transplant. This time continues to accrue without interruption even if you are listed as “temporarily unavailable” due to an acute illness or if you are away from the transplant area because of vacation or for other personal reasons.

You may choose to be listed at another transplant center as well as at FAHC. Please speak with a member of the transplant team and we will assist you in any we can. If you choose to have your name removed from the list at FAHC your accrued waiting time may be transferred to another program. It is the responsibility of the new transplant program to assist you with the request to transfer your waiting time.

While you are on the waiting list an annual visit will be scheduled with the Nurse Practitioner and Transplant Social Worker to ensure that you continue to be in good health and that all pre-transplant testing is up to date.

The length of time that someone is on the waitlist is unpredictable and is dependent on many factors. Monthly blood samples are required for cross match determination. The samples can be drawn at FAHC or your local blood lab and are sent to the lab in Albany, N.Y. They are stored in Albany and when a donor becomes available your blood samples are tested to determine their compatibility with the donor. This process usually happens prior to the recipient being called, but occasionally, due to time restrictions it will be done as the recipient is in route to the hospital or after they have arrived.

Patients who are listed must be able to be reached 24 hrs/day/7days a week. They must be prepared to come to the hospital day or night when they receive the phone call. When a kidney becomes available,

the transplant coordinator contacts the potential recipient. After being admitted you will be given a hospital gown and a name band. A physical exam, temperature, weight, pulse, and blood pressure will be done. Other testing such as EKG, chest X-ray and blood tests are done. If you are dialyzing and are due for a treatment, this may occur before the operation. An IV will be placed in your arm as well as in your neck. Some medications will be started prior to your leaving for the operating room.

THE TRANSPLANT OPERATION

All the preparation and testing have led you to the moment where you and an available organ are brought together. Once in the operating room, you will first be given anesthesia, which will make you comfortable and bring on sleep. A tube (foley catheter) will be inserted into your bladder allowing us to measure your urine output during and after surgery. The catheter will be removed 4-5 days after surgery. A small tube (nasogastric or N.G. tube) may be put through your nose into your stomach to help prevent nausea and vomiting after surgery and is usually removed before you wake up.

The surgery takes 3-6 hours. The new kidney will not be placed where your own kidney lies. It will be placed on the right or left lower part of the abdomen just above the groin area. The blood vessels of the donor kidney are attached to your own blood supply and the ureter is joined to your bladder. A stent is placed in

the ureter between the kidney and the bladder to ensure the ureter does not narrow or close while healing. The stent will be removed in the Urology clinic 4-6 weeks after the operation.

The muscle and skin incision will be closed using staples or sutures that will be removed during a follow-up clinic visit.

AFTER SURGERY

After the operation, you will be cared for in the Surgical Intensive Care Unit (SICU) located on McClure 3 for 24-48 hours. You will be transferred to Baird 6 for the remainder of your hospital stay (average total hospital stay is 3-5 days for a kidney and 7-10 days for a kidney/pancreas or pancreas alone). In the SICU, you will be monitored carefully and your vital signs will be taken frequently (blood pressure, pulse, breathing, and temperature). Your urine output will be measured hourly. Your blood work will be checked several times a day. You will receive intravenous (IV) fluids.

Due to the effects of the anesthesia and the manipulation of your intestines during surgery, the normal action of your intestines slows. You will be encouraged to walk as early as possible after surgery to help bowel function return to normal. Bowel sounds will return and you will begin to pass gas. When bowel function returns, you can begin to advance your diet slowly. You will receive IV fluids until you can eat and drink. The IV will be removed before you are discharged.

Patients are asked to turn in bed, cough, and deep breathe at least every 1-2 hours while awake.

You will be given an spirometer, a breathing device, to help gauge your progress. Walking, coughing, and deep breathing are crucial parts of your post-op care. You will be less likely to develop complications such as pneumonia, constipation, or blood clots in your legs. You will feel better sooner if you cough, deep breathe, and walk.

At first, you will have a pump that delivers medicine into your IV whenever you need it. This is called a PCA (patient-controlled analgesia). After 24 to 48 hours, you will switch to pain pills. It is important to use your pain medicine so that you can cough, deep breathe and walk. You will go home with a prescription for pain medicine.

The surgical incision will be covered with a dressing initially and you will be taught how to care for and clean your incision. It is essential that you be involved in your care so that you are aware of any changes that could indicate infection, rejection, or other problems.

The transplanted kidney usually begins working immediately although it is not unusual for kidney function to be delayed for days or even weeks. When that happens, some individuals resume dialysis treatments until their new kidney “wakes up” and is functioning at an adequate level. A small number of kidneys (less than 1%) may never work.

It will be your responsibility to learn how to take care of yourself and your new kidney. This means learning how to monitor your own blood pressure, temperature and daily weights. It will also be important for you to learn the signs and symptoms of kidney rejection and, most importantly, your medication routine. This includes being aware of the name of the medications, the strength of each pill, the doses, and the side effects of each medication.

NORMAL LAB VALUES

Laboratory tests are initially performed daily in the hospital. Once you are discharged, labs are done 3 times/week at first, and eventually they are done 1/month.

The following lab values are approximate numbers. Values vary from person to person and from one laboratory to another.

- Creatinine (measures kidney function) 0.5- 1.5
- BUN (measures kidney function) 10- 20**
- Potassium (important for heart function) 3.5- 5.5
- Hemoglobin (amount of red blood cells in the blood) 11.6-15.2
- White Blood Count (WBC fight infection) 5,000- 10,000
- Therapeutic immunosuppressive levels 4-12

****Foods high in protein may increase the BUN reading**

IMMUNOSUPPRESSIVE MEDICATION



Immunosuppressive medications are drugs that reduce the risk of your body rejecting the new organ after transplant. These medications work to either prevent the production of white blood cells (WBC's) associated with rejection or inactivate the WBC's after they have been produced. Immunosuppressive regimens will be tailored for each patient.

All transplant patients will take some combination of anti-rejection medications for the rest of their lives or the life of the transplanted organ. If you stop taking your medication, your body is likely to reject the organ and you may have to resume dialysis treatments and/or insulin therapy.

A successful transplant depends on you:

- Knowing what, why and how much medication to take.
- Taking your medications on time each day.
- Knowing the side effects of your medications. If you experience any side effects from the medications, please report them to your transplant coordinator,

your physician, or nurse practitioner.

- Taking only the medications prescribed by your doctor.

It is essential that you know what type of medication you are on, and why you are taking them. In addition to anti-rejection medications, other drugs will be prescribed. While you are in the hospital, you will be given a supply of your medications and the regimen will be reviewed with you. Taking your medication as prescribed is essential for a successful transplant, and it is your responsibility to accurately follow the prescribed regimen.

Sometimes these medications can cause unwanted side effects. Your medication dosage will be monitored at every clinic visit. Doses of many medications may be changed or lowered throughout treatment. As dosage is decreased, the side effects usually decrease and may even be eliminated. The side effects are listed so you can be aware that they can occur, but that does not mean that you will experience these effects.

COMMONLY USED POST-TRANSPLANT MEDICATIONS:

FK-506 (Prograf, tacrolimus) or Sirolimus (Rapamune)

These are powerful anti-rejection medications that have significantly improved the success of transplants. We can measure the levels of the drug in your blood to determine if the dose is therapeutic.

Purpose: Prevents rejection

Side effects:

- ***Tacrolimus or Prograf:*** headaches, tremors, skin rash, nausea/diarrhea, changes in mood, increased blood sugars, increased blood pressure, thinning of hair, and difficulty sleeping.
- ***Sirolimus or Rapamune:*** increase in cholesterol and/or triglycerides, headaches, decrease in platelet and white blood counts.

Cellcept or Myfortic (mycophenolate)

When you receive a transplant your body sees the new organ as a foreign object and your white blood cells respond by increasing in number. Cellcept helps in decreasing the white blood count so cells won't attack the transplanted organ.

Purpose: Prevents rejection

Side effects:

- increased chance of infection, GI distress (diarrhea and/or constipation), rash, yellowing of skin/eyes (jaundice), fever, headache, decreased white blood cell count

Prednisone

Prednisone is a steroid and an anti-inflammatory drug used to reduce swelling in your transplanted kidney and helps to prevent rejection. Not all patients will leave the hospital on Prednisone.

Purpose: Prevents rejection

Side effects:

- rounding of the cheeks, weight gain, acne-like rash, steroid induced diabetes/increased blood sugar, increased appetite, gastrointestinal distress, changes in mood, increased chance of infection, increased chance of high cholesterol, cataracts, night sweats, thinning of hair, easy bruising, increased blood pressure, joint problems, increased sun sensitivity

OTHER MEDICATIONS

These medications are important to aid the other body systems that may be effected by the immunosuppressant drugs and /or the transplant surgery.



Antacids (Prilosec, Pepcid, Protonix)

These help prevent stomach ulcers associated with steroids. They are taken frequently in the early weeks after surgery and will then be reduced in the later weeks. Possible side effects of antacids include constipation and diarrhea.

Antibiotics, antivirals and antifungals

A transplant recipient is at high risk for infection because of the anti-rejection drugs that suppress the immune system. Antibiotics help to prevent infections. Side effects of antibiotics include gastrointestinal distress and super-infection.

- ***Bactrim*** is an antibiotic used to prevent a special type of pneumonia called Pneumocystis.
- ***Fluconazole*** is used to prevent fungal or yeast infection.
- ***Nystatin*** is used to prevent a fungal infection in your mouth (oral thrush). The immunosuppressant medications can cause fungus to grow rapidly.
- ***Valgancyclovir*** is used to prevent viruses in the herpes family. You will take this medication if you or the donor has had Cytomegalovirus (CMV) which is indicated by blood tests. CMV is a common virus that can make individuals taking immunosuppressant medications very ill.



After Your Hospital Discharge

After discharge from the hospital each patient will be required to return to Fletcher Allen Health Care for clinic 1-3 mornings a week. You will have your blood drawn at 8:00a.m and then you will need to wait to see the nurse practitioner, nephrologist, and/or surgeon. Keep in mind that the actual visit with the team will be brief, and may require a long waiting time as the team works to assist each newly transplanted patient. We recommend that you plan for a visit to last from 45 minutes to several hours. We may need to wait for the results of your blood tests before we send you home, or we may need to schedule other tests. There may be many patients to be seen. This is a good time to speak with your social worker as needs arise or simply to check in with her.

The type and frequency of your care will vary as you become well or if you have a rejection episode. Typically, individuals will be seen at Fletcher Allen 1-2 mornings/week for the first several weeks, then 1/ 2 weeks and, finally, at the UHC Campus (1 South Prospect St., Burlington, VT 05401) once each month. Eventually, you may be seen every few months, but blood work is usually done more often.

The transplant coordinators and nurse practitioner are in constant contact with your surgeon and nephrologist and will be handling much of your care after the transplant. Remember that any questions or concerns you have continue to be important. You should feel free to contact any member of the team listed on the first page of this booklet.

Medical follow up will be needed for the rest of your life or the life of the transplanted organ.

RENAL AND PANCREAS TRANSPLANT DISCHARGE INSTRUCTIONS

The following are the discharge instructions that will be reviewed with you prior to leaving the hospital.

1. Take **ONLY** the medications listed on your Medications List. You may take Tylenol (acetaminophen) for discomfort or headache. Take **NO** other medications, herbal supplements, or herbal teas for symptom management without calling the transplant team.
2. If you forget to take your medicine, **DO NOT** double the next dose. **CALL US** if you forget more than one dose of medicine.
3. Check your temperature twice each day, morning and evening. **CALL US** if your temperature is higher than 100.5F or 38C.
4. You will be coming to see us at the hospital clinic in the Ambulatory Care Center (ACC) on the 5th floor East Pavilion. Come to the outpatient lab on the first floor where you will register. You should be there by 8 a.m. Have your labs drawn when you arrive. We will call you to see the doctor after that. *The visit with the doctor will be brief and may require a long waiting period before being called.*

If you have questions or concerns, the nurse coordinator is available to speak with you before/after the physician visit.

The social worker is often at clinic and is also available to speak with you. At first, you will come to clinic 1-2 times a week. Clinic is held on Mondays, Fridays, and occasionally on Wednesday. Over time, you will be able to come less often. In clinic, we check your weight, blood pressure and temperature. If you have been keeping track of your blood pressure or blood sugars, bring those records with you to your visit.

5. If you are taking Prograf/FK or Sirolimus/Rapamune **DO NOT** take them your on clinic days until your blood has been drawn. You may eat breakfast unless we tell you not to. Bring your medication with you to all clinic visits.

Levels are drawn in the morning. Prograf levels are reported that afternoon and Sirolimus levels are available in 48 hours. If we need to make changes in your dose, we will call you at home.

6. Call the transplant team for any pain over the transplanted organ, significant decrease in urine output, dark urine, nausea with vomiting, or any questions or concerns.

WEEKDAYS: call the transplant office at 847-4774 and our secretary will direct your call to the appropriate person.

EVENINGS, NIGHTS, AND WEEKENDS: call the Transplant Coordinator (802-847-0000). There is always a Transplant Coordinator on call who can deal with your concerns or direct them to the appropriate physician.

7. You should not continue to take Nephrovite. If you wish, you may switch to any over-the-counter multivitamin.
8. Good oral hygiene is important while you are on immunosuppressive medications. Regular brushing and flossing, including brushing your tongue, help prevent infections. See your dentist regularly. When you go for cleaning or other dental procedures, you will need to take antibiotics to prevent bacteria from entering your blood and causing infection. If you have been on dialysis, you are familiar with this protocol (subacute bacterial prophylaxis). You can get a prescription for these antibiotics from us or from your primary physician. The usual prescription is taken 1 hour before each dental visit.

9. Anti-rejection medicine can cause cataracts in the eyes. You will need eye exams every 6 months to check your eye health.

10. If your home has well water that water should be tested on a regular basis for Giardia and cryptosporidium.

11. Prednisone may cause increased appetite. It is important that you maintain a stable weight. Unless we prescribe a special diet at discharge, you have few dietary restrictions.

12. Stay away from people who have an infection such as colds or "flu." Also, try to stay away from large groups of people in the first weeks after transplant (malls, for example). **HANDWASHING** is the best way to prevent infections.

13. You may feel like resting more after surgery. Slowly start to do more each day. Rest when you feel it is needed. Talk to us before you start vigorous exercising. Walking is the best form of exercise. During the first 3 months after surgery, do not bend a lot, lift heavy objects or play contact sports like football.

14. **DO** use a seatbelt. If necessary place a folded towel or small pillow over your surgery area for comfort before closing the seatbelt.

15. Avoid working in the soil for 3 months after transplant. After that, wear gloves.

16. Avoid handling animal waste. **DO NOT** clean birdcages, fish, or turtle tanks. A cat litter box should be covered and taken outside the patient's home before it is changed.
17. You will not be able to get immunizations, including a flu shot, in the first 3 months after your transplant. In general, you and your household contacts should receive inactivated influenza vaccine. **CALL US** if you or any household member intends to receive any vaccinations. You should not be exposed to vaccines that consist of live viruses (oral polio, measles, mumps, German measles, chickenpox, yellow fever or smallpox).
18. For parents of children who have had transplants. Ask the school nurse to notify you immediately of any communicable diseases that may be circulating in your school (for example, measles, chicken pox).

DIET & EXERCISE

A balanced diet and regular exercise are important factors in



living a healthy lifestyle. After transplant you will be able to enjoy a wide variety of foods with very little restrictions.

It is important to remember, however, that some transplant medications have side effects that will impact

choices you will need to make to ensure optimal health. For instance, some of the immunosuppressive medications help your body retain sodium (salt). As with any healthy diet it will be important to avoid foods with high sodium content. These medications can also make your body more sensitive to sugar. Desserts, candies, and regular sodas should be limited.

It is very common for transplant patients to experience increased appetites. To avoid weight gain, eat three well-balanced meals and limit snacks between meals. If you do snack, choose low fat foods like unbuttered popcorn, unsalted pretzels, low-salt crackers, fresh fruit, or yogurt. Use unsaturated fats when cooking. The best types are olive, peanut, or canola oils. Limit your intake of chocolate, cheeses, and egg yolks to help keep your cholesterol level in a healthy range.

Exercising on a regular basis after your surgery is also important to maintaining your health. After your operation, you will need to take things slowly. Pace yourself and rest when you are tired. You should not lift anything more than 10-15 pounds for the first three months. As soon as the doctor allows, start with low impact exercise such as walking or biking short distances each day. Gradually build up the time you spend being active to keep your weight down and your bones and muscles strong. As you recuperate fully, you should plan to exercise 3-4 times/week for 30-40 minutes of moderate intensity (fairly light to somewhat hard exercise).

SEXUAL RELATIONS AND INTIMACY

Many transplant patients achieve fulfilling relationships with their sexuality remaining an important aspect of their lives. You may begin to have sexual relations when you feel up to it. Avoid any position that causes you pain or puts strain on your incision.



If you are female and of childbearing age it will be important to use reliable contraception. Most patients wait at least a year before considering pregnancy. You must be completely well after your transplant before having children. Pregnancy puts strain on your health as a transplant patient and the fetus will be exposed to transplant drugs. Not all transplant medications are safe for pregnant women.

Preparing for and having a transplant has undoubtedly brought changes into your life. Medication, diet, stress and sleep all have significant effects on our sexuality and how we feel about our bodies and ourselves. It can be reassuring to remember that intimacy need not only be equated with sexual performance. Many have found there are countless ways to show and experience intimacy other than performing sexually. Open communication, patience and willingness to compromise between you and your partner is essential. Be sure to speak with your transplant doctor, nurse, or social worker if you have questions or concerns about intimacy.

A helpful booklet on this subject is:

- **Speaking Frankly: A Guide to Sexual Issues and Transplantation**, Roche Laboratories, Inc., 340 Kingsland Street, Nutley, New Jersey 07110-1199.

ORGAN REJECTION

Rejection is a normal response by the body to fight off the transplanted kidney because the recipient's body sees it as a foreign object. Medications are taken after transplant to avoid rejection. Even with these precautions, however, a rejection episode is possible.

A rejection is possible at any time after transplant but is most likely three to six months after surgery. Most people experience at least one episode of rejection. Rejection can be reversed (greater than 95%) with the proper treatment. Loss of the transplanted kidney can usually be avoided if rejection is recognized and treated quickly.

Possible signs of rejection:

- Increase in temperature
- Decreased urine output
- Blood in urine
- Sudden increase in weight
- Ankle swelling
- Pain, swelling, or pus near the kidney site/incision
- Aching all over
- Increase in creatinine

If you recognize any of these signs, call the transplant coordinator immediately.

Often a person will not recognize when a rejection episode is occurring but the transplant team will be able to confirm this through blood work (i.e. increasing creatinine). This is why it is very important to keep all regularly scheduled clinic appointments.

TYPES OF REJECTION

Acute Rejection

Acute rejection means the body's immune system is attacking the transplanted kidney. This type of rejection episode, if detected, is most often treatable. It may occur within the first few days of a new transplant

However, it appears most commonly from 2 - 12 weeks post-transplant.

You may have none of the symptoms when starting a rejection episode. For this reason, you must have your blood tests done regularly and keep your clinic appointments.

Acute rejection will be diagnosed on the basis of your lab work and symptoms. Other tests may include an ultrasound or renal scan. A biopsy of the kidney may be performed. The biopsy procedure involves inserting a needle into the kidney and taking a very small piece of tissue to examine under a microscope. Patients receive a local anesthetic in the skin to prevent pain. Biopsies may be done on an outpatient basis.

There are different treatments for acute rejection, depending upon how severe it is. In general, you would be given more anti-rejection (immunosuppressive) medication. Sometimes, this requires admission to the hospital. Early detection of rejection is the key to successful treatment.

Chronic Rejection

Chronic rejection occurs gradually over a period of time. This type of rejection is characterized by a gradual loss of organ function.

If you experience a rejection episode, or if you need other treatment related to your kidney transplant, our team requests that you return to Fletcher Allen Health Care for treatment. You are free to see the doctor of your choice for care of common ailments such as the cold or flu. However, it is important that you contact your transplant coordinator about these visits, especially when any medication is prescribed. Certain medications can interfere with your immunosuppressive regimen, and they can adversely affect your transplant.

Rejection can occur any time if you stop taking your anti-rejection medications as prescribed.

RESOURCES

There are many local and national organizations dedicated to providing accurate information on finances, support, and education for transplant recipients. An immense amount of information is available on the Web and we offer the following websites to help guide your search. We encourage you to get as much information as you can in preparation for transplant.

The United Network of Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a concern you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is 1-888-894-6361.

Organization	Contact Information	Website
National Kidney Foundation	1-800-622-9010	www.kidney.org
American Kidney Fund	1-800-638-8299	www.akfinc.org
Transplant Patient Partnering Program	Transplant information and materials	www.tppp.net
American Association of Kidney Patients (AAKP)	1-800-749-2257	www.aakp.org
Polycystic Kidney Research Foundation	1-800-753-2873	www.pkdcare.org
Network of New England ESRD	1-203-387-9332	www.networkofnewengland.org
Transplant Recipients International Organization, Inc.	1-800-TRIO-386	www.trioweb.org
UNOS (United Network for Organ Sharing)	Patient Services 1-888-894-6361 Cadaver organ information kit 1-888-894-6361	www.unos.org
DiabetesPortal.com	1-314-991-8004	www.insulinfree.org

