Emory Transplant Center
Making a difference in the lives of our patients and our community

Your Kidney and/or Pancreas Transplant
At Emory University Hospital
A Journey for Life
The most important information you may ever read

Now that you are considering a kidney transplant, you must understand what to expect before, during, and after your transplant. The purpose of this book is to provide you and your family with that information. Please read each section carefully. Feel free to jot down notes in the margins and ask questions about anything you don't understand or concerns you may have.

At Emory University Hospital we consider kidney transplantation an excellent treatment for many patients with chronic renal failure. It can offer many people the chance to return to a more normal and productive lifestyle.

Transplantation, however, is not a cure for kidney disease but another treatment option that requires close follow-up and patient commitment. That is why the Emory transplant team seeks to educate every candidate about transplantation. Post-transplant management can be difficult and demanding. You and your family must completely understand the risks, limitations, and benefits of transplantation before you can make an informed decision.

The Emory kidney transplant team is committed to helping you if you are committed to the demands and requirements of transplantation. Your attitude about surgery and recovery and your participation in your care will play a vital role in the ultimate success of your kidney transplant.
Why you may need a kidney transplant

THE HEALTHY KIDNEY
The kidneys perform several critical functions including:
• Filtering the blood to remove waste products such as nitrogen and creatinine that can become toxic if left to accumulate.
• Removing excess fluid that can accumulate around the heart and lungs.
• Returning nutrients to the blood stream.
• Producing a substance that helps regulate blood pressure.
• Producing a substance that is necessary for red blood cell production, thus preventing anemia.

The kidneys are two bean-shaped organs, weighing about four to six ounces each in adults and located on either side of the spine behind the upper abdominal organs. About one-fourth of the blood volume pumped during each heartbeat goes to the kidneys. This adds up to about 160 quarts of blood every 24 hours. From this, about 1½ quarts of urine are eliminated through the bladder. The kidneys filter the blood using tiny components called nephrons and glomeruli.

THE FAILING KIDNEY
Some of the most common causes of kidney failure include:
• hypertension (high blood pressure)
• diabetes mellitus
• kidney stones
• inherited kidney disease
• inflammatory disease of the nephrons and glomeruli
• side effects of drug therapy for other diseases

When your kidneys fail to remove waste products from the blood, a condition known as uremia develops. Since you normally have more kidney functioning ability than you need, most people do not develop symptoms of kidney failure until 90% of kidney function is lost. Once this occurs, the work of your kidneys must be done by dialysis (an artificial means of filtering the blood) or function must be replaced by transplantation. One main advantage of transplantation over dialysis is quality of life. Many people prefer transplantation because they are able to return to a more normal lifestyle.
HISTORY OF KIDNEY TRANSPLANTATION
The first human-to-human kidney transplants were performed in 1933. These early transplants were unsuccessful because the body's immune system recognized the kidney as foreign and destroyed it. This immune process is known as rejection. At that time, there was little understanding of the immune system and its role in transplantation.

By the 1950s, physicians were gaining a knowledge of the immune system but still had no way of preventing rejection. Breakthroughs came when several successful living donor transplants occurred between identical twins. Because identical twins share the same biological make-up, their immune systems did not recognize the transplanted kidneys as foreign.

Rapid medical and surgical advances followed. Now transplant doctors have a much greater chance of controlling rejection with the use of immunosuppressive or anti-rejection medicines, allowing for an excellent success rate in organ transplantation. The good news for the transplant recipient is that survival results continue to improve with the development of better medicines to prevent and treat rejection.

TYPES OF KIDNEY TRANSPLANTS
Kidneys for transplantation come from two sources:
• *Living donors* - family members, spouses, or friends, who are at least 18 years of age.
• *Deceased donors* - people who have died and donated their organs for transplant.

Living Donors
The Emory Transplant Team encourages living donor transplants for the following reasons:
• One of your blood relatives may provide a closer genetic match. The long-term success rate of living donor kidney transplants is excellent.
• A living donor’s kidney will be removed in a scheduled surgery, thus eliminating the wait for a deceased donor.
• The likelihood of immediate functioning of your kidney after a living donor transplant is greater because of the short length of time the donor kidney is without blood supply.

You may feel uncomfortable asking family members or friends to donate a kidney. But while the subject may be difficult to talk about, you may find that your family and friends are indeed interested in being evaluated as living donors. Remember, the Emory transplant team will evaluate your donor very carefully and only
accept him or her as a donor if he or she is healthy and able to
donate. You will receive more detailed information about living
donors during your evaluation. If you have any questions, please
feel free to call your transplant coordinator.

Deceased Donors
If you have been approved for transplant and do not have any
living donors or if you are unsure about living donors, then you
will be placed on the deceased donor waiting list. Once you are
accepted for transplant, your name is placed on the national
waiting list which is maintained by the United Network of Organ
Sharing (UNOS).
• The United Network of Organ Sharing (UNOS) is the national
agency that regulates organ-sharing. Whenever a kidney
becomes available in Georgia, LifeLink of Georgia reports it to
UNOS so their computer can search the entire country for the
best genetic match for that kidney. If a kidney from another
state matches perfectly with you as an Emory patient, that kid-
ney will be offered to Emory for you. This policy is called
“mandatory sharing” and was instituted because of the
improved success rate of perfectly matched kidneys. If no per-
fecely matched candidate to a Georgia donor can be found any-
where in the United States, then the donor kidney is offered to
the person on the Georgia list who is the most appropriate
recipient for the donated kidney.
• LifeLink of Georgia is the non-profit agency that evaluates and
manages all potential deceased donors in Georgia, following strict
guidelines and testing procedures to maximize the safety and
success rate of kidney transplantation. LifeLink coordinates the
recovery and placement of deceased donor organs within the
state or region.

SURVIVAL STATISTICS
Many factors may affect the estimated length of time a kidney
transplant will function, including:
• first transplant versus retransplant.
• donor age.
• cause of the recipient’s end-stage renal disease.
• recipient’s compliance with medications and health care follow-up.
• PRA level of the recipient – the level of circulating panel reac-
tive antibodies, or preexisting antibodies, that a patient has
developed from previous exposure to foreign tissue, such as
blood transfusions, previous transplants, or pregnancies.
• HLA (human lymphocytic antigen) match – the degree of anti-
gen match, often referred to as “tissue-matching.”
• **Cold ischemic time** of the kidney - the time the donated organ is in iced storage between the donor and recipient (usually minutes for a living donor, hours for a deceased donor transplant).

Overall, the national one-year patient survival rate after deceased donor kidney transplantation is 94.2%, while the national one-year kidney survival rate is 88.4%. At Emory University Hospital, one-year patient survival rate after deceased donor kidney transplantation is 95.1%, and one-year kidney survival rate is 92.53%. The one-year pancreas survival rate at Emory is 83.33%. New immunosuppressant medications may further improve kidney and pancreas survival statistics.

The following table compares the estimated length of time a deceased donor kidney will survive compared to a living donor kidney, as measured in half-life. Half-life means that half of the kidneys within the particular category will function fewer than the stated years and half will survive longer. For example, with HLA-identical living-donor kidneys, half of the transplanted kidneys will function fewer than 26.5 years and half will function more than 26.5 years.

This data comes from the United Network of Organ Sharing (UNOS) Scientific Renal Transplant Registry as published in *Clinical Transplants* 2002 and is based on data from 1998-2001:

<table>
<thead>
<tr>
<th>Type of kidney transplant</th>
<th>Kidney graft half-life in years</th>
</tr>
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<tbody>
<tr>
<td>Living Donor</td>
<td></td>
</tr>
<tr>
<td><em>HLA identical</em></td>
<td>26.5 years</td>
</tr>
<tr>
<td><em>Offspring</em></td>
<td>18.7 years</td>
</tr>
<tr>
<td><em>Spouse Unrelated</em></td>
<td>15.8 years</td>
</tr>
<tr>
<td><em>Distant Relative</em></td>
<td>18.4 years</td>
</tr>
<tr>
<td>Deceased Donor</td>
<td></td>
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<tr>
<td><em>HLA identical</em></td>
<td>17.3 years</td>
</tr>
<tr>
<td><em>non-HLA identical</em></td>
<td>10.9 years</td>
</tr>
</tbody>
</table>
Your transplant evaluation

Patients considered for a kidney transplant may have kidney failure from a variety of causes. The most common causes are glomerulonephritis, diabetes, high blood pressure, and polycystic kidney disease. Some patients may be considered for a transplant prior to beginning dialysis. Medical condition and age are among the factors which determine if transplantation is the optimal therapy for a particular patient’s kidney disease. Some patients with severe medical problems such as cancer or active infections may be considered not to be best served by a transplant.

Your transplant evaluation serves two main purposes. First, it provides a chance for you and your family to learn as much as possible about transplantation in order to decide if you could benefit from a kidney transplant. Second, the evaluation offers an opportunity for the Emory transplant team to learn about your medical history and determine your suitability for a transplant. Your transplant evaluation serves the important function of helping both the team and you decide if transplantation is your best treatment option.

TESTS

Your evaluation will begin with several blood tests and a urine sample. We will also perform a chest X-ray and an EKG (heart tracing test). If you are over 45 years old, have diabetes, or have other risk factors for heart disease, a cardiologist (heart specialist) will perform a stress test on your heart.

Then, depending upon the cause of your kidney disease and your age, an ultrasound, CT scan, or MRI of your abdomen may also be performed. If you have diabetes, an ultrasound of the neck will be required, and possibly a blood pressure cuff test to measure blood flow to your legs. An eye examination may also be necessary.

Other tests may include studies of your bladder and lower urinary tract. Women over 35 years of age should have a mammogram, and all women will need a current gynecological examination and PAP smear to rule out infections or other problems. A current dental examination is also recommended for all patients, to make sure you are free from potential infection.

After the transplant evaluation, your tests and lab work will be reviewed by the transplant team. You and your primary nephrologist will be notified of our recommendation by telephone and a formal letter. If we determine that you could benefit from a kidney transplant, we encourage you to contact the Mentor Project to talk to other patients who have had transplants. They may be able to give you firsthand insights and help you make your own decision about this treatment option.
MEETING THE TEAM

During your evaluation you will meet the transplant team. Each team member brings special knowledge that will help you during all phases of the transplant process. You will be introduced to our kidney transplant surgeon and transplant nephrologist. You will also meet a physician assistant, social worker, transplant psychiatrist, transplant coordinators, dietitian, and other medical specialists as necessary.

Transplant Surgeon

The transplant surgeon will perform your kidney transplant surgery and supervise your care immediately following your surgery. The transplant surgeon will also follow your progress after you are discharged from the hospital.

Transplant Nephrologist

Transplant nephrologists will manage your medical care while you are in the hospital for your transplant. They will also provide follow-up care in the transplant clinic, adjusting your medications and monitoring your progress.

Physician Assistant

A physician assistant (PA) is a member of the transplant team who practices medicine under the supervision of a licensed physician. The physician assistant may obtain your medical history, perform your physical exam and supervise your transplant evaluation. He or she will educate you about transplantation as a treatment option for kidney disease. After transplant, the physician assistant continues to serve as an important member of the health care team. He or she will follow your progress in the hospital as well as in the transplant clinic.

Transplant Coordinator

A transplant coordinator is a registered nurse who is specially trained to care for patients before and after kidney transplantation and to provide support to you and your family. Transplant coordinators work in different stages of the transplant process. One coordinator will be responsible for obtaining the results of your evaluation. This coordinator will serve as your main contact for questions from the time of your evaluation until the time of your transplant. Additional coordinators will follow your progress in the hospital and provide follow-up care at each clinic visit after you are discharged.

My transplant surgeon is

My Transplant Nephrologist is

My Physician Assistant is

My transplant coordinators are
**Social Workers**
Social workers are available for evaluation and supportive counseling for you and your family throughout the phases of transplant. If you need information about local housing, fund-raising, and other transplant resources, the transplant social worker can assist you.

**Psychiatrist**
A psychiatrist will meet with you during the evaluation to obtain a general mental health history. He or she can identify personal or social situations that may affect the likelihood of a successful outcome after transplant. Psychiatric help is available for any developing needs or concerns.

**Clinical Nutritionist**
A clinical nutritionist will see you before and after your transplant to evaluate your diet and to help you maintain a healthy weight. The nutritionist will make recommendations regarding weight management and diet prior to transplantation. After your transplant you may have difficulty maintaining your weight and controlling your cholesterol and blood sugar levels. The nutritionist will be available to see you regularly after your transplant to discuss these issues.

**Pharmacist**
A pharmacist will begin working with you after your transplant. It is important for you to clearly understand your medications and how each affects your body. The transplant pharmacist, along with your transplant coordinator and nurses, will explain the actions, dosages and side effects of your medications. The pharmacist will be available to answer questions during your hospitalization and after transplant.

**Chaplain**
A chaplain is available to visit with you while you are at Emory University Hospital, remaining on call 24 hours a day. The chaplain can help you and your family deal with the emotional and spiritual issues that can be associated with transplantation.

**Staff Nurses**
Staff nurses are registered nurses responsible for monitoring your daily care in the hospital. They will teach you how to check your vital signs and identify any signs and symptoms of infection. They will help you learn how and when to take your new transplant
medications. Staff nurses play an important role in alerting the entire team to any potential problems you or your family may have.

**Transplant Financial Coordinator**

The transplant financial coordinator is available to help you understand the financial issues of your transplant. Should you wish, he or she can discuss your financial concerns during any stage of your treatment.

**FINANCIAL CONSIDERATIONS**

The following information regarding the costs of kidney transplantation will help you begin financial planning. First of all, you will need to know how much your insurance will pay for the kidney transplant and your immunosuppressant medications. Unfortunately, neither insurance nor Medicare will cover 100% of your costs. However, your transplant financial coordinator and social worker both will be happy to help you develop a financial plan using a variety of resources to facilitate the transplant.

**Before your evaluation**

When talking to your insurance company’s benefit representative about coverage for your transplantation services, always ask him or her to read directly from the policy booklet. We recommend that you request a copy of your health insurance policy and bring it with you at the time of your evaluation.

If you are covered by Medicare, refer to the current Medicare handbook for deductibles and copayment amounts. Most insurance companies require a review of your evaluation results to see if you meet their criteria to pay for a kidney transplant. This process is often called precertification or preauthorization. To fulfill these requirements, you will be asked to sign a consent form authorizing Emory to release the medical information from your evaluation to your insurance company.

Preauthorization by your insurance company for medical services provided by Emory does not guarantee full payment of all charges. You will be responsible for the following:

- All deductibles, copayments, and noncovered services as outlined in your health plan.
- Any balance between charges and what your insurance carrier pays as “usual and customary charges.” Ask your insurer for a copy of its usual and customary charges and an explanation of how it derives them.
If you are approved as a candidate for a kidney transplant, Emory’s kidney transplant program will work with you to obtain insurance approval from your insurance company. If your insurance carrier denies authorization of benefits, the kidney transplant program will be happy to write a formal appeal for you. However, please be advised that gaining insurance approval is ultimately your responsibility.

You will meet with the transplant social worker during your evaluation to discuss financial and social issues in detail. You may also request to meet with the transplant financial coordinator during your evaluation. Call 404-727-6973 or 404-727-8976 in advance to schedule an appointment with the financial coordinator.

Billing
At all stages of your transplant from evaluation through follow-up, Emory University Hospital and the Emory Clinic will send you separate billing statements with separate billing account numbers. Emory Hospital may also assign a different account number for each admission. As long as you still have any unpaid balance on any account, you will continue to receive statements.

Emory Hospital bills for inpatient and outpatient hospital services. The Emory Clinic bills for all outpatient and inpatient physician fees, as well as many tests that take place at the Clinic. You may also receive a separate bill from an outside lab for the analysis of your lab work.

When planning a budget for your care, you may also need to consider such incidental expenses as parking, transportation, and lodging.

Payment for your Evaluation
If your Medicare effective date is March 1, 1996 or after, Medicare pays secondary to any other commercial insurance plan for the first 30 months that you are eligible to receive Medicare because of permanent kidney disease.

The Medicare ESRD program will pay for a kidney evaluation. During the evaluation process, under Medicare guidelines, you will not be held responsible for any deductibles or copayments on charges billed for evaluation testing. However, any treatment, including dialysis, will be billed to your insurance company (commercial or Medicare), and any remaining balances, including deductibles and coinsurance, will be billed directly to you and will be your responsibility.

YOU WILL RECEIVE SEPARATE BILLS FROM:
- Emory Hospital for inpatient and outpatient hospital services
- Emory Clinic for inpatient and outpatient physician fees

PAYMENT ARRANGEMENTS
Emory University Hospital and The Emory Clinic provide services to you with the expectation that you will make the payment in full, not your insurer.

If you will not be able to pay the balance on your account in full, the hospital and clinic business offices will be happy to work with you to set up payment arrangements.

To arrange a payment plan, please call the financial coordinator at 404-727-6973 or 404-727-8976.
• If you have Commercial Primary:
On the day of your evaluation if your primary insurance is not Medicare, Emory will bill your insurance company. Once your insurance pays, the balance of your kidney evaluation testing will be billed to Medicare. Any treatment will be billed to your insurance company. Any remaining balances will be billed to you.

• If you have Medicare Primary:
On the day of your evaluation, if your primary insurance is Medicare, all hospital and physician charges relating to your kidney evaluation testing will be billed to Medicare. Treatment will also be billed to Medicare and to any other secondary insurance you may have. Any remaining balances will be billed to you.

Payment for your Kidney Transplant and Follow-Up Care
Although you may not owe money after your kidney evaluation, you will owe some money for your kidney transplant and transplant follow-up care. How much money you owe will depend on the type of insurance you have.
• Some examples of money you may owe include deductibles, coinsurance and noncovered items (such as personal items).
• You will also need to pay any differences between what Emory charges and what your insurance company pays as "usual and customary."

If you feel that you will not be able to pay remaining balances on your hospital or clinic bills, the transplant financial coordinator will be happy to work with you and the hospital or clinic business offices to establish a payment plan.

We will also work with you to develop a financial plan to cover your outpatient medications and transplant-related follow-up care. To make sure you understand and are able to cover these costs, the transplant team may ask you to provide your financial plan in writing.

In summary, the following are some charges you can expect:
• hospital charges relating to the kidney transplant admission.
• physician charges (surgeon, anesthesiologist, nephrologist and clinic charges) from the date of transplant, including 90 days of follow-up care.
• annual outpatient immunosuppressant medications.
• other medications (high blood pressure, cholesterol, insulin).
• follow-up clinic charges.
SAMPLE QUESTIONS TO ASK YOUR INSURANCE COMPANY:

1. Do I have benefits for kidney transplantation?

2. Am I in a preexisting period of coverage so that treatment for my condition is not covered? If yes, what conditions need to be met to pass the preexisting period?

3. What are my deductibles, coinsurance and out-of-pocket expenses? How much have I paid this year toward my deductible and out-of-pocket?

4. What is my lifetime maximum benefit? How much have I used toward that maximum?

5. Do I have a separate annual maximum benefit? How much have I used toward this maximum?

6. Do I have a separate transplant maximum benefit from the lifetime maximum benefit? (Insurance companies may “carve out” transplant benefits. For example, your lifetime maximum may be unlimited, however, you may only have a $500,000 lifetime transplant maximum.)

7. Is organ acquisition/procurement covered? If yes, is there any limitation on how much my insurance will pay?

8. Are donor services covered? If yes, is there any limitation on how much my insurance will pay?

9. Does my insurance plan have only certain transplant centers, sometimes called “Centers of Excellence,” where I must go to receive transplant services? If yes, is Emory University Hospital an approved transplant center?

10. Is there a specific nurse case manager who will coordinate my transplant care? If yes, what is his/her name and direct number?

11. Are outpatient prescription drugs covered? Specifically immunosuppressant (anti-rejection) medications such as Cellcept®, Neoral®, and Prograf®, or the antiviral, Cytovene®? How much of the cost for outpatient prescription drugs is my responsibility? Is there a preferred mail-order pharmacy which my insurance company recommends that I use to provide the least out-of-pocket costs?
12. What is considered reasonable and customary charges? How much am I likely to pay?

13. Do I need to obtain authorization/precertification for outpatient office visits and medical services?

14. Do I have any transportation or lodging benefits?

15. Are ambulance or air ambulance services covered at the time of transplant?

Please request a copy of your health insurance policy for your records.
Waiting for your transplant

THE DECEASED DONOR WAITING LIST
Due to the critical shortage of deceased donors, adults can wait on the UNOS list for more than two years before being transplanted. Your wait for a kidney may depend on the availability of organs, your blood type, your tissue type, and your level of preexisting anti-HLA antibodies.

Once you have been listed, your dialysis unit or doctor’s office will send a monthly blood sample to Emory. This sample is used to check your compatibility with any potential donor kidneys that become available. To remain eligible for a transplant, it is necessary to send in this blood sample every month.

Remember that a kidney can become available at any time and your transplant team must be able to get in touch with you. Your transplant coordinator can discuss obtaining a beeper. Since the donor kidney can only be preserved for a limited amount of time before transplantation, we must be able to contact you quickly so the kidney does not get too old and unsuitable for transplant. You must keep the transplant team updated with any changes in your phone numbers, address, health status, and how to contact you if you are out of town. If the transplant team cannot reach you in a timely manner when a kidney becomes available, the next suitable candidate on the list will be offered the kidney.

ANXIETY IS NORMAL
You may experience personal, physical, psychological, spiritual, and financial stresses during any phase of kidney transplantation. Helpful ways of coping with stress may include:

• Keeping up your normal daily routines as much as possible.
• Talking with someone on your team to help sort out your feelings. This could include your transplant coordinator, social worker, or physician. While waiting for a transplant, just "checking in" with your coordinator on a regular basis allows you to get questions answered and to talk about any anxiety you may be having.
• Contacting the Georgia Transplant Foundation’s Mentor Project. This program has been developed for both recipients and family members to provide one-on-one contact between people living with a transplant and people who are new to the world of transplantation. More information will be available on this program during your evaluation.

Remember: we are working as a team, so do not hesitate to call your coordinator at any time with any questions or difficulties.

It is recommended that you complete the Hepatitis B vaccine series of three injections prior to transplant and have a detectable response to vaccination.

SUPPORT GROUPS:
Going to the hospital

LIVING DONOR TRANSPLANT

Once you have been approved for a living donor transplant, a date will be scheduled for your surgery. Approximately a week before your transplant, you and your donor will have blood drawn for a final cross match test. This test makes sure you do not have any antibody sensitivities against your donor that could cause immediate rejection of the kidney.

Generally, you and your donor will be admitted to the hospital the day of the surgery. One week prior to surgery, you and your donor will come to the 6th floor A-wing preoperative clinic for a final medical examination. Preoperative testing will include a chest X-ray, EKG, blood work, and a health history and physical exam to make sure neither you nor your donor have developed any new medical problems.

DECEASED DONOR TRANSPLANT

The Phone Call

When a donor kidney becomes available, a transplant coordinator will telephone you at the numbers you have provided. If you receive a message from us, please call back immediately since we only have a limited amount of time to contact you before moving on to the next suitable candidate on the list.

The coordinator will let you know that a potential donor kidney is available, and then will do some basic health screening over the phone to make sure you are still able to be transplanted. If you have a fever, nausea, vomiting, recent heart problems or surgery, it may not be safe for you to be transplanted at that particular time.

Once you are instructed to come to the hospital, it will be important that you come here as soon as possible. Be sure to keep your directions to the hospital handy so that you will be prepared to find Emory whenever you receive the call.

The first call you get does not always mean the transplant will occur. The coordinator will explain to you that the surgeon must examine the organ before giving the final approval for your transplant. You will also have your blood tested against the donor to make sure you are not sensitized against this donor, a situation which would result in rejection of the kidney.

Arriving at the Hospital

Your coordinator will direct you as to the check-in location when you arrive at Emory. This time will be very hectic because the nurses and doctors will be preparing you for surgery. Some final
testing will be done to make sure you are healthy enough for surgery. These tests may include: chest X-ray, EKG, blood and urine tests, and a health history and physical exam.

Depending on the results of your blood tests and the timing of your last dialysis, you may be dialyzed at Emory Hospital before your transplant.

**THE KIDNEY TRANSPLANT SURGERY**

Your transplant surgery will last about three hours. Your family may wait in your hospital room or they may be directed to wait in a family waiting room while the surgery is taking place. After your surgery is completed, the surgeon will talk to your family to let them know how you are doing.

After arriving in the operating room, you will be given general anesthesia and put to sleep. The surgeon will make an incision on one side of your lower abdomen (usually the right side for first transplants) and the donor kidney will be placed in your pelvic area where it will be well protected. The blood vessels from the kidney will be connected to your large blood vessels. A small incision is made in the top of your bladder and the ureter (the tube that connects the kidney and the bladder) will be stitched to your bladder. This allows the urine from your new kidney to flow down to your bladder.

*A ureteral stent* is usually placed during the transplant surgery. A stent is a hollow plastic tube that is inserted inside the ureter to help keep it open while it heals. You will be informed if you receive a stent during surgery so you can receive the appropriate follow-up. Staples or dissolvable stitches will be used to close the incision.

Tubes and monitoring equipment will be used to check your recovery progress after surgery. You can expect to wake up from surgery with an IV line in your arm, a larger IV in your neck (*central line*), a small tube called a foley catheter in your bladder to collect your urine, and EKG pads on your chest to monitor your heartbeat. When you wake up, you will be in the recovery room. Then you will be transferred to either the transplant floor or the surgical intensive care unit (ICU).

Initially you will be under the effects of the anesthesia; you will be sleepy and may not remember the first time your family visits. During your recovery period, we will frequently check your vital signs, draw blood and collect urine for lab tests, monitor your urine output, and administer medications. In order to monitor your kidney function, you may have some of the following tests:

* *serum creatinine* - this blood test measures kidney function. It is checked each day while you are in the hospital.
• **renal scan** - this test monitors blood flow to the kidney and kidney function.
• **renal ultrasound** - this test checks the kidney for any blockages or fluid collections around the kidney.
• **kidney biopsy** - this test is used to check for rejection.

You can expect to spend three to five days in the hospital after surgery. Your nurses will help you regain your strength, teach you how to care for yourself when you go home, and prepare you for discharge from the hospital.

Close follow-up is essential for the success of your transplant, so after you are discharged, you may need to return to the transplant clinic daily for a few days for lab work. If you live out of town, you and your family may stay with friends or relatives in Atlanta, in a hotel, or in the Mason Guest House until you are stable enough to return home.
INTRODUCTION

Your decision to undergo a simultaneous kidney-pancreas transplant should involve many considerations. The contents of this section will assist you with this decision and provide you with important knowledge regarding what to expect before, during, and after your transplant. Specifically, we will address the differences between a kidney-only transplant, which is explained throughout this book, and a simultaneous kidney-pancreas transplant. You are encouraged always to ask questions and express any concerns you may have.

At Emory University Hospital, we consider kidney-pancreas transplantation for patients with Type I diabetes who are on, or close to requiring, dialysis. A kidney-pancreas transplant can offer a better quality of life for such patients. With a new kidney, you will no longer experience renal failure, but your new pancreas also will maintain your blood sugars at a normal level. Kidney-pancreas transplantation thus can offer you the chance to return you to a more normal, productive lifestyle.

The Emory kidney-pancreas transplant team strives to thoroughly educate every candidate about transplantation. Post-transplant management can be difficult and demanding. You and your family must completely understand the risks, limitations, and benefits of a kidney-pancreas transplant before you can make an informed decision concerning the procedure. It is important that you understand that a kidney-pancreas transplant is an ongoing treatment, not a cure for your disease. You will need daily medications and rigorous follow-up by the transplant team and your local physician for the rest of your life.

HISTORY OF KIDNEY-PANCREAS TRANSPLANTATION AT EMORY

The first combined kidney-pancreas transplant at Emory Hospital was performed on August 10, 1989. Since 1997, pancreas transplant after kidney has become another option. By the end of 2003, twenty pancreas after kidney transplants were performed at Emory.

THE HEALTHY PANCREAS

Your pancreas is a slender gland located between your stomach and spinal cord. This gland performs two major functions. First, it secretes two substances that control the amount of blood sugar in your body: insulin and glucagon. Insulin helps your body absorb blood sugar from the blood into your cells to produce energy. This process, however, also lowers your blood sugar level. Glucagon, on
the other hand, raises your blood sugar level by stimulating sugar production in various organs.

The other function of your pancreas is to produce enzymes that are secreted into the small intestine to help with digestion.

**DIABETES MELLITUS AND ITS EFFECT ON THE KIDNEYS**

*Diabetes mellitus* is a disease in which the pancreas either manufactures very little or no insulin or the pancreas makes insulin but the body is unable to use that insulin properly.

There are two types of diabetes. Type I diabetes occurs early in life, usually by the age of 25. In this type of diabetes, your body's immune system attacks the insulin-producing cells of the pancreas. As a result, your pancreas makes little or no insulin, causing the level of your blood sugar to rise. If you have Type I diabetes, you must use insulin injections or an insulin pump to help control your blood sugar.

Type II diabetes occurs later in life. In Type II, although the pancreas still makes insulin, your body resists the action of that insulin. One key difference between Type I and Type II is that Type II is easier to control, usually by diet and exercise. When these are not effective by themselves, patients with Type II diabetes may take medications by mouth or require insulin injections.

While both types of diabetes may lead to serious, long-term complications, Type I is more likely to do so. In the United States, 7.3 million people are living with diabetes. Of those, about 700,000 have Type I diabetes. Each year 30,000 new cases of Type I diabetes are diagnosed.

Over a period of time, the kidneys of patients with diabetes may also become damaged by the body’s inability to maintain the proper balance of glucose. Kidney disease, one of the most serious complications of diabetes, causes at least one third of patients with Type I diabetes to experience kidney failure within 20 to 30 years after the onset of their disease.

**BENEFITS OF SIMULTANEOUS KIDNEY-PANCREAS TRANSPLANTATION**

If you have both Type I diabetes and kidney failure, we may recommend a transplant that includes both a healthy kidney and a healthy pancreas instead of just a kidney transplant. One key reason why is that your newly transplanted pancreas will produce proper amounts of insulin to maintain your blood sugar at normal levels. Since elevated blood sugar is associated with kidney damage, returning your blood sugar level to normal may protect your new kidney from diabetic damage. A kidney-pancreas transplant may also help prevent other complications of diabetes from becoming worse. Most patients with diabetes are able to stop taking insulin injections following a kidney-pancreas transplant.
YOUR TRANSPLANT EVALUATION

To qualify as a kidney-pancreas transplant candidate, you must meet certain requirements. You must have Type I diabetes, exhibit overall good health, and understand and accept the risks and responsibilities associated with this procedure. If you suffer from severe heart disease and/or peripheral vascular disease, kidney-pancreas transplantation may not be an optimal therapy. If you smoke, you must be nicotine-free for at least six months before being listed for a kidney-pancreas transplant.

To decide if you would benefit from a kidney-pancreas transplant, you will undergo an extensive evaluation. Your kidney-pancreas evaluation is similar to the kidney evaluation but may include a few additional tests or consultants for you to meet.

MEETING THE TEAM: ADDITIONAL CONSIDERATIONS

During the kidney-pancreas evaluation, you will meet the same team members as described in the kidney transplant evaluation. In addition, you may also have appointments scheduled with some other specialists. An endocrinologist (diabetic specialist) will evaluate your diabetes and provide information about the kidney-pancreas transplant. You may also need to see an ophthalmologist (eye doctor) if the transplant team is concerned about the effects of your diabetes on your eyes. If you are already under the care of an ophthalmologist, it would be helpful to provide a current report from your doctor.

THE KIDNEY-PANCREAS TRANSPLANT SURGERY

All kidney-pancreas transplants at Emory are performed using organs from deceased donors. Therefore, the waiting list and pretransplant period will be similar to that described above for kidney recipients.

After arriving in the operating room, you will receive general anesthesia and be put to sleep. The surgeon will make an incision in the center of your abdomen from just below your breast bone to your pubic bone. The donated kidney will be placed in the left lower part of your abdomen in a protected area. The blood vessels of the kidney will be connected to your large blood vessels nearby. The ureter (the tube that connects the kidney to the bladder) will be stitched to your bladder so that urine can flow from the kidney, through the ureter, to your bladder.

During the same operation, the donor pancreas will be transplanted. The pancreas is placed in the
right lower part of your abdomen. Blood vessels are connected to supply blood flow to the pancreas. A section of the donor small intestine, called the duodenum, is removed along with the donor pancreas. This section of donor intestine is sewn onto your small intestine so that the digestive enzymes secreted from the pancreas will empty into your intestine. Once the pancreas is in place, the incision is closed using staples and a sterile dressing is placed over the incision.

You will likely remain on an insulin drip, continuous IV insulin infusion, for the first several days after your kidney-pancreas transplant. While you are in the hospital, your blood sugar levels will be followed closely and your insulin adjusted as your new pancreas begins to function.

You will have several tubes and monitors for the first few days after surgery. A nasogastric tube (NG) will be placed through your nose down into your stomach. This tube helps keep your stomach empty, or "decompressed," to protect the area where the pancreas is attached to your small intestine. You will also have a foley catheter, a small tube placed into your bladder to drain and measure your urine output. A main IV line will be inserted in your neck so that labs can be drawn and the many medications and IV fluids you will receive can be administered. These tubes and IVs will be removed gradually as your recovery progresses.

After surgery, you will be taken to the recovery room and then either to the transplant unit or the surgical intensive care unit. The length of your stay in the hospital for kidney-pancreas transplant typically ranges from six to ten days.

**FOLLOW-UP CARE**

After discharge, you will be seen at least once a week, for the first six weeks, in the Transplant Outpatient Services clinic. You should continue to check your blood sugar at least twice a day at home. Record your blood sugar levels along with your daily weight, temperature, and blood pressure. Bring these records with you to your clinic visits.

Some kidney-pancreas transplant recipients still require insulin injections at the time of their discharge, usually due to the side effects of the large doses of prednisone after transplant. Usually, as your dosage of prednisone is decreased, or tapered, you will no longer need extra insulin.
Possible complications after transplant

People who receive a transplant may develop complications after their surgery. Your transplant team will help you understand the warning signs of possible complications, discuss your care, and recommend further treatment when necessary. The more common complications include rejection of the organ, infection, acute tubular necrosis and post-transplant diabetes.

Donor organs are screened for various diseases in accordance with standards required by the United States Department of Health and Human Services—Centers for Disease Control and Prevention (CDC) and the United Network for Organ Sharing (UNOS). However, transplant recipients may be at risk for contracting certain diseases from the organ donor, such as various types of infectious diseases and cancers, which are not detected during the organ donor screening process.

REJECTION
Rejection occurs when your immune system recognizes the transplanted kidney as foreign and attacks it. The immune system is your body’s natural defense against other foreign invaders such as viruses, bacteria, and some types of cancers. To help prevent rejection of your new kidney, you must take immunosuppressant medications which will weaken your immune system. These medications must be taken on time, and as prescribed, in order to reduce the risk of rejection. It is necessary for you to take them as long as your transplanted kidney is functioning.

Sometimes your immune system can overcome the effects of the medication and begin to reject the new kidney. You may feel good and have no symptoms, yet still be experiencing rejection. The best way for the transplant team to recognize possible rejection is to follow your lab work closely. An increase in your serum creatinine or an increase of protein in your urine may be warnings of rejection. This is why we will check your lab work frequently during the first few months after surgery. Most rejection episodes can be treated successfully with medication, especially if detected early.

INFECTION
Immunosuppressant medications decrease the risk of rejection of the transplanted organ; however, they also increase your risk of infection. This risk is greatest in the early period after transplant when dosages of medications are at their highest. It is always important to protect yourself from exposure to infection. Here are some suggestions:

POSSIBLE SIGNS OF REJECTION
Notify a member of the transplant team immediately if you notice any of these symptoms:

- Fever greater than 100 degrees Fahrenheit.
- Feeling excessively tired or fatigued.
- Decrease in urine output.
- Increased pain, swelling, or tenderness in the area of the new kidney.
- Increased swelling of hands and feet.
- Weight gain greater than 3 pounds within a 24-hour time period or 10 pounds within a week.
- Loss of appetite, nausea or vomiting.
- Discolored, bloody, or foul-smelling urine.
- Blood pressure greater than 170/100.

TRANSPLANT OUTPATIENT SERVICE (2D)
Hours: 7 a.m. - 4 p.m.
Monday - Friday
Local: 404-712-5676
Toll Free: 800-727-8370
• Wash your hands frequently.
• Avoid contact with people with known infections like colds or the flu.
• Clean cuts or scrapes with soap and water.
• Avoid sharing eating utensils with others or drinking from the same container.
• Notify a member of the transplant team if you notice any possible signs of infection.

**ACUTE TUBULAR NECROSIS**

_Acute tubular necrosis_ (ATN) is the medical term for a transplanted kidney which is slow to function due to factors associated with the transplant procedure. This condition is sometimes called a "sleepy" kidney. If this condition occurs, you may need dialysis temporarily to give the kidney time to heal. Limiting potassium and fluids may also be necessary. It may take several weeks for a transplanted kidney to start to function. You will return to your local dialysis center until your kidney begins working. You will continue to be followed closely by the transplant team.

**HIGH BLOOD PRESSURE**

Some immunosuppressants can raise blood pressure; therefore, some transplant recipients must take additional medications to control their blood pressure. Your blood pressure is recorded as a top (systolic) and bottom (diastolic) number. Normal blood pressures range from 100/70 to 130/80. After your transplant you will take your own blood pressure daily and record it in the records section provided in this notebook. Notify a member of the transplant team if your blood pressure goes above 170/100 for two readings in a row. Untreated high blood pressure may damage your heart and other organs.

**POST-TRANSPLANT DIABETES**

Some of the immunosuppressant medications that you take may increase the likelihood of diabetes. _Diabetes_ is an increased level of sugar in your blood. Signs of diabetes may include excessive thirst, frequent urination, blurred vision, drowsiness or confusion. Notify the transplant team if you notice any of these signs. In some cases, high blood sugar can be reduced and managed by weight loss, careful diet, and exercise; however, you may need an oral diabetes drug or insulin injections. If you get diabetes, you will be given special teaching about how to deal with this problem.

**INFECTION WARNING SIGNS**

*If you have any of these signs of infection, notify a member of the transplant team:*

• Fever, chills, sore throat
• Nausea, vomiting, diarrhea
• Headache, sinus drainage
• Coughing up phlegm or mucus
• Wound redness, swelling, or pus
• Pain or burning with urination
• Enlarged neck glands or persistent running nose
• Pain in your head, chest, stomach, throat, or ears

**TRANSPLANT OUTPATIENT SERVICE (2D)**

*Hours: 7 a.m. - 4 p.m.*
Monday - Friday
Local: 404-712-5676
Toll Free: 800-727-8370

*FOR EMERGENCIES ONLY:*
After hours, weekends, or holidays, call 404-778-5000 and ask for the kidney transplant physician on call.
CYTOMEGALOVIRUS (CMV)

*Cytomegalovirus* or CMV is a very common virus. About 70% of adults have been exposed to CMV at some time. It usually causes a flu-like illness with fever, general body aches, and a decreased appetite which lasts for two or three days. After exposure to the CMV virus, your body forms antibodies in your blood to protect you from future exposures to CMV. This is similar to what happens after you have chicken pox. We are able to do blood tests to check both the transplant recipient and donor for the presence of CMV antibodies.

Because of the immunosuppressant medications, you will be at risk for infection with CMV after transplant. During the first few months, while the immunosuppressant doses are highest and your immune system is especially weak, the CMV virus can "reactivate" or "wake up." A CMV infection can range from flu-like symptoms to more serious infections involving your stomach, kidney, or lungs (pneumonia).

If either you or your donor were positive for CMV antibodies, you will be given an antiviral medication for the first few months after your transplant. As your doses of immunosuppressants are lowered over time, your risk for CMV will decrease as well and the medication will be stopped. If you develop an active CMV infection, you will be treated with medication in the vein.

POLYOMA BK VIRUS

Polyoma BK virus is another very common virus. About 90% of people in the United States are affected with this virus by the time they are 12 years old. The symptoms at the time of infection are non-specific, like cold symptoms that eventually go away. However, the virus itself does not totally leave the body. It becomes dormant, asleep in the kidneys and bladder.

When the immune system is weakened with anti-rejection medications, the virus can reactivate, primarily within the first year after transplantation. In general, there are no symptoms that let you know you have been affected by the virus. Therefore, it is necessary that we routinely screen all transplant recipients with a blood test several times during the first year post-transplant. In some cases Polyoma BK virus can cause severe kidney damage, perhaps even loss of the transplanted kidney. Currently, the primary treatment of the virus is to decrease the immunosuppressive medications, to allow your own immune system to fight off the virus. This treatment may require a more intense monitoring of your kidney function tests. Unfortunately, there is no drug that has been shown to effectively treat the virus.

**SIGNs AND SYMPTOMS OF CMV:**

- Flu-like symptoms: fever, chills, body or muscle aches, fatigue, decreased appetite.
- Lab work findings: low white blood cell count, high liver enzymes.
LYMPHOCELE

A lymphocele is a collection of lymph fluid around the kidney. It is normal for some fluid to collect around the kidney after transplant, but usually your body is able to reabsorb this fluid as healing occurs. Sometimes, however, a large build-up of fluid may put pressure on the kidney and the ureter and prevent urine from draining easily. In these cases, the lymph fluid will need to be removed. This can be done by placing a drain tube through the skin into the fluid collection and allowing it to drain into a bag over several days. Another option is for the lymphocele to be drained surgically. This operation is relatively simple and usually requires an overnight stay in the hospital.

SIGNS AND SYMPTOMS OF A LYMPHOCELE:

• Swelling of one leg (on the side where the kidney is located).
• Swelling over the kidney.
• Increase in creatinine
Medications

After your transplant, you will have to take certain medicines called immunosuppressants. These medicines suppress your immune system to help prevent your body from rejecting your transplant. They are also called anti-rejection medications. These are very important medicines that you will need to take for as long as you have your transplanted organ. If you do not take these medicines as instructed, your transplanted organ can fail.

LEARNING ABOUT YOUR MEDICATIONS

You may feel overwhelmed by the number of medicines and pills that you have to take after your transplant. Your nurse will work closely with you to make sure that you are comfortable taking all your medicines. You will practice taking your new medicines while in the hospital with the help of your nurse. The nurse will provide you with a list of medicines with pictures and teach you how to keep medication records.

In this section, you will learn about:

I. Immunosuppressants (anti-rejection medications)
   A. Immunosuppressants for prevention of rejection
      • Neoral®/Gengraf®, and Prograf®
      • Cellcept® and Imuran®
      • Rapamune®
      • Prednisone
   B. Immunosuppressants for treatment of rejection
      • Solu-Medrol®
      • OKT-3®
      • ATGAM® and Thymoglobulin®

II. Antibiotics and Antivirals
   • Bactrim®
   • Cytovene® or Valcyte®

III. Other Medications
   • Pepcid®, Zantac®, Axd®
   • Multivitamin
   • K Phos Neutral®
   • Blood thinner

IV. Research Protocols

PLAN AHEAD:
Before you have your transplant, arrange for your medications with the pharmacy of your choice.

My home pharmacy is

Phone#

My Atlanta-area pharmacy is

Phone#

TIPS FOR TAKING MEDICATIONS

• Understand why you are taking each medication and its side effects.
• Notify your transplant coordinator or physician if you experience any side effects.
• Take your medicines every day. One of the main causes of transplant failure is noncompliance.
• If you miss one or two doses, DO NOT double the dose.
   Please call the transplant coordinator for instructions

(More tips on the next page)
I. IMMUNOSUPPRESSANTS (ANTI-REJECTION MEDICATIONS)

Why do I have to take immunosuppressants?
The job of your immune system is to help you fight off things that are harmful or foreign to your body (infection, cancer). A transplanted organ, although human, is new to your body so your immune system will try to reject ("fight off") the transplanted organ. Immunosuppressant medications suppress, or "weaken," your immune system to prevent rejection of your organ.

How long do I have to take immunosuppressants?
You will have to take immunosuppressants for as long as you have your transplanted organ so that your body will not reject the organ. One of the main reasons why patients lose their transplant is they fail to take their immunosuppressants.

How many types of immunosuppressants do I have to take?
Patients can be prescribed two to four different types of immunosuppressants at one time. Your transplant doctor will decide which immunosuppressants to prescribe for you. The types of immunosuppressants you will take on a daily basis are used to prevent rejection. If you have a rejection episode, you will be prescribed a stronger, more potent immunosuppressant to treat your rejection.

Why do I have to take so many types of immunosuppressants?
Different immunosuppressants work in different ways to prevent your transplanted organ from rejecting. By using a combination of immunosuppressants, you have less chance of rejecting your organ than if you just took one type of immunosuppressant.

How much do I have to take?
In general, the doses of your immunosuppressants are highest during the first months after your transplant since your risk for rejection is greatest then. Over time, your doses will be decreased depending on how you and your transplanted organ are doing.

What are the overall risks of taking immunosuppressants?
Because these medicines weaken your immune system, you are at increased risk for infections. You will take certain medications for the first several months to help prevent infections. As your doses of immunosuppressants are reduced over time, your risk for infection will go down. You are also at increased risk for certain types of cancers. You can help prevent skin cancer by always using sunscreen (Sun Protection Factor/SPF-15) whenever you are outdoors.

MORE TIPS FOR TAKING MEDICATIONS:
• If you are sick or nauseated, and cannot take your medications, call the transplant coordinator or physician immediately. You may need to be admitted to the hospital to receive your immunosuppressants through the vein.
• Bring a list of medications with the current dose and frequency each time you see a health professional.
• Do not take any new prescription or over-the-counter medications without checking first with someone from the transplant team. Many drugs interact with immunosuppressants.
• You may take plain or Extra-Strength Tylenol®, NEVER take aspirin, Motrin®, Alleve®, or any other nonsteroidal anti-inflammatory drug (NSAID) unless approved by your transplant physician.
• Do not take any herbal or natural product without consulting your transplant physician. Unfortunately, there is very little information on how these products interact with immunosuppressants.
• Make sure you request refills of your immunosuppressants 3-5 days in advance in case your pharmacy needs to order the medication.
• Store your medications in a safe and dry place away from heat and light. KEEP OUT OF REACH OF CHILDREN.
A. Immunosuppressants for Prevention of Rejection

Most patients will take either cyclosporine or tacrolimus (Prograf®) unless they are enrolled in a clinical trial. These medicines work very much the same way to prevent rejection and have similar side effects. You will never be on both drugs at the same time.

Cyclosporine (Neoral®, Gengraf®, Sandimmune®)

What does cyclosporine look like?
There are different types of cyclosporine: Neoral®, Gengraf®, Sandimmune®, and some generic brands. Your body absorbs each type differently. You should not use one type in place of the other. Always take the type prescribed by your transplant doctor.

<table>
<thead>
<tr>
<th>Brands of cyclosporine</th>
<th>Color and form</th>
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<tbody>
<tr>
<td>Neoral®</td>
<td>25mg, 100mg gray gelcaps or liquid</td>
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<tr>
<td>Sandimmune®</td>
<td>25mg, 100mg brown gelcaps or liquid</td>
</tr>
<tr>
<td>Gengraf®</td>
<td>25mg, 100mg white gelcaps</td>
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How much cyclosporine do I take?
Your dose will be adjusted based on a special blood test (cyclosporine blood level). Your dose may change frequently for the first several weeks. Over time, your cyclosporine doses and blood levels will be lowered.

How often do I take cyclosporine?
Generally cyclosporine is taken twice a day 12 hours apart.

What are the main side effects of cyclosporine?
- increase in creatinine (kidney lab work)
- high blood pressure
- high potassium level
- hair growth on the arms and face
- redness or soreness of the gums
- slight tremors and shaking of the hands (potential sign that your cyclosporine blood level is too high)

Note: Patients on cyclosporine cannot eat grapefruit as it interacts with medication. Many medications can interact with cyclosporine so check with your transplant physician before starting any new medication.

IMPORTANT:
The evening before your clinic visit, take your cyclosporine 12 hours before your appointment. On the day of clinic, wait to take your morning dose of drug until after your labs and drug level have been drawn.
For example: Patient takes cyclosporine at 9 a.m. & 9 p.m., but has a 10 a.m. clinic visit on Monday

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<thead>
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<th>AM dose</th>
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<td>Sat.</td>
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<td>Sun.</td>
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<td>Mon.</td>
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<td>Tues.</td>
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*12 hours before appointment.
**after blood tests.
**Prograf® (tacrolimus)**

You will likely take either Prograf® or Neoral® to prevent rejection.

*What does Prograf® look like?*
Prograf® is also known as FK-506. There is only one brand name – Prograf®. It is available in small white (1 mg), pinkish (5 mg), and yellow (0.5 mg) capsules. There is no generic form available.

*How much Prograf® do I take?*
Your dose is initially based on your weight. Your dose will be adjusted based on a special blood test (Prograf® blood level). Your dose may change frequently for the first several weeks. Your Prograf® level should be between 10-15 ng/ml. Over time, your Prograf® doses and blood levels will be lowered.

*How often do I take Prograf®?*
Tacrolimus is taken twice a day 12 hours apart.

*What are the main side effects of Prograf®?*
- increase in creatinine (kidney lab work)
- high blood pressure
- high potassium level
- increase in blood sugars
- slight tremors and shaking of the hands (potential sign that your Prograf® blood level is too high)

*Note:* Patients on Prograf® cannot eat grapefruit as it interacts with medication. Many medications can interact with Prograf® so check with your transplant physician before starting any new medication.

**Cellcept® (mycophenolate mofetil)**

You will take either Cellcept® (mycophenolate mofetil) or Imuran® (azathioprine) to prevent rejection. Cellcept® is a newer, more potent immunosuppressant agent that is used in place of Imuran®. Imuran® has been used for many years as an immunosuppressant agent.

You will never be on both drugs at the same time. You should always take the one prescribed by your physician. Never take one in place of the other.

*What does Cellcept® look like?*
Cellcept® is available as a 250 mg blue and orange capsule or as a 500 mg purple tablet. There is no generic form available.

---

**IMPORTANT:**
The evening before your clinic visit, take your Prograf® 12 hours before your appointment. On the day of clinic, wait to take your morning dose of drug until after your labs and drug level have been drawn. For example: Patient takes Prograf® at 9 AM & 9 PM, but has a 10 AM clinic visit on Monday.

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<td>Mon. 10 a.m.**</td>
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<tr>
<td>Tues. 9 a.m.</td>
<td>9 p.m.</td>
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</table>

*12 hours before appointment. **after blood tests.

**IMPORTANT:**
Women of childbearing age should use some method of birth control while taking Cellcept®. Cellcept® has been associated with birth defects. If you are interested in becoming pregnant, speak to your transplant doctor about your options. Our transplant program recommends waiting at least two years after your transplant before becoming pregnant. Pregnancy is most successful if serum creatinine is less than 1.6 yield.
**How much Cellcept® do I take?**
Your initial dose will be 1000 mg or 1500 mg twice a day. Your dose may be adjusted if you experience significant side effects.

**How often do I take Cellcept®?**
Cellcept® is taken twice a day 12 hours apart.

**What are the main side effects of Cellcept®?**
- nausea and vomiting
- diarrhea
- low white blood cell count

**Imuran® (azathioprine)**

**What does Imuran® look like?**
Imuran® is available as a 50 mg yellow bow-tie tablet. The generic form (azathioprine) is available as a 50 mg white tablet. This transplant program is comfortable using the generic form.

**How much Imuran® do I take?**
Your dose is based on your weight. Doses range from 75 mg to 150 mg daily. Your dose may be adjusted if you experience a low white blood cell count.

**How often do I take Imuran®?**
Imuran® is taken once a day. You may take it any time during the day or evening.

**What are the main side effects of Imuran®?**
- low white blood cell count
- nausea and vomiting

**Rapamune® (sirolimus)**

Rapamune® is an immunosuppressant agent that is used to prevent rejection of your transplanted organ.

**What does Rapamune® look like?**
Rapamune® is available in a white, triangular-shaped, 1 mg tablet. It is also available as an oral liquid in individually packaged 1 mg, 2 mg or 5 mg packets (like ketchup packets) or in 60 ml or 150 ml bulk bottles at a concentration of 1 mg/1 ml. There is no generic form available.
How much Rapamune® do I take?
Your initial dose will be 5 mg once a day in the morning. Your dose will be adjusted in clinic based on a special blood test (Rapamune® blood level). Your dose may change frequently for the first several weeks. Your Rapamune® blood level should be between 10-15 mg/L.

When do I take Rapamune®?
Rapamune® is taken once daily with your morning Prograf® or Neoral®/Gengraf dose.

What are the main side effects of Rapamune®?
- increase in cholesterol and triglycerides.
- low white blood cell count
- low platelet count

Prednisone
Prednisone is a steroid that can also be used to prevent rejection or treat a rejection episode. Prednisone is also used for many other medical conditions including asthma and arthritis.

What does prednisone look like?
Prednisone is available as a generic medication and can come in a variety of strengths and colors. Your transplant program is comfortable using the generic product. Deltasone® is one brand name.

How much prednisone do I take?
Your dose of prednisone will change every day while you are in the hospital. The initial doses are high, but then the dose is reduced each day. After you are discharged, your dose slowly will be reduced to 10 mg once a day. Follow the dates of your prednisone taper schedule given to you by your nurse.

How often do I take prednisone?
For the first several days, you will take it twice a day—once in the morning and again in the evening. Afterwards, you will take it once a day in the morning. Prednisone should be taken with food or milk.

What are the side effects of prednisone?
Prednisone has side effects that usually lessen as the dose is reduced. In most cases, other medicines and the transplant diet help control adverse effects of the medicine.
Most common side effects:
• increase in appetite and weight gain
• salt and fluid retention
• increase in blood sugar
• increase in fatty tissue, especially the cheeks and abdomen
• acne on the chest, back, and face
• irritation of the stomach lining – take with food!!
• blurred vision

Possible side effects (more commonly associated with larger doses):
• difficulty sleeping
• hallucinations or vivid dreams
• night sweats
• mood swings
• chills

Possible long-term side effects:
• muscle weakness
• bone and joint changes
• cataracts

B. Immunosuppressants for Treatment of Rejection

If you have a rejection episode, it does not mean you will automatically lose your transplanted organ. If we diagnose the rejection process early, we can often reverse it by giving you stronger IV immunosuppressants. A biopsy of your transplanted organ will help the physicians decide which treatment to give you for your rejection episode.

Solu-Medrol® (methylprednisolone)

Solu-Medrol® is used to treat mild rejections. It is an IV steroid that is very similar to oral prednisone. We give you very high doses of Solu-Medrol® over 30 minutes for three days. Depending upon where you live, we can sometimes arrange for you to complete the course as an outpatient. Side effects are similar to prednisone.

OKT-3® (muromonab-CD3)

OKT-3® is used to treat more severe rejections. An antibody that is targeted against the cells that are causing the rejection, it is given IV over 60 seconds for seven to 14 days. It is a very potent immunosuppressant so you have to begin your therapy in the hospital. Patients commonly experience side effects similar to a very bad case of the flu. These side effects are most severe during the
first few days and may include high fevers, chills, headaches, dia-
rhea, and shortness of breath. You will be given Tylenol®,
Benadryl®, and other medications to help relieve the side effects.
After a few days, most patients begin tolerating OKT-3® well
enough to complete the therapy as an outpatient.

Thymoglobulin® (Anti-thymocyte Globulin)
This immunosuppressant may also be used to treat severe rejec-
tions. An antibody that is targeted against the cells that are causing
the rejection, it is given through an IV in your neck or arm over
four to six hours for seven to 14 days. It is a very potent immuno-
suppressant so you have to begin your therapy in the hospital.
Patients sometimes experience side effects that are similar to a very
bad case of the flu. These side effects are most severe during the
first few days and may include high fevers, chills, rash, itching,
headaches, diarrhea, decreased white blood cells and platelets.
You will be given Tylenol®, Benadryl® and other medications to
help relieve the side effects. After a few days, most patients begin
tolerating Thymoglobulin® well enough to complete therapy as an
outpatient. However, due to the long infusion time of Thymoglobulin®,
options for outpatient therapy are more limited.

II. ANTIBIOTICS AND ANTIVIRALS
As mentioned before, one of the overall risks of taking
immunosuppressants is the increased risk of infection. Your risk
for developing an infection is greatest during the first months after
your transplant since your doses of your immunosuppressants are
the highest.
During this high-risk period, you may be prescribed one or more
of the following medications to help prevent infection.

Bactrim®/Septra® (sulfamethoxazole/trimethoprim or
SMX/TMP)
Bactrim® is a sulfa antibiotic commonly prescribed to treat various
types of infections. You are prescribed Bactrim® for two reasons:
• to prevent a type of pneumonia called pneumocystis carinii
  pneumonia or PCP.
• to prevent a urinary tract infection in your newly transplanted
  kidney.
It is available as a generic and comes as a regular strength and
double strength tablet (e.g. Bactrim® and Bactrim DS®). You will
take Bactrim® once a day for at least six months. If you are allergic
to sulfa antibiotics, you will be prescribed an alternative medica-
tion such as Dapsone or Pentamidine.
**Possible side effects:**
- rash
- increased sun sensitivity
- nausea
- low white blood cell count

**Valcyte® (Valganciclovir)**
Valcyte® is an antiviral agent used to prevent and treat cytomegalovirus (CMV – refer to Complications). Depending on the CMV antibody status of you and your donor, you may take Valcyte® for three months to decrease the likelihood of a CMV illness. It is available as a 450 mg red tablet.

**Possible side effects:**
- low white blood cell count
- low platelet count
- nausea and vomiting
- decreased appetite

**III. OTHER MEDICATIONS**
Additional medications may be needed after your transplant:

**Pepcid® / Zantac® / Axid®**
These are referred to as H2-antagonists. All of these medications work the same way to block acid production in your stomach to prevent ulcers. You will take the medication every day until your prednisone is tapered to 10 mg. (Reminder: prednisone can irritate your stomach so take with food or milk). These medications have few side effects. They are also available over the counter in non-prescription strengths. If you decide to purchase the over-the-counter product, you will need to take twice the number of tablets to equal the prescription strength.

<table>
<thead>
<tr>
<th>Prescription</th>
<th>Over The Counter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pepcid® (20mg tab)</td>
<td>Pepcid AC® (10mg tab)</td>
</tr>
<tr>
<td>Zantac® (150mg tab)</td>
<td>Zantac 75® (75mg tab)</td>
</tr>
<tr>
<td>Axid® (150mg tab)</td>
<td>Axid AR® (75mg tab)</td>
</tr>
</tbody>
</table>

**Multivitamin**
You will need to take a multivitamin every day. You may purchase any brand name (e.g. Centrum®) or generic multivitamin over the counter. Ask your local pharmacist to help select one that has no potassium. Before your transplant, you may have been taking a prescription multivitamin (e.g. Nephrovite®, Nephrocaps®) or folic
acid. You may finish taking any pills you have left, but you do not need to refill these prescriptions unless otherwise instructed by your transplant physician.

**K Phos Neutral®**

Now that you have a working kidney transplant, that kidney is able to eliminate phosphorous. Because your body is not used to a working kidney, it may eliminate too much phosphorous and your levels may become too low. You will need to take a phosphorous supplement called K Phos Neutral® to correct the low phosphorous levels. K Phos Neutral® is available as a 250 mg tablet. Doses vary, but most patients take two tablets three times a day for several months. There are other phosphorous supplements available, but they contain much more potassium. K Phos Neutral® has almost no potassium. Your dietitian will also inform you of foods that you can eat to help increase your phosphorous levels.

**Blood Thinner**

You may be prescribed some type of blood thinner to help prevent you from developing clots that may block the blood supply to your new transplanted organ. Your transplant physician will determine the type of blood thinner and length of therapy.

**IV. RESEARCH PROTOCOLS**

Emory has taken a leading role in advancing organ transplantation. Many of today’s advances have come from research conducted here at Emory. Research to improve the delivery of patient care is vitally important, and we remain committed to finding better ways to help those in need of organ transplantation. When you are admitted for your transplant, you may have the opportunity to participate in a research protocol. If you have any questions, please ask your transplant physician.

**WHERE TO GET YOUR MEDICATIONS**

Soon after your transplant surgery, your transplant coordinator will ask you what pharmacy you will use to get your medications. The immunosuppressant medications you will be taking may not be stocked by your local pharmacy or may have to be ordered a few days before you are discharged home. It is helpful to begin making arrangements for where you will obtain your medications before your transplant.

Your transplant medications are very expensive. Their cost will range from $1400 to $2000 per month. A portion of this cost is paid for by Medicare for three years after your transplant, subject
to Medicare coinsurance and deductible provisions. However, most retail pharmacies will not bill Medicare and may require payment up front for these medications when you receive them.

Some mail-order pharmacies specialize in serving transplant patients. Your transplant coordinator can provide information about mail-order pharmacies that can assist with billing and shipping the medications to you. If you decide to use a mail-order pharmacy, it is your responsibility to call and initially set up the service.

Prior to your discharge from the hospital, the transplant coordinator or pharmacist will provide you with prescriptions for your pharmacy, or call in the prescriptions for you, when possible. Most prescriptions will be written for a month’s supply with several refills available. You will need to contact the pharmacy each month to request refills. To make sure you do not run out of medicines, remember to contact your pharmacy several days before you actually need them.

If you need new prescriptions, please remember to call the Transplant Outpatient Clinic during normal business hours, a few days before the medications will be needed.
Going home from the hospital

Going home after your transplant is very exciting. However, it can also seem overwhelming. Before you go home, we will thoroughly review with you and your family what you need to do to take care of yourself and your new kidney. Your transplant coordinator, pharmacist, social worker, and nurses will begin preparing you for discharge the day after surgery.

VITAL SIGNS
You will need to check your temperature and blood pressure daily. The nurses will teach you how to check these vital signs so that you will feel confident doing this before you go home. If you do not already have a blood pressure cuff and thermometer, you will need to buy these from a pharmacy or medical supply store.

A daily journal is provided for you (at the end of this book) to record your vital signs. Your nurse will tell you acceptable ranges for the vital signs so that you know when to call if a reading is abnormal. It is important that you keep good records and bring these with you each time you come to the Outpatient Transplant Clinic for follow-up.

DAILY WEIGHT
You need to weigh yourself every day. Please try to do this at about the same time each day (preferably in the morning after you have emptied your bladder) and while wearing about the same amount of clothing. Record your weight with your vital signs in your daily journal. If you have gained more than three pounds in a day, or more than five to seven pounds in a week, you should call the transplant team. This weight gain may be a side effect of your medications or possibly a sign of transplant rejection.

MEDICAL ALERT IDENTIFICATION
We suggest that you obtain a special medical alert bracelet or necklace. In case of a car accident or other type of emergency, this will inform health care professionals that you have had a transplant. The identification bracelet or necklace can be purchased at many pharmacies or ordered through the mail for a nominal cost.

DISCHARGE FROM THE HOSPITAL
You can expect to spend a total of three to five days in the hospital for your transplant. If you live a great distance from Emory, you may be asked to stay in the Atlanta area for a few additional days so we can closely monitor your progress.
The Mason Guest House of Emory University offers private, low-cost lodging for transplant candidates, recipients, and families. Individuals from out of town coming to a transplant evaluation or follow-up care may also stay at the Mason Guest House (see section on Mason Guest House for more information).

WHEN TO CALL THE TRANSPLANT TEAM
You should call the Transplant Team if you experience any of these symptoms, or any time anything about your health changes, even if it is not related to your transplant:

• Temperature of 100°F Fahrenheit or greater
• Blood pressure greater than 170/100 for two readings in a row
• Weight gain of more than 3 pounds in a day or 5 to 7 pounds in a week
• Cough, shortness of breath, sore throat, chills
• Nausea, vomiting or stomach pain
• Diarrhea
• Decreased appetite
• Blood in the urine or bowel movements, painful urination
• Increased pain, redness, or pus-like drainage at the incision
• Pain, tenderness or swelling in the area of the new kidney
• Feeling unusually tired
• Persistent headache or flu-like symptoms
• Any unexplained rash, sores, or bruising
• Swelling of the hands, feet or ankles
• Unable to take medications for any reason
• Anything that concerns you about your health

IMPORTANT PHONE NUMBERS

Transplant Outpatient Services
(2D)
Hours: 7am-4pm, Monday – Friday.
404-712-5676
1-800-727-8370 for scheduling appointments

After hours/emergency, call the hospital paging operator at
404-778-5000
(Ask for the kidney transplant physician on call)

Mason Guest House
404-712-5110

Outpatient Transplant Coordinator’s Office,
Monday – Friday,
8am-4:30pm
404-727-8938
1-888-247-9052

Prescription Refill Nurse
404-712-1438
Going for Check-Ups

OUTPATIENT TRANSPLANT SERVICES

Your kidney transplant follow-up appointments will be scheduled in Transplant Outpatient Services, which is located on the second floor, D-wing of the hospital (2D). On the day of discharge, we will schedule your first appointment for lab work and a follow-up visit. This office visit will include seeing a member of the transplant team who will perform a physical exam, review all of your medications, and discuss how you have been feeling. This is a great opportunity for you to express any concerns or ask questions. Please remember to bring your daily records and a list of all your medications with you to each follow-up visit.

When you arrive for a clinic follow-up appointment, blood will be drawn for lab tests and you will be asked to give a urine sample. A nurse will check your vital signs and weight and ask some general questions about your health. It takes one hour for your lab results to come back. During this time you can wait in the waiting area, or you may wish to go to the cafeteria or gift shop. Once your lab results are ready, you will be placed in an exam room to be seen by one of the transplant physicians.

Clinic Visits and Lab Tests

For the first six weeks after your transplant, you must come to Emory once a week for a follow-up visit. You will have lab work done and see the transplant team. After six weeks, if all is going well, visits and lab work will be needed less frequently. Eventually, you will need a follow-up appointment at Emory only once every three to six months.

In addition to your weekly visit at Emory, you must have blood drawn for laboratory tests one additional time each week for the first six weeks. These tests can be done locally at your doctor’s office, hospital, or dialysis center. We will provide a special order form for laboratories outside Emory. It explains what lab tests need to be drawn and how to send the results to us. If you prefer to have your lab work done at Emory, please call Transplant Outpatient Services (2D) at (404)712-5676 in advance to make an appointment.

If your lab work is abnormal, the transplant coordinator will call you with any medication changes and let you know when to have your blood checked again. You may be asked to come to Emory to be seen by a transplant physician.

To schedule appointments:
Transplant Outpatient Services (2D):
404-712-5676
1-800-727-8370

REMEMBER:
You may eat breakfast and take all medicines EXCEPT Neoral®/Sandimmune®/Gengraf® or Prograf® prior to your clinic visit.

ALSO:
Prior to your first visit in the Outpatient Transplant Clinic, you or a family member must go to the admission department to set up an outpatient account. You may do this the day you are discharged from the hospital, or on the morning of your first appointment, but please arrive about 20 minutes early to allow time to set up your account before your appointment.

You may also set up your outpatient account by calling FAST TRACK at 404-686-5270 or 1-800-640-9293. This will eliminate the need to go to Admissions.
ROUTINE BLOOD TESTS

Monitoring your blood through lab tests is one way that we can make sure your kidney is working well and check for possible side effects of your medications. When we draw your blood we will do several lab tests that measure your kidney function and the level of medication in your blood:

- **cyclosporine (Neoral©/Gengraf©/Sandimmune©) or Prograf® level** - the blood level of immunosuppressant medication. This will tell us if a change in your dosage is needed.
- **creatinine** - measures kidney function. Creatinine is a waste product that is normally removed from your blood by the kidney. Creatinine may be increased for several reasons including rejection, dehydration, or high cyclosporine or Prograf levels.
- **potassium** - a mineral that is regulated by the kidney. It may be elevated after transplant depending on kidney function, diet, and medication levels. Potassium levels may be low if you take diuretics or water pills.
- **hematocrit** - measures the number of red blood cells. The hematocrit is usually very low in patients with kidney disease, but improves slowly after transplant.
- **white blood cell count (WBC)** - measures the number of white blood cells. It may be elevated because of infections or due to high doses of prednisone. The WBC can also be low due to viral illnesses or as a side effect of Cellcept or other immunosuppressant medications.
- **cholesterol** - a substance produced by the liver. Cholesterol levels can be increased as a side effect of cyclosporine, Prograf, and prednisone. High cholesterol levels can contribute to heart disease; limiting the fat intake in your diet helps control your cholesterol levels.
- **amylase/lipase** - enzymes secreted by the pancreas, part of the routine lab work in pancreas transplant recipients. An increase in either of these enzymes indicates the pancreas may be inflamed or irritated.

URETERAL STENT REMOVAL

Most transplant recipients will have a ureteral stent placed as part of their kidney transplant surgery. If you have a stent, you will be informed of this by the transplant team. The urine which is made in your new kidney flows to your bladder through the ureter. The ureter came with the donor kidney and was connected to your bladder with a small incision. The stent is a thin hollow tube which is placed inside the ureter to keep it open and allow the connection to your bladder to heal.
The ureteral stent needs to stay in place for about six weeks after the transplant. By this time, healing will be complete and your stent can be removed. A urologist who works with the transplant team will remove the stent during a brief procedure called a cystoscopy. You will not be put to sleep, and no incision or surgery is needed. A flexible tube (the cystoscope) is inserted into your bladder, and the stent is removed through the cystoscopy tube. You may feel some brief discomfort or pressure. This procedure takes about 30 minutes.

A couple of weeks after you get home from the hospital, you will be contacted by the urologist’s office to arrange an appointment time to have the stent removed. You may schedule this appointment on the same day you have an appointment scheduled in the Outpatient Transplant Clinic.
Staying healthy

Now that you have had your transplant, we encourage you to resume your normal activities as much as possible and take good care of yourself. Here are some suggestions:

YOUR DAILY ROUTINE

Developing and adhering to a daily routine of checking vital signs and weight and taking your medications is the best way to detect post-transplant problems early.

• Take your vital signs (temperature and blood pressure) about the same time each day when you are relaxed and comfortable. Record them in your daily records.
• Weigh first thing in the morning and record your weight in your daily journal. Weigh around the same time and in the same amount of clothing. You may use bathroom scales.
• Develop a schedule for taking your medications that works with your daily routine. Your medicines must be taken at the same time every day.
• Take your cyclosporine (Neoral®, Gengraf®, Sandimmune®) or Prograf® and Cellcept® every 12 hours.

BATHING

Your staples will be removed about 14 days after surgery. Until that time, keep the incision clean and dry. You may shower, but allow the water to flow over your incision, wash lightly with soap, then gently pat dry. You may bathe in a tub once your staples have been removed and the incision has healed. If you feel weak when standing in the shower, you may wish to use a plastic chair or stool. You may feel tired or dizzy after bathing, so take it slowly and have someone close by in case you need help.

DRIVING

You should not drive for 3-4 weeks after your transplant. Your reaction time may be decreased because of pain and medications. It also takes four to six weeks for your incision to heal properly. You may not have the strength and quickness to apply your brakes adequately in an emergency. You may ride in a car during that time, but you must always wear a seatbelt. For comfort during the first few weeks, you may want to pad your incision with a small pillow or folded bath towel. The belt and buckle will not harm your kidney.

HELPFUL HINTS

• Keep all clinic appointments.
• Refill prescriptions early so you do not run out of medications. Routine prescription refills should be called in to Transplant Outpatient Services during normal business hours.
• Report any changes in your health to the transplant team.
• Check with the transplant team before taking any over-the-counter drugs or filling any prescriptions given to you by another health care provider. Many medicines may interfere with your immunosuppression medications.
• Avoid smoking.
• Avoid smoke-filled areas. Ask family members not to smoke.
• Avoid lifting more than 20 lbs. and avoid strenuous physical activities for at least 8 weeks after transplant.
EXERCISE

Kidney disease and dialysis can cause a decrease in energy levels. After transplant, it is common for patients to comment on how much more energy they have. Physical exercise, especially walking, is encouraged for all transplant patients. Exercise helps counteract the weakening effects of your pre-transplant illness and helps reduce some of the possible side effects of the immunosuppressant medications such as weight gain, water retention, high blood pressure, elevated cholesterol and blood sugar, and weakened bones and muscles. Regular activity also promotes confidence and a sense of well-being.

Walking is usually encouraged within one or two days after surgery. Initially after your discharge from the hospital, walking and riding a stationary bike are excellent exercises. After your staples have been removed and your incision is healed, swimming is another good form of exercise. With any exercise program, start out slowly and gradually increase to at least 20 minutes a day three times a week.

Stop the exercise if you become dizzy, short of breath, nauseated, extremely tired or if you are sweating excessively. Avoid these activities during the first eight weeks after surgery:

• lifting more than 20 pounds
• forceful pushing or pulling
• abdominal exercises such as sit-ups or leg lifts
• riding a regular bicycle
• contact sports
• twisting exercises such as golf and tennis

Limit your activity level if you have an infection, fever, or if you are being treated for rejection.

Talk with the transplant team if you wish to resume your usual sports activities or start a fitness program, or if you have any questions about your exercise program.

NUTRITION AND DIET

Proper nutrition is necessary before and after your transplant. A balanced, healthy diet will help you maintain an acceptable body weight and promote wellness. Our clinical nutritionist will meet with you and your family to evaluate your diet and teach you the right foods to eat to meet your individual needs. After your transplant you may be able to eat foods you once had to restrict. Making healthy food choices is essential for your best outcome.

After your transplant, you will need to follow healthy dietary guidelines which will help minimize some of the possible side effects from the medications you will be taking.

FLUIDS

Are you drinking enough fluids? Drinking plenty of fluid is important after a transplant. Dehydration will raise your creatinine level! It may be difficult to remember to drink fluids after being on a fluid restriction. If you are having trouble drinking enough, carry a sports bottle full of fluid with you. Or make a habit to have a large glass of water every time you brush your teeth.

What fluids are best? Anything that does not contain sugar, caffeine, or alcohol counts towards your fluid intake. (Caffeine and alcohol are diuretics.) You need at least eight large glasses per day. In the summer or when you are working hard and sweating, you need to drink even more.

GOOD FLUID CHOICES:

• Fresca
• Diet Sprite, diet ginger ale, diet orange soda, etc.
• Caffeine-free Diet Coke
• Sugar-free lemonade such as Crystal Light or sugar-free Country Time Lemonade
• Sugar-free punch such as Kool-Aid
• Skim or 1% milk
• Apple, cranberry and grape juices
• Fruit nectars
• Decaffeinated coffee and tea
• Water
For example, protein is needed after surgery to promote healing and combat any muscle weakness which may be caused by immunosuppressant medications. For the first six weeks after your transplant, your diet should be high in protein, including lean meat, skim milk, low-fat yogurt and cheese. Unlike your damaged kidneys, your new transplanted kidney will allow you to use protein and dispose of the waste products caused by protein breakdown. Once you have healed from your surgery, you will need to limit your protein intake to a moderate amount each day so that you do not overburden your new kidney.

Your medications also may cause your cholesterol level to rise. Having an elevated cholesterol places you at higher risk for cardiovascular (heart) problems. You can help control your cholesterol by limiting dietary cholesterol and saturated fat found in foods such as eggs, butter, whole milk, fried foods and high-fat cuts of meat.

The medication prednisone can cause some people to have elevated blood sugar levels. You may need to limit starches and eliminate sugar from your diet to help control high blood sugar.

Prednisone may also cause the loss of calcium in your bones. To help prevent osteoporosis, include at least three servings of a calcium rich, low fat food in your diet daily. You may also need a calcium/vitamin D supplement. After your transplant, you will need to talk with your doctor about a calcium plan designed to fit your particular needs.

A moderate (less than 4 grams per day) sodium diet is usually sufficient to help reduce fluid retention. In some patients a more strict sodium restriction might be necessary.

**SEXUAL ACTIVITY**

You may resume sexual activity when you feel ready. This will not harm your new kidney. Some positions may be more comfortable than others, so adjust accordingly. You may find that relaxation, a sense of humor, and using pillows or different positions may help you. If you experience any difficulties with enjoying sexual activity, please let someone on the team know.

Many people with long-standing diabetes, or who take some blood pressure medications, may experience different degrees of sexual difficulties, including low desire, erectile difficulties, and problems achieving orgasm. Please feel free to discuss these concerns with the transplant team. We may need to change your medication or refer you to a specialist.

Remember that because your immune system is suppressed, you can be easily infected with sexually transmitted diseases. Unless you are in a long-term, monogamous relationship, always use condoms to protect yourself and your partner. If you suspect that you have
been exposed to a sexually transmitted disease, tell the coordinator or doctor so that treatment can be started as soon as possible.

For many men and women with kidney failure, it was not possible to have children. Now, however, with a normal functioning kidney, pregnancy may be possible. Men and women should discuss birth control methods and potential pregnancy with the transplant physician. Since little current data exists on transplant patients and pregnancy, advice on whether or not to become pregnant must be made on an individual basis. In general, women are advised to wait at least two years after transplant before becoming pregnant to give their bodies time to adjust to the donated kidney and medications. IUDs (intrauterine devices) should not be used by female transplant recipients.

**SMOKING**

If you currently smoke, you should quit. Potential transplant recipients with heart disease or diabetes will not be considered for transplant until they stop smoking. If you smoke and wish to quit, discuss this with the transplant team. We may be able to recommend smoking cessation resources to help you. You should also avoid smoke-filled areas, and ask others not to smoke around you.

**PROTECTING YOURSELF FROM INFECTION**

In the first six to eight weeks after transplant, you will be on the highest doses of immunosuppressant medications. This is the time when you will be more likely to get an infection, but there are certain things you can do to protect yourself:

- Wash your hands thoroughly and frequently. This is the single most effective way to decrease the spread of germs and to prevent infection.
- Avoid sharing eating utensils and glasses or cups.
- Once home from the hospital, you may have visitors, but ask friends or family members who may have colds, flu, or any other suspected illness not to visit until they are well.
- Small children may expose you to colds and other illnesses. Remember to wash your hands frequently.
- Avoid large crowds of people for the first six to eight weeks after transplant. You may go to the store, to a restaurant, or to a place of worship, but try to plan your trip to avoid times when these places might be most crowded.
- Keep cuts and sores clean and dry. Inspect these areas regularly and notify the transplant team if you see any signs of infection such as: redness, tenderness, swelling or drainage.
- Normal sore throats and ear infections can turn into bigger problems in transplant patients because your immune system is
suppressed. Please notify the transplant team of any signs of infection such as: fever, shortness of breath, cough, sore throat, fatigue, headache, or flu-like symptoms. If you are nauseated or vomiting and cannot keep your medications down, notify the transplant team immediately.

- In most cases you may be around pets. Because of your lowered immune system, however, you should use caution when handling any animals or pets. Cats which are allowed to eat raw meat or prey can have an infection called toxoplasmosis, which may be passed on to humans through handling of fecal material in cat litter or soil. If possible, have a family member dispose of cat litter. Birds, such as parakeets, pigeons, and chickens, can also carry a fungus which can cause a serious infection, so avoid exposure to bird droppings. It is recommended that you not bring a new bird into your home after transplant.

- Avoid exposure to dust from old dry wall or plaster during renovation projects. There is a fungus called Aspergillus which can grow in plaster and dry wall that can cause a serious respiratory infection in immunosuppressed people.

- Wear a mask if you come in contact with molds, dust, or decaying matter.

**RETURNING TO WORK**

One of the goals of our transplant program is to help patients return to work. If your work does not involve heavy lifting, strenuous activity, or being around crowds of people, you may be able to return to work or school as early as three to four weeks after surgery. This decision should be made on an individual basis, after discussion with the transplant team.

Returning to work may be as easy as returning to a previous job. However, because of your illness, you may not have worked in long time, may lack current job skills, or may need to change jobs because of physical or other limitations. If so, you may benefit from career counseling. The social worker will be happy to assist you with a referral.

**TRAVEL TIPS**

If you plan to travel long distances for an extended period of time, please notify the transplant coordinator. We can tell you the location of the transplant center nearest your destination in case any problems should arise.

If you plan to travel overseas, contact the transplant team. Some required vaccinations may be harmful to transplant recipients.

When flying, always take your medications with you on the plane in case your luggage is lost in flight. Also remember to bring
extra medications in case your return is delayed or some medication is lost.

We suggest that you wear a medical alert bracelet or necklace and carry an ID card that identifies you as a transplant recipient. This identification should have the contact number of the Emory transplant team. It is a good idea to carry a list of your current medications with you at all times in case of emergency.

**ROUTINE MEDICAL CARE**

Routine medical care is important for early detection and treatment of disease. The transplant team is specialized in caring for the unique health needs of kidney transplant patients, however, we recommend that you regularly see a primary care physician for annual check-ups, including a complete health history and physical exam.

Be sure to tell all your health care providers that you are a transplant recipient and are immunosuppressed. Ask them if any prescribed medications or treatments would have an effect on your transplant or immunosuppressant medications. They should discuss your care with the transplant physician or coordinator before beginning treatment.

**Dental Care**

Be sure to tell your dentist that you have had a transplant and are immunosuppressed. To avoid tooth and gum problems, we recommend that you brush and floss daily as well as have dental visits at least every six months. Some transplant patients on cyclosporine experience problems with gum hyperplasia or tender, swollen gums. If problems do arise, you may need to see a periodontist (a dentist specializing in gum problems).

You will need to take a dose of antibiotics before any dental procedure, including routine cleaning. This is to prevent infections which can be caused when bacteria from the mouth get into the bloodstream. Call Outpatient Transplant Services prior to any scheduled dental appointments so that the appropriate antibiotic can be prescribed. In general, we recommend waiting six months after transplant before seeing a dentist for routine dental exam and cleaning.

**Vision Screening**

We recommend regular vision screening at least every two years or annually if you wear glasses or contacts. Prednisone and other medications can cause changes in eyesight, including blurry vision, cataracts, or glaucoma. Tell your ophthalmologist that you had a transplant so he or she may specifically test for these conditions. If possible, delay getting your lenses changed until at least six months after your transplant. By this time, any visual changes as a side effect of prednisone should have resolved.
Healthy Skin
One of the complications frequently seen in transplant recipients is changes in the skin. Prednisone can cause acne and make the skin more fragile, dry, and easy to bruise. Some of your medications may make your skin more sensitive and you may be more likely to develop skin cancers.

Skin cancer is the most common cancer in the United States. Prolonged exposure to the sun, especially if it results in sunburn and blistering, plays a key role in beginning skin cancer. Immunosuppression further adds to the risk of developing skin cancer. The majority of skin cancers occur on parts of the body not protected by clothing, such as the face, neck, forearms, and back of the hands.

We recommend that you use sunscreen with a Sun Protection Factor (SPF) of 30 or greater any time you will be outside in the sun. Also, wear a hat that will shade your face and neck.

Most skin cancers are easily treatable if detected early. If skin lesions develop, or you notice a mole that is changing in size, shape, or color, you will need to see a dermatologist.

You may also be more prone to developing mouth sores or ulcers, and thrush which is a yeast infection in the mouth. Please let the transplant team know if you notice any unusual lesions or ulcers on your skin or any sores or white patches in your mouth. Suspicious lesions should always be examined by a physician.

Bone Density Screening
Osteoporosis is common after transplant. Up to 60% of kidney transplant patients develop osteoporosis, as early as within the first 18 months after transplant. There are a number of factors that contribute to the development of osteoporosis, including hyperparathyroidism, which often affects renal failure patients on dialysis. Post-transplant, the medications you are taking to prevent rejection of the transplant can also contribute to the development of osteoporosis. Prednisone decreases new bone formation and Neoral® / Genfra® or Prograf® can increase resorption of bone. We recommend routine bone density screening to monitor for bone loss. A baseline bone density scan is recommended within the first one to three months post-transplant. Bone density scans are recommended every six months until the second year after transplant, then annually. Calcium and vitamin D supplements may be ordered to help prevent osteoporosis. If you show signs of osteoporosis, another medication from the family of drugs called bisphosphonates may be ordered to help treat and even reverse bone loss.
**Immunizations**

All transplant candidates should receive a pneumococcal vaccine to protect against pneumonia. We recommend that all transplant recipients and their family members receive yearly flu shots (unless allergic to eggs), and all recipients should also receive a diphtheria and a tetanus booster shot every 10 years.

However, you should not receive any vaccinations, even flu shots, without first talking with your transplant team. Transplant recipients should avoid live vaccinations because they can actually cause the disease they are meant to prevent. Live vaccines include: measles, mumps and rubella (MMR), oral polio (OPV), and the varicella and smallpox vaccines. Household contacts, siblings, or children of immunosuppressed transplant recipients should not receive either the oral polio vaccine (OPV) or smallpox vaccine because they are easily transmitted. Household contacts may receive the MMR vaccine, and children of transplant recipients can safely receive the chicken pox vaccine because person-to-person transmission does not occur. The Hepatitis B vaccine is strongly recommended in preparation for kidney transplant.

**Colon Cancer Screening**

The American Cancer Society recommends the following colorectal cancer screening guidelines for both men and women. Beginning at age 50, you should follow one of these three screening options:

- yearly fecal occult blood test plus flexible sigmoidoscopy every five years, or
- colonoscopy every 10 years, or
- double contrast barium enema every 5-10 years.

A digital rectal examination should be performed at the time of each screening sigmoidoscopy, colonoscopy, or barium enema examination.

People should begin colorectal cancer screening earlier and/or undergo screening more often if they have any of the following colorectal cancer risk factors:

- a strong family history of colorectal cancer or polyps (cancer or polyps in a first degree relative younger than 60 or in two first degree relatives of any age),
- families with hereditary colorectal cancer syndromes (familial adenomatous polyposis and hereditary non-polyposis colon cancer),
- a personal history of colorectal cancer or adenomatous polyps,
- a personal history of chronic inflammatory bowel disease.

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**IMMUNIZATION SCHEDULE:**

- **PNEUMONIA VACCINE:** one time only.
- **FLU SHOT:** annually.
- **TETANUS BOOSTER:** every 10 years.
FOR WOMEN ONLY:

Pap Smears
Women taking immunosuppressant medications may be at an increased risk of developing cervical cancer. Regular pap smears and gynecological exams are necessary for early detection and treatment of cervical cancer, as well as some early cancers of the digestive, respiratory, and renal systems. A pap smear is the primary test for detecting cervical cancer because there are usually no physical signs of this problem. Cervical cancer is 100% curable if it is detected early enough.

The transplant team and the American Cancer Society recommend annual pap smears and pelvic exams for all women over the age of 18. This should include a rectal exam to check for blood in the stool. Women who are or have been sexually active should have yearly exams, regardless of age. A urinalysis and complete blood count (CBC) should also be included in this annual exam.

We also recommend good health practices such as prompt treatment of vaginal and cervical infections, limiting the number of sexual partners, and using condoms to prevent sexually transmitted disease.

Breast Self Exam (BSE)
As many as 95% of breast cancers are accidentally discovered. All women should perform regular breast self-exams (BSE) monthly (usually seven to 10 days after each menstrual period for premenopausal women) as a routine good health habit. Your local physician or gynecologist should be able to instruct you in this practice. We also recommend a breast exam by a physician annually.

Mammography
A mammogram is a test for screening and early detection of breast cancer. It uses a very small, safe amount of radiation. The American Cancer Society recommends that all women have a baseline mammogram done between the ages of 35 and 39. Women aged 40 and older should then have a mammogram every year.
FOR MEN ONLY:

**Testicular Exam**
Most testicular cancers are discovered by men themselves. We do not know how to prevent testicular cancer, but if treated early, there is an excellent chance for its cure. The American Cancer Society recommends that all males over the age of 15 perform testicular self-examinations monthly. Your local physician can instruct you on this practice.

**Prostate Exam**
All men should have a rectal exam annually. During this exam, the prostate is examined to see if it is enlarged and the stool is checked for blood. All males over the age of 50 should also get a special blood test called a prostate-specific antigen (PSA) done each year. If there is a family history of prostate cancer, annual PSA testing should start at age 45.

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**TESTICLE/PROSTATE HEALTH SCHEDULE:**

**TESTICLE SELF EXAM:**
*every month.*

**RECTAL, STOOL, AND PROSTATE:**
*exam annually.*

**PSA EXAM:**
*after age 50.*
Other Helpful Information

MASON GUEST HOUSE
The Mason House is a private retreat that offers low cost housing for organ transplant candidates, recipients, living donors, and families. Guests who book one of the 15 bedrooms, each with a private bath, will find a comfortable bed-and-breakfast environment. In addition, a two bedroom suite is available with its own kitchen, living area and private entrance. Several bedrooms and bathrooms are wheelchair accessible. Continental breakfast is provided, but guests may cook their own meals. Other amenities include laundry facilities, TV’s in the gathering rooms, private phones, a VCR, stereo and a computer. The Mason House is a home-away-from-home, created to make transplant candidates, recipients and their families feel far away from a hospital environment, yet close enough to feel secure should they need medical assistance. Please call 404-712-5110 for reservations.

THE MENTOR PROJECT
What is the Mentor Project?
The Mentor Project provides one-on-one contact between people living successfully with a transplant and people who are new to the world of transplantation. The project pairs a “veteran” organ transplant recipient, primary caregiver or living donor with someone who is waiting for a transplant, a recent transplant recipient, family members of a transplant recipient or a living kidney or liver donor. Through these connections, even the smallest questions get answered, experiences are shared, and support is provided to both patients and families.

Who are mentors?
Mentors are organ recipients, parents or other supporting family members and living donors who are at least six months out from their transplant date or the transplant date of their loved one. Mentors attend a full day of training to learn how to draw on their personal experiences to address the needs of others that they mentor. Mentors are updated periodically on services and assistance available to transplant families within the transplant community, and the mentor network is an excellent connection to these resources.
How do I get a mentor?
If you live in Georgia, you can be referred to the Mentor Project by your social worker, transplant coordinator, clinical nurse specialist or physician. A mentor is never assigned without the consent of the potential mentee. Georgia residents may also call the Mentor Project and request a mentor directly.

For more information about the Mentor Project contact the Georgia Transplant Foundation at 1-866-(GATX411) or 770-457-3796.

JOBLINK
A career development and return-to-work program for transplant recipients in the state of Georgia

JobLink is an assistance program that helps Georgia transplant recipients and candidates return to the work environment. JobLink offers needed information and training in order for the transplant recipient to reach career goals.

The objective of JobLink is to provide transplant recipients and candidates a quick and successful re-entry into the work force. Skilled placement specialists evaluate work needs and provide both necessary skills training and access to the appropriate vocational and rehabilitation services.

JobLink offers access to the state's vocational rehabilitative services and provides a comprehensive return-to-work program — at no cost to you. The return-to-work program can be the link that completes the goal of transplantation in returning recipients to a productive lifestyle.

Services include:
• Career interest testing and development
• Assistance with Social Security issues
• Information on state vocational rehabilitation services
• Job skills training
• Resume development and interview techniques
• Job placement
• Early return-to-work programs
• Americans with Disabilities Act (ADA) awareness
• Post-placement intervention to ensure success
• Enrollment in Ticket to Work program

For more information, call 770-457-3796 or 1-866-428-9411. Your transplant social worker also will be happy to assist you with a referral.
HELPFUL WEBSITES FOR THE TRANSPLANT PATIENT

Emory Transplant Center
www.transplant.emory.edu

American Academy of Family Physicians
www.aafp.org/patientinfo

Infonet Johns Hopkins (support group links & 800 numbers)
infonet.welch.jhu.edu/advocacy-html

Health Answers
www.healthanswers.com

Healthfinder (U.S. Government site)
www.healthtouch.com

InteliHealth (Johns Hopkins)
www.intelihealth.com

National Library of Medicine (Health Info for Consumers)
www.nlm.nih.gov

Wellness Web: The Patient’s Network
www.wellweb.com

The United Network of Organ Sharing (UNOS)
www.unos.org

Coalition on Donation
www.donatelifeline.net

National Kidney Foundation of Georgia
www.nkfg.org

Search Engines
www.healthatoz.com
www.hon.ch
www.achoo.com

Kidney-Pancreas Related Web Sites
www.eGroups.com/list/kptx/info.html
www.transweb.orginsulinfree
**My Records**

Keeping records is very important. While you are in the hospital, please ask your nurse to help you record your weight, blood pressure and temperature every morning. You should also always know what your creatinine level is. Creatinine is a blood test that tells us how well your kidney is working. The lower the number, the better. Everybody’s creatinine will be a little different, so don’t compare yourself to others.

When you go home, please continue to record your daily weight, blood pressure and temperature. You will also receive copies of your blood work, so you may record your creatinine and other labs if you wish. Please bring these records with you when you come to clinic.

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