

Your guide to organ/tissue transplantation

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Introduction

The mission of the National Institutes of Health (NIH) is to improve health through biomedical research. The Organ and Tissue Transplant Program, a part of NIH, also works toward this goal by helping people with kidney (renal) failure and diabetes through transplantation research.

Research studies (protocols) are under way to develop better ways to prevent tissue or organ rejection. These efforts complement worldwide efforts to help transplant recipients live fuller, healthier lives.

Everyone treated in our program is a volunteer in an experimental study. Our staff strives to deliver state-of-the-art care to every patient. This handbook reflects our commitment to making your stay here as pleasant as possible. It contains important information to help you understand and cope with the challenging health issues you will face before, during, and after transplantation. Knowledge is powerful medicine, especially when paired with complex treatments to prevent transplant rejection.

This information will add to, but not replace, your close working relationship with the health care team. Call on them whenever you have a question or concern. They are always ready to help you.

History of transplantation

Since the early 1900's, it has been known that organs transplanted from one person to another were destroyed by the immune system. This process of destruction is known as "rejection." Though many attempts at transplantation were made up to 1955, none succeeded. During the 1940's, however, research into the cause of rejection showed that genes controlled rejection.

With this new knowledge, Dr. Joseph Murray performed the first successful kidney transplant between identical twins in 1955, a feat that earned him a Nobel Prize. Once it was shown that transplantation was technically possible, efforts began to prevent the immune system from rejecting the transplanted tissue.

The discovery of new drugs that suppressed the immune system made transplantation from unrelated donors feasible for individuals with kidney failure. Successes in kidney transplantation prompted doctors and surgeons from other specialties to work on other transplant treatments. As a result, doctors treating patients with life-threatening diseases of the heart, lung, and liver also began to offer transplantation as an option.

In the 1980's, other new drugs were found, which made transplantation an even more acceptable treatment choice. Although rejection remained a problem, these new drugs allowed doctors to

manage problems by raising the doses or combining the new drugs with current treatments. Rejection became more chronic than acutely life threatening. However, because the new drugs impaired normal immune system function, infection grew into a serious threat. Also, patients treated with potent immunosuppressive drugs had higher risk for certain cancers, especially skin cancers.

The overall national 1-year success rate for transplanted organs has stayed between 85 and 95 percent in recent years. Scientists, including those at NIH, are testing new ways to prevent rejection of organs or tissues while lessening the side effects of current treatment. The ultimate goal is to find a way to transplant life-saving organs and avoid rejection without increasing the risk of infection or cancer.

Pancreas/islet cell transplantation

Insulin was discovered by Drs. Frederick Banting and Charles Best and was first used in humans in January 1922. Although insulin has saved the lives of millions of individuals with diabetes, it treats the symptoms of the disease and is not a cure. Complications from diabetes, such as blindness, kidney failure, nerve damage, and heart attacks, still plague us. Clearly, better treatments are needed.

Pancreas transplantation has advanced over the past 15 years. However, the

surgery for this type of transplant is very complicated. Transplanting just the islet cells (insulin-producing cells in the pancreas) is much simpler. In fact, the islets are transplanted into conscious patients in the x-ray suite—patients are never even taken to the operating room. In the past, islet transplants have rarely succeeded. However, that poor success rate appears to be improving with a new technique being tested at NIH. Obtaining an adequate supply of islet cells is an ongoing problem. Also, drugs that prevent rejection can be toxic to islet cells. Scientists at NIH are working to overcome these problems.

The United Network for Organ Sharing (UNOS)

The United Network for Organ Sharing is a private agency that manages organ allocation in the United States. Transplant centers, organ procurement organizations, and certain transplant laboratories must follow established UNOS rules.

UNOS divides the United States into 11 regions; NIH is in Region 2. Local organ procurement organizations (OPOs) in each region help find and manage donors and distribute organs. The Washington Regional Transplant Consortium (WRTC) is the OPO for the Washington, D.C., area.

When a potential donor is found and the family gives consent to donate, information is sent to UNOS through the OPO. Plans are then made for fair and

equitable organ distribution. UNOS keeps a computerized system that guides organ distribution according to many factors. Compatible size and blood type are important for most organs. Livers and hearts are distributed according to severity of illness, as well as size and blood type.

Part 1: Evaluation for transplantation at NIH

Many people in the United States await a new kidney, pancreas, or islet cell transplant. Unfortunately, there are not enough organs and tissues for everyone who needs them.

Some people who need a new kidney ask a friend or family member to be evaluated as a potential donor. Kidneys from living donors usually work better and longer than organs from cadaveric donors even if the match is not as good. An evaluation process is needed for both the donor and the recipient to assure the best outcome.

Evaluating potential donors

All potential kidney donors must have these four characteristics: a blood type compatible with the recipient, no diseases that can be given to the recipient, two healthy kidneys, and the ability to live well with just one kidney. The tests we do will tell us if an interested friend or family member is a potential donor. Great care is taken to ensure that

potential donors have freely made the offer to donate.

Evaluating patients

Patients evaluated for transplantation undergo a series of tests and visits (consults) with other doctors, a dentist, and a social worker. A transplant coordinator will provide education to patients and families about transplantation and participation in research. This is a good time to learn more about NIH and our program's research. Ask questions freely!

Tests

Blood work

Blood tests help us evaluate compatibility between a donor and recipient. They tell us about the health of your kidneys and liver as well as your blood type, tissue type, and past exposure to viruses or diseases (such as hepatitis, chickenpox, or HIV)

Urine studies

Some patients make urine even though they need a new kidney. If you can give us a urine sample, we will check how well your kidneys filter waste. We will also check for infections.

Chest x-ray and EKG

These tests are done routinely on all patients to look for heart or lung problems.

Abdominal ultrasound

This test uses sound waves to check the size and shape of your kidneys.

Ultrasound also shows whether your gallbladder has gallstones that could cause problems after your transplant.

Echocardiogram

This is like the abdominal ultrasound. Sound waves are bounced off your heart to look at the size of your heart and how well it works.

Pap smear and mammogram

All women entering transplant protocols at NIH must have these tests. They should be done by a private doctor before visiting NIH as a transplant candidate. These tests should also be done yearly after transplantation.

PSA (Prostate-Specific Antigen)

This blood test should be done on all men over age 45 before transplantation and yearly after transplantation. The test measures a substance that may be a marker for prostate cancer.

PPD skin test

This test checks whether you have been exposed to tuberculosis. It must be done on each patient before transplantation. If you have a reaction to this test, you may need medication to prevent a more serious infection after transplantation.

Consults

You will need to visit other doctors who are specialists in the following:

Kidney diseases

Even though you may have a doctor who sees you regularly for kidney disease, you will meet with our program's

doctor who will help us manage your care after transplantation.

Diabetes specialist

If you need a pancreas or islet cell transplant or if you have diabetes, you will be seen by our diabetes specialist.

Transplant surgeon

One of our transplant surgeons will examine you to see which research studies you would fit in to. This doctor will also discuss your surgery with you.

Anesthesiologist

One of our transplant anesthesiologists may also see you. This doctor will ask whether you have allergies or smoke. This information helps the anesthesiologist use the safest way to put you to sleep during your transplant.

Dentist

To prevent dental infections after transplantation, your teeth and gums must be examined. A full series of dental x-rays may be taken to look for potential trouble spots.

You may need to undergo more tests to give these specialists the information they need to ensure the best possible outcome for your surgery. The transplant study you take part in may require more tests, too. Your transplant coordinator will help you schedule your pre-transplant tests and consults.

Part 2: Waiting for your transplant

For patients who cannot receive a transplant from a friend or family member, the waiting time for a suitable donor organ can be long—even discouraging. Some patients wait more than 3 years. Nevertheless, it is important to stay healthy before transplantation.

Staying healthy

If you smoke—quit! If you are overweight, exercise with your doctor’s guidance and start a diet recommended by our dietitian. Studies have shown that patients who exercise before transplantation recover quicker after this surgery. Ask your transplant doctors or coordinators what exercises are best for you. The better your condition at the time of transplant, the stronger you will be to handle the stress of surgery and hospitalization.

Staying in touch

Many patients waiting for transplantation at NIH are with the Department of Defense and live far from Washington, D.C. It is important for all patients to keep in contact with their NIH transplant coordinators, whether they live far or near.

Blood tests

You must send blood samples to us monthly, or sometimes weekly. These samples help us monitor your antibody level. (High antibody levels mean that your body may react with donor organs

and quickly reject them.) Our program’s research aims at “teaching” your immune system to accept its new kidney. Our researchers also want to understand why organs are accepted or rejected.

Your transplant coordinator will help you schedule the required blood tests at NIH. By talking with your coordinator before having tests done in your local area, you may be able to avoid having so many blood drawings.

Other tests

Some tests must be repeated each year as you wait for a transplant. Women must have yearly Pap smears; those over 40 must have yearly mammograms. Men over age 45 need annual prostate exams with a simple blood test.

Be sure to tell us the following:

1. Changes of address or phone numbers.
2. Changes in your dialysis center or frequency of dialysis.
3. If you are hospitalized.
4. If you go on a trip, where you will be and for how long.
5. Changes in your health or medications.

As you stay in touch with us, please keep us aware of changes in your health. Medical problems undisclosed until the day of transplant could cause surgery to be canceled.

Part 3: Before your surgery

Getting that important call

When a suitable donor kidney is found, you will be called by the transplant coordinator-on-call. This person will tell you how to come to NIH. You may be the first, second, or third in line for this kidney, and the coordinator will explain where you fit in this order. You will probably be told not to eat or drink anything for the next few hours.

Preparing for surgery

When you arrive at NIH, the nurses will start your preparations for surgery. You will be asked a series of questions and may need an EKG and chest x-ray, if these have not been done recently at NIH. You will shower or bathe with special soap and be given an enema. Patients who have been on dialysis may be dialyzed before surgery.

Several doctors will visit you to ask questions and do a physical examination. The anesthesiologist will also meet with you to discuss how you will be put to sleep for surgery.

Your nurses will teach you the following:

- coughing and deep breathing methods needed after surgery
- how to use a pillow to support your wound after surgery
- how to use the special breathing device (spirometer). You must use this often after surgery
- how to control your pain after surgery

- how to let your nurses know if pain is going away (on a scale from 1 to 10).

Your nurses will also talk to you about the procedure and the equipment that will be used in your room when you return from surgery: heart monitors, intravenous (I.V.) lines, blood pressure monitors, and special devices on your legs to prevent blood clots.

Part 4: Your surgery

You will be taken to the operating room on a stretcher. There, an operating room nurse and an anesthesiologist will meet you. You will be given some medication through your I.V. to help you relax. Antibiotics may also be given to you this way while you are prepared for surgery.

When you are in the operating room, one of the first things you will notice is that the temperature is cold. We will drape you with blankets to keep you warm. Also, the operating room is very bright. If the lights bother you, just keep your eyes closed. The nurses will explain everything to you.

When the surgeons are ready to begin your operation, you will get medicine through your I.V. lines. This medicine will make you sleep during the whole operation. You will be monitored very closely during the procedure. The doctors and nurses will constantly check your blood pressure, breathing, and heart rate. At times during surgery, a machine may help your breathing. This is routine during

surgeries like yours requiring general anesthesia. When surgery is over, you will breathe on your own.

Your new kidney will be placed in your abdomen on the lower right or left side, or possibly in the center. Your own kidneys will usually not be removed during this surgery. Most new kidneys begin working in the operating room. But some (up to 30 percent) take longer to work.

After surgery, you may notice that one of your legs is swollen. This is because it is retaining fluid. If your new kidney is put on the right side of your abdomen, your right leg may retain fluid. The same will be true for your left leg if your new kidney is implanted on your left side. Once your new kidney is working well, this extra fluid will go away.

After surgery

Immediately after surgery, you will be taken to the postanesthesia care unit (PACU). There, you will gradually wake up. PACU nurses will constantly check your blood pressure, pulse, and urine output while you recover. You will have a catheter (draining tube) in your bladder when you wake up, and you may feel pressure in that area. You will spend 1 to 2 hours in the PACU before you are taken back to your room.

The surgeon will talk with you and your family when you are in the PACU. You will be given medication to help lessen any pain.

On your unit

Once you are fully awake in the PACU, you will be transferred from the PACU

back to your unit. Sometimes, the doctors want a patient to go to the intensive care unit for a day or two after transplantation. Whether you are in the intensive care unit or on your unit, you will be closely monitored for the first 24 hours. The following will be attached to you: I.V. lines, heart monitor wires, a blood pressure line, and a catheter from your bladder. You will be able to control your pain with a pump our nurses will show you how to use.

When you come back to the unit, a nurse will work closely with you to assure good urine output by measuring your urine often. It is normal to feel pressure in your bladder from the catheter placed there. This tube will stay in your bladder for 3 to 4 days after surgery. When it is taken out, we will ask you to urinate every 2 hours. This prevents a pressure build-up on the connection between your bladder and your new kidney. Be sure to collect your urine so that the nurses can measure it.

As we continue to check on your new kidney, we will draw your blood every morning. This blood is usually drawn from one of the central I.V. lines, so you will not need a lot of needlesticks.

You may hear beeping noises from the machines used in your room, but we will try to give you plenty of time to rest. The first day after your transplant, your nurses will help you sit up and take short walks. *Do not try to walk the first time without your nurse.*

Part 5: Your new kidney

It is not uncommon for a new kidney to take a few days or even a few weeks to work normally after being transplanted. If this is the case with you, hemodialysis may be needed until your new kidney begins to work well. Because of the risk for infection, we will not do peritoneal dialysis after transplantation.

Once you and your new kidney adjust to each other, your nurses and transplant coordinators will teach you how to take care of yourself with your new organ. You will learn about signs and symptoms of infection and rejection, what your medications do, and general self-care at home. Some of this information is presented in a slide program. You will receive printed copies of the slides to review once you are home. Your family is invited to take part in these education sessions.

If you need more information than is covered in these sessions or in this material, please feel free to ask us.

Part 6: Possible complications after transplantation

As with any major surgery, there are possible complications after kidney transplantation. This section explains some of them.

Delayed graft function

Delayed graft function is not graft rejection. As mentioned before, it is not uncommon for a new kidney to delay working for several days, or even sever-

al weeks. Causes for delayed graft function include mild trauma to the kidney during removal, or receiving a kidney from an older donor. Usually, the kidney recovers slowly on its own.

Renal artery thrombosis

Blood clots may form in the renal artery of your new kidney within the first 2 or 3 days after transplantation. The most common symptom is a sudden decrease or stoppage of your urine output soon after your surgery. If your doctors suspect a blood clot, they will probably order a painless procedure called a renal ultrasound. This test looks at blood flow in the renal artery where the blood clot is suspected. Surgery may be needed to remove the clot so that your new kidney is not damaged.

Urine leak

Urine leaks are uncommon, but they may occur within the first few days after transplantation. They are caused by poor tissue healing of the connection between the newly transplanted kidney and your bladder. Symptoms include

- abdominal pain
- decreased urine output
- increased creatinine.

This problem is usually diagnosed with an intravenous pyelogram. Urine leaks are usually repaired with surgery.

Rejection

There are many forms of rejection. When rejection is detected early, we can

alter your medications to control it. You may not realize your kidney is being rejected. You may feel fine, but if your lab tests show high creatinine or Beta 2 levels, rejection is occurring.

Hyperacute rejection rarely happens because we check your blood often before the transplant. If this type of rejection occurs, it happens in the operating room or within a few hours after surgery. In most cases of hyperacute rejection, the transplanted organ fails.

Acute rejection may occur 4 days after the transplant; the greatest risk is during the first 6 months.

Chronic rejection develops slowly. Its cause is unknown, but many cases have been related to not taking medications properly. This type of rejection is difficult to treat.

Diagnosing rejection

Checking for rejection is done regularly at visits to your doctors and with lab tests. Because rejection often has no symptoms, it is important to keep your appointments. Early detection of rejection allows for better results.

Tests to detect rejection include

- blood tests to check for antirejection drug levels
- tests of your kidney function (creatinine and Beta 2)
- urinalysis
- renal biopsy.

Signs and symptoms of rejection

- decreased urine output
- swelling in ankles, feet, hands
- sudden weight gain
- weakness, fatigue
- flu-like symptoms
- fever
- racing pulse
- high blood pressure
- increase in creatinine and Beta 2 levels
- tenderness, warmth, swelling around or over the transplanted kidney

(Remember, there may be no symptoms of rejection.)

Controlling Rejection

You can do a few things to protect yourself from rejection.

- Follow your schedule for lab work and doctor/transplant clinic visits.
- Take all your antirejection medications exactly as prescribed.
- Report any changes in your blood pressure, pulse, and temperature.
- Notify your nurse or doctor at NIH whenever you get sick.

Do not take herbal medications, over-the-counter drugs, or prescription medications without first discussing them with the transplant doctors or coordinators at NIH.

Treating rejection

If you think you are having a rejection, and your local doctor confirms this, we will begin treatment depending on the severity of rejection:

- We may simply increase your current anti-rejection treatment.
- You may need to receive high doses of steroids intravenously at home.
- You may need to go the hospital for a course of intravenous treatment with thymoglobulin, OKT3, and Atgam.

Once treatment has started, you will have tests to find out whether these medications are working. Rejection usually resolves with treatment, but we may need to use several medications for a stubborn rejection.

Medications commonly used to prevent/treat rejection

prednisone

tacrolimus (Prograf, FK506)

CellCept (mycophenolate mofetil)

sirolimus (Rapamune, rapamycin)

cyclosporine (Neoral, SangCya, Sandimmune)

Thymoglobulin

Atgam

OKT3

azathioprine (Imuran)

cyclophosphamide (Cytoxan)

methylprednisolone (Solu-Medrol)

daclizumab (Zenapax)

Medications used after transplantation

acyclovir

ganciclovir

Septra, Bactrim

Mycelex Troche

CytoGam

pentamidine

Part 7: Going home

Soon you will be ready to go home!

Depending on where you live and how you feel, you may need to stay close to NIH for the first few weeks. Some patients need frequent visits to NIH because of their research protocols. Our social worker will help you and your family find suitable arrangements upon discharge from the hospital. You will be given instructions on when to return for clinic visits. NIH will also provide the medications and medical supplies you may need at home. You may call us at 301-496-1009.

Before being discharged, you will need to be able to do the following:

1. identify each medication you will be taking
2. state the purpose of each medication
3. understand and follow good hand-washing techniques
4. list symptoms of infection
5. describe symptoms of rejection
6. state when to call us at NIH to report problems

It is very important for you to learn about all your medications soon after your surgery so that you can go home sooner.

Part 8: Caring for yourself at home

Infections after transplantation

Leaving the hospital after a transplant can be exciting. You may be overwhelmed by all the instructions you will receive about how to take care of yourself at home. But by following them, you can help prevent complications and make your recovery more enjoyable for you and for your family.

The drugs you take to prevent rejection can also increase your risk for infection. The following information will help you recognize infections and take precautions to stay healthy and infection-free.

Good handwashing is the first step to preventing germs from entering the body. This is important for your family members, too. Germs lie on surfaces of countertops, doorknobs, handrails, and even on money— things we touch every day. Washing your hands for about 15 seconds with an antibacterial soap and water will greatly reduce the chances of infection.

Watching for infections: wound care

For the first few weeks after your transplant it will be very important to care for your surgical wound. A wound infection can be serious. Keep your incision site

clean and dry. Wash the area with soap and water, avoiding deodorant soaps or other products that may irritate sensitive skin.

Symptoms of surgical wound infection

- site becomes red or hot to the touch
- drainage
- swelling
- tenderness
- fever

Be certain to notify your transplant coordinator or doctor if any of these symptoms develop.

Urinary tract infections

A common complication after transplantation is urinary tract infection.

Symptoms

- burning or painful urination
- cloudy, concentrated, or foul-smelling urine
- frequent urination with persistent abdominal or pelvic pain
- blood-tinged urine
- fever

Cytomegalovirus (CMV)

One of the most common viral infections after transplantation is a disease called CMV. Many people in the United States have been exposed to CMV. During your transplant evaluation, you will have a blood test to determine previous exposure to this virus.

After transplantation, the risk for this disease becoming reactivated is high because the immune system is suppressed. CMV can also be transmitted through the donor organ you receive if the donor was exposed to the disease. If you have never had a CMV exposure but your donor did, you may develop the disease. If you were exposed in the past, the disease may reactivate.

Throughout your posttransplant care, CMV blood tests will be done regularly to be sure that this disease is not active. If you have any flu-like symptoms, please report them to your transplant center. We will do blood tests to determine if you need antiviral medications such as ganciclovir or acyclovir.

Immediately after your surgery, you may receive anti-CMV drugs if you or your donor have been exposed to the disease. This treatment may be restarted if you have a rejection episode requiring high doses of immunosuppressive medications. Your transplant center should follow you closely for infections such as CMV. By keeping in close touch with us, you can alert us to potential problems.

High blood pressure

High blood pressure (hypertension) is one of the most common posttransplant complications.

Causes

- changes in kidney function
- side effects from your medication

- too much sodium (salt) in your diet

Symptoms

- dizziness
- headache
- swelling of your hands, legs, and feet

Treatment

- Your doctors at NIH will prescribe medications to lower high blood pressure.
- Continue on a low-sodium diet.

Heart disease

There have been reports of kidney recipients developing heart diseases such as congestive heart failure, strokes, and heart attacks. Age, gender and hypertension all contribute to the development of heart disease. But you can control some of the risk factors by

- not smoking
- keeping your weight within a range recommended by a dietitian
- exercising regularly
- staying on your recommended diet.

Cancer

The risk for developing cancers may be increased by long-term use of standard anti-rejection medications. These medications suppress the immune system so that it cannot easily recognize malignant cells. The most common cancers reported in transplant recipients include skin cancers, cervical cancers in women, solid organ tumors, and lymphomas.

To decrease the risk of serious complications from cancers, you can:

- have annual Pap smears and mammograms (women)
- have annual prostate exams (men)
- report any unusual lumps or pains
- have annual colorectal exams (recipients over age 50)
- carefully examine your skin regularly for new moles or changes in the shape, color, or patterns of any mole.

Osteoporosis

Osteoporosis is a disease that causes bones to become thin and brittle. This is especially a problem for women after menopause. It can also be a problem for anyone who takes steroids. When bones become thin and brittle, they break more easily. This is why it may be important for some patients to take calcium supplements or other medications to help decrease bone wasting.

Steroid-induced diabetes

For patients with a family history of diabetes, or for those who have been on a diet to control diabetes, insulin may be needed shortly after transplantation if you are taking high doses of steroids.

Symptoms of high blood sugar include:

- increased thirst
- increased appetite
- weight loss
- frequent urination.

Symptoms of too much insulin include:

- headache
- sweatiness
- shakiness

Your Medications

1. Take your medications as directed.
2. Use the medication chart given to you by the transplant nurses.
3. Call NIH before taking any over-the-counter medications or before filling a prescription written by another doctor. There may be drug interactions that can be avoided.
4. Do not take herbal medication without first discussing them with NIH doctors or staff.
5. If you miss a dose of medication, especially a medication that prevents rejection, call the transplant coordinator weekdays from 8 a.m. to 5 p.m. at 1-800-451-3416. After 5 p.m. and on weekends or holidays, call 1-877-553-3866. We will help you determine what to do next.

Remember: Always take your antirejection medications at the scheduled time, but do not take antirejection medication before having your blood drawn on mornings when you are scheduled for lab tests.

Rejection still may occur even though you have followed all our instructions. Just let us know and we can intervene with several options.

- faintness
- sleepiness.

If you develop diabetes while taking steroids, the disease may improve after the steroid doses are reduced.

This may seem like a lot to remember. But as you become more familiar with your care, it will get easier. Together, we will work with you to keep your new kidney healthy.

Part 9: Life after transplantation

After getting your transplant, your lifestyle will change. The biggest change may be the increase in free time you now have without dialysis appointments or preparing your exchanges for peritoneal dialysis. Most patients feel renewed, healthier, and more energetic. Feeling better physically actually improves your mental health, as well. But to maintain these improvements, you must follow exercise, dietary, and medical guidelines.

Exercise

After transplantation, the quality of life improves for patients who exercise regularly. Studies at the University of California at San Francisco show that exercise helps decrease stress and increase a feeling of well-being. It also helps with weight loss and weight maintenance. Your transplant doctors will recommend an exercise plan to fit your new lifestyle. To keep your new “lease on life,” exercise at least three times a week. Long walks are a wonderful way

to exercise. Walking with a friend or family member is also a good time to share thoughts and feelings. It is a great way to build or rebuild relationships.

The National Kidney Foundation and several pharmaceutical companies join together each year to sponsor the Transplant Games. All participants are transplant recipients with a new pancreas, kidney, heart, lung, liver, or small bowel. Recipients compete in triathlons, basketball, badminton, bowling, biking, golf, and other sports. These games help show the world that transplantation works. Through these games, recipients like you have another means to be spokespersons for transplantation. The games are held nationally and internationally, summer and winter. Ask your transplant team members for information on how to prepare for and take part in these games. Many areas nationwide help sponsor interested participants.

Diet

For the first month after surgery, your goal is to eat enough of the right foods so that you can heal, maintain your strength, and increase your energy level. As your new transplant begins to work, food will taste better and your appetite will improve. For kidney transplant recipients, having a diet that is low in fat and high in magnesium and phosphorous is important.

Below are examples of foods that are high in magnesium and phosphorus.

Foods high in magnesium and phosphorus	
Magnesium tofu all-bran cereal nuts wheat germ spinach peanut butter	Phosphorus milk and milk products potatoes yogurt wheat germ macaroni and cheese sunflower seeds

Monitoring yourself

Temperature

- If your temperature is more than 100°F, lie down and rest. Take your temperature again in 30 minutes.
- Your temperature will be highest between 4 p.m. and 9 p.m. and lowest in the morning when you wake up.
- Notify NIH if you have shaking chills, even if your temperature is normal.
- Do not take your temperature after exercising, eating or drinking, or chewing gum. These activities raise your temperature.

Blood pressure

Your blood pressure may be highest in the morning. Record your blood pressure:

- when you wake up
- 2 hours after taking your blood pressure medication
- in the evening.

Call NIH if the lower number of your blood pressure is greater than 100.

Weight

- Weigh yourself at the same time each day.
- Call the transplant center at NIH if you gain more than 2 to 3 pounds in 24 hours.
- Exercise is important for weight control and weight loss.

Outdoor activities

- Wear sunscreen when working outside or playing games or sports.
- In hot weather, drink lots of fluids to prevent dehydration and to keep your new kidney happy.
- Wear gloves when gardening. Dirt can carry harmful bacteria and fungus.
- Treat your pets to prevent them from picking up ticks. Ticks can carry serious diseases.
- Wash all fruits and vegetables—even prepackaged ones.
- At picnics, be sure that meat is thoroughly cooked and that any mayonnaise-based products are cooled. This way, unwelcome bacteria will not make your food their home.
- Do not store your medication in the heat or direct sunlight. Heat and light can make medications less effective.

What to do if you are hospitalized outside of NIH

- Tell the doctors and nurses that you have had a transplant and are in a research protocol at NIH.

- Give the hospital staff our phone number: 301-496-1009.
- You or your family must notify us if you are admitted to a hospital.

When to call the transplant coordinator

If you notice symptoms of infection:

- fever higher than 100°F (38°C)
- chills
- tenderness or drainage at access site or incision site
- cough with sputum
- diarrhea
- painful urination
- sore throat
- earaches
- changes in your ability to think clearly
- bloody urine
- skin rashes or lesions
- mouth sores
- exposure to someone with an infectious disease such as chickenpox or tuberculosis
- shortness of breath
- increased fatigue.

If you notice symptoms of rejection:

- weight gain of more than 2 to 3 pounds in 24 hours
- pain over the site of your new kidney
- decreased urination during the day
- swelling in your hands and feet

- swelling in your abdomen
- bloody urine.

If you have any of these symptoms:

- shortness of breath
- vomiting
- bloody or dark stools
- increased or decreased heart rate
- skin growths or changes in moles
- abdominal pain
- severe headaches or blurred vision.

If you have questions about medications:

- if you want to take herbal medications or health food supplements
- if the instructions for taking your medications are unclear
- if you are given a prescription by another doctor or if an over-the-counter medication is suggested
- if you are unable to take your medications
- if your medication supply is low.

How to control infections

- Wash your hands! This is important for both you and your family members.
- Avoid handling pet waste. This includes emptying kitty-litter boxes and bird cages. Wash your hands well after petting animals.

Tips for avoiding the flu or colds

- Get a flu shot every year.
- Avoid crowded areas such as malls and stadiums during cold and flu season.

- Avoid people who have sore throats or colds.
- Do not share utensils or drinking glasses.
- Do not allow anyone to use your thermometer.
- Ask family members to throw away their dirty tissues promptly.

Returning to work after transplantation
Many patients with serious health problems such as kidney, heart, or liver disease cannot work and must go on disability or Medicare while waiting for a suitable donor. Due to the preexisting disease clause in most policies, getting health insurance was also a problem. In 1997, President Clinton signed a bill making it possible to regain private health insurance even with preexisting conditions and after a long illness. Because of this, many transplant recipients have been able to return to work.

Medicare covers the cost of posttransplant medications for 3 years only. Bills have been put before Congress to extend Medicare coverage for transplant medications. But while this extension may occur in the future, most transplant recipients are expected to return to work or school after transplantation. Private health insurance is more likely to provide continued medication coverage.

The transplant social worker will be happy to give you information on returning to work and on job retraining, if needed.

Sexual adjustments after transplantation

Your renewed energy will probably allow you to have a greater interest in sexual activity. This activity will not hurt your new kidney nor will it increase the likelihood of rejection. If you have more than one sex partner, you must protect yourself from the risk of infections such as sexually transmitted diseases by using condoms. Diseases such as hepatitis, herpes, AIDS, and gonorrhea can all be transmitted sexually. Transplant recipients have an increased risk for infection and should protect themselves.

- You may resume sexual activities 4 to 6 weeks after receiving your transplant.
- Be certain to discuss birth control methods with your transplant doctor or coordinator.
- Women who would like to become pregnant after transplantation should discuss this with their transplant doctor or coordinator.

Studies have shown that women can have successful pregnancies after transplantation. But the best outcomes have been reported in recipients who wait at least 2 years after their surgery. There have been no reported problems for male transplant recipients who wish to father a child. Men can father children at any time once they resume sexual activity.

There have been no reports of increased birth defects among children of transplant recipients.

Traveling with a transplant

Returning home to family and friends is often the first traveling you will do after your transplant. However, you may begin traveling more—for work or pleasure. Traveling can not only take you to new places; it can also lead to potential problems for your immune system.

Because you are immunocompromised, you need to be alert and sensible when traveling.

For example, when taking public transportation, realize that many people will be traveling with you, sometimes in close spaces such as buses, trains, and planes. Air is recirculated in these close spaces, which means you may be breathing air containing viruses and bacteria from other passengers. For the first year after transplantation when your immunosuppression is highest, we recommend that you avoid mass transportation whenever you can. If you decide to travel, it may be advisable to wear a mask to filter the air as much as possible.

Also, travel can take you across several time zones. This may affect when you take your medications. For the first day, keep your watch set on your own time zone and take your medication as usual. On the second day, reset your watch ahead an hour or two. Do this each day

until you reach your new time zone. Medications should be taken within an hour of the prescribed time, so when you are changing time zones, keep this in mind.

Travel outside the United States poses health risks to all travelers, whether or not they are immunocompromised, so it is wise to take extra precautions. Some countries require actual written prescriptions for medications brought into their countries. Check with your transplant coordinator or doctor about rules for traveling internationally with medications. Your transplant team can also tell you how to contact transplant centers and transplant doctors in the countries you will visit.

Before traveling outside the United States, notify your transplant center several weeks in advance. This will give the staff time to find out if the Centers for Disease Control and Prevention (CDC) recommends special vaccinations.

Part 10: Writing to your donor family—tips for transplant recipients

As a transplant recipient, you may wonder if you should communicate with the family who donated this gift. This is a very personal decision, and it may be hard to know just what to say.

Deciding to write to your donor family. Donor families often call the organ procurement organization (OPO) to ask how

recipients of their loved one's organs are doing. They want to know if the recipients are okay and that their decision to give this wonderful gift of life was the right one. Letting the donor family know you are doing well is a gift to them.

What to say—some guidelines

1. Use only your first name.

Until a comfort level is reached, it is best not to identify yourself with your full name. Do not include your address or telephone number.

2. You may wish to acknowledge the donor family's loss and thank them for their decision to donate.

3. Begin by stating that you received a kidney, kidney/pancreas, or islet cell donation.

You may wish to tell the family how long you waited for your transplant.

4. You may wish to tell the family how the transplant improved your health.

Tell them if you returned to work or school or if you had another birthday. You may even want to share a big event such as a family wedding or birth that you enjoyed since receiving your transplant.

5. Write sentences that are easy to read.

You do not need to write more than one or two paragraphs. Just thanking the family and telling them how you are doing is often enough for the first letter.

6. You may choose simply to send a card of thanks. Select a card in which the verse speaks for you.

Mailing your card or letter

1. Place your card or letter in an unsealed envelope.
2. On a separate piece of paper, write your full name and the date of your transplant. This is so that your transplant coordinator can help the OPO identify the donor family.
3. Place these items in a larger envelope and mail them to your transplant coordinator at NIH.

How the letter reaches the donor family
Give the letter to your transplant coordinator. The letter will then be sent to the OPO that helped the donor family with donation arrangements. This organization often stays in touch with the family for several months or even years. The donor family will be asked if they would like to receive your letter. Families seldom refuse, and they may write back through the OPO.

If the donor family answers

The donor family may or may not respond. Some families want to know how you are doing but do not wish to write back. Some families have said that hearing from recipients helps them with their grief. Remember, they will be contacted by the OPO to determine if they wish to receive a letter from a recipient. Most want this—they just may decide not to write back.

If you and the donor family want to meet After writing to each other, some donor families and recipients decide to meet. This is done with the assistance of the OPO. These meetings usually happen after a year or more of exchanging letters. It is up to both the donor family and the recipient to decide if they will meet. While this meeting is not necessary, it is an option you may wish to pursue. If we can help you in any way, please let us know.

Resources

Clinical Center Services

Social Work Services

A social worker is available to help you and your family with travel and housing plans during your stay at NIH. You may learn more about social support groups and individual or family counseling by speaking with the transplant social worker.

Spiritual Ministry

The Clinical Center Spiritual Ministry Department provides religious and spiritual care for patients, their families, and other loved ones while they are under the care of the Clinical Center. Our interfaith chapel is located on the 14th floor. Worship services take place on the following schedule:

- Catholic Sunday-Friday at 11:15 a.m.; Saturday at 4 p.m.
- Islamic Monday-Friday at 2 p.m.
- Protestant: Sunday at 10 a.m.

- Interfaith: Wednesday at 3:30 p.m., group meditation; Thursday at 12:30 p.m., spiritual reflection

- Other faith groups: As arranged

Our chapel is open 24 hours a day. Call the Spiritual Ministry Department at 301-496-3407 for more information.

Rehabilitation Medicine Department

The Rehabilitation Medicine Department also can provide you with services.

Among the staff available to you are

- occupational therapists
- recreation therapists
- speech/language therapists
- vocational counselors
- physical therapists.

For information about the Washington, D.C., area, ask your transplant nurse to call the recreation therapist. This staff member will help you and your family plan activities when you are on pass from the Clinical Center.

Your transplant team

transplant surgeon

transplant doctor

transplant coordinator

social worker

pharmacist

recreation therapist

nurses

The phone number to our unit is
301-496-1009 or 1-800-451-3416.

Glossary—terms you will hear during your care

Allograft—An organ transplanted between two members of the same species.

Antibody—A substance in your immune system that helps the body fight infection and foreign substances.

Antigen—A substance within your body that triggers a response from your immune system.

Biopsy—Taking tissue for examination under a microscope to find out if there is rejection or disease.

Immune response—A reaction to diseased tissue handled by the immune system.

Immunosuppression—Holding back the immune response with medication.

Intravenous (I.V.)—Inside a vein. Usually, this means inserting a thin tube into a vein to deliver medication and fluid into the body.

Rejection—An immune response against transplanted organs or tissue.

Sensitized—An immune response against an antigen to which there has been previous exposure.

Tissue typing—A blood test done to find the similarities or match between a potential donor and a recipient.

Information/website directory

American Association of Kidney Patients
100 S. Ashley Drive
Suite 280
Tampa, FL 33602-5346
1-800-749-2257
<http://www.aakp.org>

American Diabetes Association
1701 N. Beauregard Street
Alexandria, VA 22311
1-800-342-2383

National Foundation for Transplants
1102 Brookfield Road, Suite 200
Memphis, TN 38119
1-800-489-3863
<http://www.transplants.org>

National Kidney Foundation
30 East 33rd Street
Suite 1100
New York, NY 10016
1-800-622-9010
<http://www.kidney.org>

Transplant Recipients International
Organization, Inc. (TRIO)
1000 16th St. NW
Suite 602
Washington, DC 20036-5705
1-800-TRIO-386
<http://www.trioweb.org/>

United Network for Organ Sharing
110 Boulders Parkway
Richmond, VA 23255-8770
1-804-330-8500
<http://www.unos.org>

Washington Regional Transplant
Consortium
8110 Gatehouse Road
Suite 101W
Falls Church, VA 22042
703-641-0100
<http://www.wrtc.org>

This information is prepared specifically for persons taking part in clinical research at the National Institutes of Health Clinical Center and may not apply to patients elsewhere. If you have questions about the information presented here, talk to a member of your health care team.

Products/resources named serve as examples and do not imply endorsement by NIH. The fact that a certain product/resource is not named does not imply that such product/resource is unsatisfactory.

National Institutes of Health Clinical Center
Bethesda, MD 20892

Questions about the Clinical Center?
<http://www.cc.nih.gov/comments.shtml>
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