Kidney Transplantation
A Patient Handbook
Welcome

Welcome to the Kidney Transplant Program at Northwestern Memorial Hospital. A kidney transplant can help make patients with end-stage kidney disease live better and longer.

This handbook will help you understand:
- What is involved in the kidney transplant process
- What it means to live with a transplanted organ
- The risks and benefits of a kidney transplant
- Your role in taking care of yourself and your new kidney after transplant

Once you understand this information, you will be ready to make the decisions about your health that are best for you. This is called informed consent. This handbook helps provide you with the information you need to make the decision to undergo a kidney transplant.

This handbook provides you and your family with important information about your kidney transplant.* It describes:
- The evaluation and listing process
- Your time on the waiting list
- Your hospital stay
- How to take care of yourself at home after the transplant

Know that there are other treatment options for you. You have the right to know what those options are. Perhaps you may choose a treatment other than transplant or you may choose no treatment at all. As always, you have the right to change your mind at any time.

The entire multidisciplinary transplant team, which is referred to as “transplant team” throughout this handbook, is here to help you with your decisions and your care. The team will provide you with the best care possible before and after your kidney transplant. Your transplant team is a group of healthcare professionals, who have special training and experience in transplantation, including:

- Nephrologists
- Transplant surgeons
- Transplant nurse coordinators
- Nurse practitioners
- Staff nurses
- Registered dietitians
- Licensed social workers (LSWs)
- Licensed clinical social workers (LCSWs)
- Clinical coordinators
- Patient financial liaisons
- Physical therapists
- Occupational therapists
- Pharmacists

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

Para asistencia en español, por favor llamar a el departamento de representantes para pacientes al 312-926-3112.
During and after your hospital stay, the transplant team welcomes any questions you may have. Please contact us at 312-695-0828.

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

### Transplant Physician and Surgeon On Call

**On call** means

*Available to you…*

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

### Opportunities for Your Feedback

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

There are several ways for you to provide feedback.

- Please feel free to take one of the Patient Comment Cards that are found in the waiting area in our outpatient clinic.
- A Patient Satisfaction Survey will be mailed to your home after you leave the hospital.
- You can share your feedback by calling the Patient Representative department at 312-926-3112.
- Feel free to call any member of the Kovler Organ Transplantation Leadership Team:
  - Lead transplant nurse coordinator: 312-695-0828
  - Director: 312-695-4383

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

Each of your two kidneys is about the size of a clenched fist. Your kidneys lie under your ribs in the back, just above the waistline, with one kidney on each side of your spine. (See Figure 1.) Each kidney usually has one renal artery that supplies it with blood. One renal vein returns the blood to the general circulation.

Figure 1

Normally, kidneys help your body:
- Maintain a balance of water and chemicals, called electrolytes
- Filter the body’s waste products out of the blood, which then leave the body in the urine
- Keep a steady blood pressure
- Secrete erythropoietin, a hormone needed to make red blood cells
- Maintain strong bones

There are more than one million nephrons inside each kidney. These nephrons are special filtering units that perform the work inside the kidneys and make urine. Urine travels from the kidneys by tubes called ureters to the bladder, where it leaves the body.

When nephrons stop working, this is called end-stage renal disease (ESRD). There are many causes of ESRD. Your nephrologist, or kidney specialist, can talk to you about why your kidneys failed.
Symptoms and Complications of Kidney Disease

Kidney disease can cause:
- Fluid overload
- Swelling (edema) of hands and legs
- Anemia, which is low red blood cell (RBC) count
- Chronic fatigue (weakness and muscle loss)
- Osteoporosis

See Table 1 for more details about potential complications. Remember that the risk and complications differ with each patient.

Table 1: Complications of Kidney Disease

| Anemia: Decreased number of red blood cells (hemoglobin) can cause: |
| Fatigue |
| Shortness of breath |
| Dizziness |
| Headache |
| Difficulty sleeping |
| Fast heart rate |
| Low blood pressure |
| Fluid Overload and Edema: The kidneys are not able to rid the body of enough water. |
| Hypertension: High blood pressure |
| Osteoporosis: With kidney disease, there is a calcium imbalance in the blood that can weaken the bones. |
| Sexual: |
| - Loss of sex drive (libido) |
| - Menstrual cycles may stop in women. |
| - Men may suffer impotence. |
| Psychosocial/Financial: |
| - Inability to work due to dialysis schedule |
| - Inability to get health, life or disability insurance due to chronic illness |
| - Child-care issues because of your dialysis schedule |
| Fatigue: Being tired all the time even after you rest |

When kidneys stop working, treatment is needed. Your options include dialysis or, possibly, a kidney transplant. Dialysis filters, or cleans, your blood. This prevents waste products from building up inside of you and damaging your health. The 2 types of dialysis are hemodialysis and peritoneal dialysis. To select the right dialysis therapy, several things need to be considered. These include your work, lifestyle, other medical conditions and personal preference. Your kidney doctor (nephrologist) will talk to you about the options.

Kidney transplantation restores the functions of the kidney. With a new kidney, you should not need dialysis any longer and you should have a better quality of life.
Indications for Kidney Transplantation
You will be considered for a kidney transplant if:

- Other treatments for kidney disease did not work.
- Other treatments are not expected to work.
- A transplant could improve your quality of life.

Every potential kidney transplant candidate will be evaluated by a team of specialists. The team will work together to weigh the risks and benefits of a kidney transplant.

Criteria for acceptance as a kidney transplant candidate are:

- A kidney transplant could improve your quality of life.
- You have no other diseases that cannot be treated.
- You are not so sick that you are not likely to survive the transplant surgery.
- All other medical or surgical treatments either have not worked or are not a good choice for you.
- There are no other contraindications.
- You and your support systems (family, friends) understand and accept the risks of having a kidney transplant.
- You and your support systems are fully committed to and compliant with what is needed before and after the transplant, to make the transplant a success. This would include access to funding for the transplant procedure, post-transplant medicines and other healthcare costs. The social worker and patient financial liaison may be able to help find other ways to pay for your care.*

Never will race, ethnicity, religion, national origin, gender or sexual orientation have any part in deciding if a patient is a transplant candidate

Contraindications for Kidney Transplantation
A kidney transplant is not an option for patients who have:

- Severe, untreatable heart or lung disease
- Active or uncontrollable cancer
- Untreatable mental illness
- Alcohol or drug addiction
- Severe neurologic deficit
- Severe peripheral vascular disease (PVD)
- Uncontrollable infection that will not go away with a transplant
- Uncontrolled HIV infection with AIDS despite optimal medical therapy
- Irreversible brain disease or damage
- Failure of other organs that will not improve with a transplant
- BMI greater than 45

*See the Insurance/Financial Support section found on page 14.
Other conditions that may disqualify you from getting a kidney transplant include:
- Age greater than 70 with other serious illnesses
- Obesity (BMI between 40-45) depending on other health risk factors
- Chronic active Hepatitis B

If you would like a copy of our selection criteria, please ask a member of the transplant team.

**Results of Kidney Transplantation**
About 90% of all transplanted kidneys still function 1 year after a transplant. We will provide you with Northwestern Memorial’s most recent results as listed in the Scientific Registry of Transplant Recipients (SRTR). You also can go to the SRTR Web site www.srtr.org to view results from Northwestern Memorial as well as from all other transplant centers in the United States. This database is updated every 6 months.

**Risks of Kidney Transplantation**
The transplant process includes a complete evaluation. This includes blood tests and exams. The transplant team will review all screening and test results. If the team recommends a transplant for you, it is because they believe you:
- Are likely to do well
- Have a good chance for a better quality of life

However, a kidney transplant is major surgery. There may be risks, including complications or even death. You need to know about these as well.

**Potential Complications**
Complications of kidney transplantation can occur early, in the first 3 month after your transplant or later, beyond the 3 month post-transplant period.

**Early complications can include:**
- Primary non-function (the kidney never works)
- Delayed kidney function (the kidney doesn’t work right away)
- Bleeding that requires surgery
- Clotting of major blood vessels to the kidney
- Rejection (usually in first 3 months)
- Infections

**Late complications can include:**
- Rejection
- Infections
- Recurrent disease
- Kidney disease and other side-effects of anti-rejection medications
- Cancer
- Diabetes
- High blood pressure
The table below lists some of the complications that may occur after a kidney transplant.

### Potential Complications of Kidney Transplant Surgery

<table>
<thead>
<tr>
<th>Surgical</th>
<th>Medical</th>
<th>Psychosocial / Financial</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Death</td>
<td>▪ Fatigue</td>
<td>▪ Post-surgical depression related to coping with complications of:</td>
</tr>
<tr>
<td>▪ Bleeding</td>
<td>▪ Nausea and vomiting</td>
<td>- Surgery</td>
</tr>
<tr>
<td>▪ Infection</td>
<td>▪ Heart attack, stroke or major blood clot(s)</td>
<td>- Medications</td>
</tr>
<tr>
<td>▪ Pain</td>
<td>▪ Cardiac arrhythmias and cardiovascular collapse</td>
<td>- Lifestyle changes</td>
</tr>
<tr>
<td>▪ Hernia</td>
<td>▪ Pneumonia</td>
<td>- Feeling that you are a burden</td>
</tr>
<tr>
<td>▪ Complications of general anesthesia, including brain damage or death</td>
<td>▪ Damage to other organs and organ failure</td>
<td>- Body image</td>
</tr>
<tr>
<td>▪ Need to stop the surgery</td>
<td>▪ Failure of the new kidney to work</td>
<td>- Family tensions</td>
</tr>
<tr>
<td>▪ Need to return to the operating room for reasons such as:</td>
<td>▪ Rejection of the transplanted kidney</td>
<td>▪ Loss of work or inability to work due to:</td>
</tr>
<tr>
<td>- Bleeding</td>
<td>▪ Primary or recurrent cytomegalovirus (CMV) or BK virus</td>
<td>- Illness</td>
</tr>
<tr>
<td>- Wound breakdown</td>
<td>▪ Need for re-transplantation</td>
<td>- Evaluation testing</td>
</tr>
<tr>
<td>- Infection</td>
<td>▪ Blood clots causing the kidney to stop working</td>
<td>- Surgery</td>
</tr>
<tr>
<td>- Urine leaks</td>
<td>▪ Unidentified donor-related risks for reasons such as:</td>
<td>- Recovery time</td>
</tr>
<tr>
<td>▪ Need for blood products during surgery</td>
<td>- Unreported illnesses by donor family</td>
<td>▪ Financial and emotional concerns due to loss of work</td>
</tr>
<tr>
<td>- Risk of blood-borne viral infection</td>
<td>- Unknown viral or bacterial infection</td>
<td>▪ Inability to obtain future employment or afford health, life or disability insurance</td>
</tr>
<tr>
<td>▪ Need to be on a ventilator</td>
<td>- Unknown cancer</td>
<td>▪ Inability to afford medication</td>
</tr>
<tr>
<td>▪ Surgical scars at the incision site</td>
<td>▪ Chronic rejection</td>
<td>▪ Financial risks or childcare costs due to the need for follow-up care</td>
</tr>
<tr>
<td>▪ Damage to the nerves in your legs (often short-term)</td>
<td>▪ Medication side-effects</td>
<td></td>
</tr>
</tbody>
</table>

A few of these complications are more common.

**Wound problems.** Your incision may not heal easily or it might open. You may need surgery to repair the incision or you might require dressing changes while the wound gradually closes and heals.
**Rejection.** A major concern after transplant surgery is the risk of organ rejection. Rejection happens when your body stops accepting your new kidney. When this happens, your immune system “attacks” your new organ, as if it doesn’t belong in your body. This triggers your body to make **white blood cells** and **antibodies** that harm your new kidney.

- **Acute** rejection often happens in the first several months after transplant. But rejection can occur at any time. It is important to always take your medicines to help guard against rejection. Most acute rejections can be reversed with higher doses of anti-rejection medicines or with other medicines. Treatment often requires blood work and a biopsy to confirm the diagnosis. In some cases you need to come to the hospital for treatment.

- **Chronic** rejection sometimes develops later. This type of rejection usually develops slowly, over months or years, and it can be hard to treat.

**Infection.** Anti-rejection medicines limit the action of your white blood cells (WBCs). These cells help your body fight infection, so when you take anti-rejection medicines you have a greater chance of getting infections. **It is very important that you:**

  - **Try to prevent infection**
  - **Watch for signs of infection**

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

BK virus causes an illness like a cold in very young children. After you have BK virus, it stays dormant or asleep in your kidneys and bladder for the rest of your life. After your transplant, and because of the anti-rejection medicines, the virus may “wake up.” This happens in about 5% to 10% of kidney transplant patients. The virus damages the new kidney and could cause the new kidney to fail. After your transplant, we check to see if you have the BK virus. If you do, your doses of anti-rejection medicines may be lowered or an anti-viral medicine may be prescribed. If the virus is caught early, **before you have any symptoms,** it can be treated before it harms your new kidney. It will be important to follow your screening schedule.

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

**Cancer.** The anti-rejection medicines can weaken your immune system. This increases your risk for certain kinds of cancers, such as skin cancer. You will learn how to protect yourself from cancer risks.
There also is a potential for psychosocial problems after your transplant. While most patients will have a better quality of life and manage side effects with success, it can be a difficult course. Some patients feel depressed and worry about their health. You may feel anxious and even guilty about depending on others for help. It is important to have support systems at home – people to help you understand what is happening and what your responsibilities are, to share what you are feeling and to get any treatment you might need. Your transplant team members are good resources for help. Please refer to Appendix A, Stress, Emotions and the Transplant Process, for more information.

**Alternative Treatments**
Kidney transplantation is not the best option for every patient. You and your family may decide that you do not want a kidney transplant. You might choose to remain on dialysis. Or, you may choose not to undergo any treatment. We will support whatever decision you make.

**Kidney Sources**

The person giving the organ is known as the donor. The person who receives the new organ is the recipient.

Kidneys for transplantation can come from two sources:
- Living donors
- Deceased (non-living) donors

All organs are carefully screened for disease or damage before being considered for transplant.

It is important that you know, the sale or purchase of human organs is a federal crime and it is unlawful for any person to knowingly acquire, receive, or otherwise transfer any human organ for valuable consideration for use in human transplantation.

**Living donor kidney transplantation** is an option if a family member or friend is willing to donate a kidney. Once the transplant team determines that transplantation is an option, you may want to contact potential donors. Since the wait for a deceased kidney donor is usually 4 years or more, we suggest that all patients think about living donor transplantation. Ask potential donors to come to a group education meeting to learn about living donation. Potential donors also can call us and we can send them a screening health questionnaire. They should fill out the health questionnaire and then schedule a time to come to one of the education meetings.

All potential donors will have a blood test done to check their blood type. If they are of a compatible blood type, they will have more testing to make sure that they are medically able to donate. (In some cases, donors who do not have a compatible blood type also might be considered.) The transplant team is very thorough in making sure it is safe for the donor, both at the time of surgery and in the future.
All potential living donors must:
- Be in good health
- Undergo a thorough evaluation process
- Understand and accept the surgery and its risks, including medical, psychosocial and financial implications
- Volunteer to be a transplant donor
- Understand and accept that the outcome of the transplant might not be as expected
- Be able to tell the team clearly their reasons for donating once they are aware of all of the benefits and risks

After donating a kidney, the donor’s remaining healthy kidney will grow until it is able to do the work of 2 kidneys. Living kidney donors have a normal expected life span and do not have a greater risk for kidney disease. Their lifestyle and activities are not restricted in any way. Women who have donated a kidney do not have any added risk in pregnancy or childbirth.

**Deceased donor transplantation** is based on your:
- Blood type and 2 other blood tests
  - Your antibody level or PRA
  - Tissue type matching
- Wait time (how long you have been waiting on the list for a transplant)

There are 2 main types of deceased organ donors. The most common donors are those whose hearts are still beating but whose brains do not function. These donors cannot survive without life support such as a ventilator. These donors are known as *Donation after Brain Death* (DBD) donors.

The others are donors who die when their hearts stopped beating. These donors are called *Donors after Cardiac Death* (DCD). If a DCD organ is being offered to you, you will be told that it is a DCD organ. You also will be told of any added risks if you accept the organ.

All kidneys from deceased donors are carefully screened by the transplant center. Only kidneys that meet our transplant center’s criteria are used for transplant. The donor’s medical history, cause of death and organ function is evaluated by the transplant surgeon before an organ is offered to you.

**Risks from the Donor**
Any time human tissue, blood or organs are transplanted from one human (living or deceased) to another; there is a small risk of transferring diseases or infections.
Some of these are listed in the table below.

### Table 2: Risks from the Donor

<table>
<thead>
<tr>
<th>Infections</th>
<th>Malignancies (Cancers)</th>
<th>Other</th>
</tr>
</thead>
</table>
| - Infections of the central nervous system  
  - Encephalitis (bacterial, fungal or viral)  
  - Meningitis  
| - JC virus (causes progressive multifocal leukoencephalopathy)  
  - Hepatitis A, B and C  
  - West Nile Virus  
  - Cryptococcal and other fungal infections  
  - Creutzfeldt-Jakob disease  
  - Cytomegalovirus (CMV)  
  - Herpes  
  - Epstein-Barr Virus (EBV or mononucleosis)  
  - Human Immunodeficiency Virus (HIV)  
  - Human T-Lymphotropic Virus (HTLV) I/II  
  - Trypanosoma cruzi, Leishmania, Strongyloides, Toxoplasmosis  
  - Tuberculosis (TB)  
  - Severe Acute Respiratory Syndrome (SARS)  
| - Syphilis  
| - Rabies  
| - Melanoma, Merkel cell (including Kaposi’s sarcoma)  
| - Hodgkins disease and non-Hodgkins lymphoma  
| - Multiple myeloma  
| - Leukemia  
| - Aplastic anemia and agranulocytosis  
| - Other carcinomas (cancers)  
| - Any new, potentially communicable (spreadable) diseases identified by the Centers for Disease Control and Prevention (CDC)  
| Special Donor Circumstances  
We do everything we can to prevent the transfer of infection or disease, but there always is some risk. If your potential donor is what we call a high-risk donor, we will let you know. You can decide to either accept the offer or turn it down. Remember, a high-risk kidney is only offered to you if your doctor believes that the benefits outweigh the risks for you.

Some donors meet the criteria known as an Expanded Criteria Donor (ECD) organ. An ECD donor is a deceased donor:
- Older than 60  
  or  
| Special Donor Circumstances  
| - Hepatitis B Core Antibody Positive  
| - Hepatitis C antibody  
| - High-Risk donor  
| - Donation after Cardiac Death (DCD)  
| - Expanded Criteria Donor (ECD)  
| - Donor with other risk identified  
| A deceased donor older than 50 who has 2 of the following:  
- High blood pressure  
- Stroke as the cause of death  
- Elevated creatinine  

Some donors meet the criteria known as an Expanded Criteria Donor (ECD) organ. An ECD donor is a deceased donor:
- Older than 60  
  or  
This is only offered to you if your doctor believes that the benefits outweigh the risks for you.

Some donors meet the criteria known as an Expanded Criteria Donor (ECD) organ. An ECD donor is a deceased donor:
- Older than 60  
  or  
- A deceased donor older than 50 who has 2 of the following:
  - High blood pressure  
  - Stroke as the cause of death  
  - Elevated creatinine

Special Donor Circumstances

- Hepatitis B Core Antibody Positive
- Hepatitis C antibody
- High-Risk donor
- Donation after Cardiac Death (DCD)
- Expanded Criteria Donor (ECD)
- Donor with other risk identified
Kidneys from an EC donor often have less than ideal kidney function. But every donor is different. Some ECD kidneys have good kidney function. We usually obtain a biopsy from ECD kidneys. A small piece of tissue, taken from the kidney (biopsy), is closely examined. If the quality of tissue is good, we believe that the kidney will work well.

We believe that accepting a carefully screened and biopsied ECD kidney is a good decision in many cases. If an ECD organ is being offered to you, you will be told that it is an ECD organ. You will be told of any added risks of accepting it. Following UNOS (United Network for Organ Sharing) rules, you will need to sign a special consent to be considered for an ECD kidney. We recommend that all patients sign this consent — you always have the choice to say yes or no to a kidney when it becomes available.

You can read more details about special donor circumstances in Appendix F.

**Organ Allocation**

Organs are offered to patients on the wait list based on their waiting time on the list and their percent reactive antibodies (PRA). In each blood group, the patient who will be called first is the one who has:
- The highest PRA
- A negative crossmatch
- Been on the wait list for the longest time

**PRA or Antibodies**

Antibodies are the way your body protects you from infection or other foreign tissues. For example, when you get a flu vaccine, your body forms antibodies to help prevent the flu. Then, if you are exposed to the flu, your antibodies will attack and destroy the flu germs and help keep you from getting sick.

Your body also makes antibodies when it is exposed to tissue or blood from another person. This also can happen with pregnancies and blood transfusions. When you have these antibodies in your bloodstream and are exposed to human tissue (such as a kidney) with a similar genetic code, your body will attack it just as it does the flu germs.

We measure what antibodies you have against human tissue with a PRA test. The higher your PRA, the harder it is to find organs that your body will not reject right away.

**Crossmatch**

You will have blood samples drawn every month while you are on the wait list. The Gift of Hope (GOH) uses your stored blood samples to make sure that your body will not reject your new organ right away. The test between donor tissues and your stored blood sample is called a crossmatch. The crossmatch must be negative for the kidney to be offered to you.
Chapter 2: Evaluation and Listing Process

Medical Evaluation Process
Your first clinic appointment starts the process of learning about kidney transplantation.

We ask that you bring friends and/or family members with you to this meeting. This appointment lasts most of the day, often up to 5 hours.

Before the meeting we will send you a letter to remind you of the date, time and place to meet. This letter also will tell you how to get to the Kovler Organ Transplantation Center and will include directions for discount parking.

Along with the letter there will be a health insurance form and a health history form. Please fill out these forms and return them in the enclosed self-addressed envelope before your appointment. It also is very helpful to send any recent medical tests to the transplant program before your first appointment. This will allow the doctors to review your health history before they meet with you.

Your appointment starts with a 1-hour group session. The transplant surgeon or doctor will talk about kidney transplantation with you and your family members. There may be other patients and their families at this meeting as well. Your questions are most welcome. We want you to understand the transplant process and the positive changes a kidney transplant can make in your life. It is our job to educate and inform you the best that we can.

After the meeting you will meet with various members of the transplant team and have the opportunity to ask questions of the transplant team members. The team includes:

- Nephrologists
- Transplant surgeons
- Transplant nurse coordinators
- Transplant nurse practitioners
- Clinical coordinators
- Registered dietitians
- Psychiatrists
- Licensed clinical social workers
- or licensed social workers
- Transplant financial liaisons

Evaluation Clinic
A physician assistant (PA) will meet you first and will ask you about your medical history and do a physical exam. Then you will meet either one of the transplant surgeons or a nephrologist. The doctor will explain more about the transplant process and answer your questions. The transplant surgeon and the nephrologist make most of the decisions about what other tests might be needed for your transplant evaluation process.

The transplant nurse coordinators and clinical coordinators will be your main contacts during the evaluation and until the time of your transplant. They will schedule any tests or procedures you will need at Northwestern Memorial. They also will talk to you and your family about the transplant process and answer questions you may have.
You will see the **dietitian** if you have specific nutrition needs or if you have weight problems (underweight or overweight). Good nutrition is very important to help manage your kidney disease, prevent complications and promote good health.

The **transplant financial liaison** and **social workers** will help you with your insurance. The financial liaison will explain your specific benefits and coverage. He or she will know if you need to apply for more insurance(s) to cover the costs of the evaluation, surgery, medications, post-transplant care, etc. If you have questions, have bills that you do not understand or need help, the transplant financial liaison can assist. If your insurance policy requires referral forms, be sure to bring them with you on the days of your visits or procedures.

Northwestern Memorial offers a range of financial assistance programs to ensure that quality healthcare is accessible to everyone, including those who are least able to afford it. Our financial counselors can help you further understand if you qualify for any of the programs and can assist you with the application process.

The **social workers** also are there to offer support and counseling to you and your family.

As part of our transplant protocol, you might also meet with the **transplant psychiatrist**. This might happen on your first visit, or at a follow-up appointment. You can meet with the psychiatrist alone or with your family member(s).

**The Plan**

After you meet with the doctor, the transplant team will decide on a plan for your transplant evaluation. Based on your health status and needs, the team will order various blood work and other tests. Depending on your results, the initial plan may change. We also will send a letter to your primary-care doctor. We tell the doctor that you have met with us and describe your evaluation plan. We prefer that you have your testing done at Northwestern Memorial.

**The Transplant Team**

| Nephrologists | Social workers |
| Transplant surgeons | Psychiatrists |
| Transplant nurse coordinators | Financial liaisons |
| | Dietitians |
| | Pharmacists |

Every week the entire transplant team meets to talk about all kidney transplant candidates. The team reviews each patient’s test results to see if there is a need for other exams or treatments. The team also decides which patients are transplant candidates. If you would like a copy of our selection criteria, please ask a member of the transplant team.
Blood Tests
To become a candidate for a kidney transplant, you will need a complete medical evaluation. Tests are done to:
- Identify the extent of your kidney damage
- See if kidney transplant is an option for you
- Make sure your health will not be made worse by a transplant

All evaluations include several main types of blood tests:
- Complete blood counts (CBC) with platelets
- Chemistry panel

These chemistry values need to be within a certain range for the body to stay healthy and do its work. Appendix D describes these tests in more detail.

Blood Type
All transplant candidates are placed on the wait list according to blood type (A, B, O or AB). Your blood type will be checked and confirmed by the blood bank. All patients must have ABO typing done at least two times to prevent any chance of error. Most of the time:
- Blood group O can accept only blood group O
- Blood group A can accept blood group A or O
- Blood group B can accept blood group B or O
- Blood group AB can accept blood groups A, B, O and AB

Diagnostic Tests and Procedures
Based on your diagnosis and the results of your initial exams, you might need to have other tests. For example, you might need special tests that look at your heart or other organs. The transplant clinical coordinators will help you schedule any tests or procedures that will be done at Northwestern Memorial. If your insurance covers it, some of the exams may be done near your home. All tests must be done at approved facilities. Before each test, you will be told what to expect from the test and any special guidelines that you need to follow. Some of these tests are described in Appendix E.
Research Studies

Northwestern Memorial is affiliated with Northwestern University Feinberg School of Medicine. You may be asked to participate in a clinical research study. If asked to take part in a study, know that the decision is yours. The research nurse will explain any study in detail.

Dental visit

You will have to see your dentist and have your teeth cleaned and checked. Infections or certain other problems will have to be taken care of before the transplant.

Insurance/Financial Support

Insurance coverage for kidney transplant varies with each insurance company. For this reason we have a transplant financial liaison to help you learn about the benefits your insurance plan offers. The doctor will write to your insurance provider on your behalf to request prior approval for the transplant.

The transplant financial liaison helps you look at all options for transplant insurance coverage, including Medicare. If your insurance changes or will change, please tell the transplant financial liaison right away. The liaison can check to make sure the new insurance also will cover your transplant. Some patients may qualify for free or discounted care. Your social worker can discuss this with you.

It is important to understand your insurance benefits. You must have coverage or financial resources for care after the transplant, including for your medicines. Depending on your policy, health problems related to the transplant may not be covered. As with most chronic illnesses, you may not be able to get medical disability or life insurance after the transplant. The social worker or transplant financial liaison can help you understand your policy and look for other financial resources (e.g., programs to help pay for the medicines, supplemental insurance policy, fundraising, etc.)

Because the donated kidney always retains its original identity, you will need to take anti-rejection medicines for the rest of your life. If you do not take these medicines it will lead to rejection and failure of your new kidney. But the costs of these needed anti-rejection medicines are high and you need to know before the transplant how to pay for them after the transplant. For this reason, it is the transplant center’s policy not to put patients on the wait list until there is a plan in place for paying for medicines needed post-transplant. Please talk to the social worker or patient financial liaison before surgery if you have any concerns or questions about money or insurance.

Your transplant social worker also can help you with many issues that come up about your transplant. For example, he or she can work with you to plan how to make sure you can always get the needed anti-rejection medicines. If the transplant is not done in a Medicare approved center, it could affect your ability to have your anti-rejection medicines paid for by Medicare Part B.

You can reach the transplant financial liaison at 312-695-6322 or the social worker at 312-695-0828.
Transplant List
After your evaluation and if the transplant team decided that you are a candidate for transplant, you can be placed on the transplant wait list.

Patients who are put on the list before they need dialysis might not be able to have their waiting time add up right away. Your primary care doctor will order a creatinine clearance test. Anyone with creatinine clearances higher than 20ml/min still has enough kidney function and will not accrue time on the list (the time will not add up). When the creatinine clearance goes below 20ml/min, your time on the list starts to accrue so you start “moving up on the list.”

So that you will be credited the right amount of waiting time, you must let us know these lab results every month or let us know when you start dialysis.
Chapter 3: While you Wait for a Transplant

Ongoing Tests
It is impossible to know how long you will be on the list before you are called for your transplant. It depends on your wait time and on your PRA level.

You need to make sure that you have your blood samples sent every month to the Gift of Hope (GOH).

Monthly Gift of Hope Serum (blood) Samples
- Every patient on the transplant waiting list must send in a sample, even if they are waiting for a live donor transplant.
- The blood samples are used to match you to potential donors, living or deceased.
- The GOH shares some of the blood with our lab at Northwestern University to test against your potential living donor.
- If you are on dialysis, the tubes will be mailed to your dialysis center every month. Be sure to check with your dialysis nurse to make sure the blood is being drawn and mailed to the GOH.
- If you are not on dialysis, the tubes will be mailed to your home. You can go to any hospital or doctor’s office to have the blood drawn. You then are responsible for mailing the tubes back to the GOH in the box provided.
- You will start getting these tubes 1 month after your name has been added to the transplant list.
- If you move or change dialysis centers, you should notify us immediately so we can let the GOH know where to send the tubes.
- If the GOH does not have current samples on file for you, you will not be eligible to receive organ offers until the GOH receives new samples.

We will ask the dialysis unit to let us know how you are doing. You may need to repeat some of the evaluation tests or get new tests:
- If your health changes
- As you get closer to the chances of being called for your transplant

We will contact you if any testing is needed.
Preventing Infection
There are some simple, but important, steps you will need to take to help prevent infection.
- Avoid contact with persons who have a cold or flu or other illness
- Practice good hand washing:
  - Wash your hands for 30 to 60 seconds using soap and warm water. Scrub all areas, including between the fingers, under the fingernails and around the nail beds.
  - You also can use alcohol-based hand rubs and wash for 20 seconds.
  - Use plain soap and water for visibly dirty hands.
  - Use alcohol-based hand rubs when your hands are not visibly dirty, for example, before and after eating.
  - Always wash your hands when visibly soiled, after you use the bathroom and before and after you eat.

Maintaining Your Health
Keep yourself in the best possible health while you are on the transplant waiting list. This means making choices so that you:
- Keep all of your dialysis appointments
- Work to keep your blood sugars under control (if you have diabetes)
- Get enough rest
- Exercise and take walks each day (as you are able)
- Take only your prescribed medicines
- Do not take any medicines without your doctor’s approval (that includes over-the-counter medicines, vitamins, herbs and supplements)
- Keep up to date on your appointments and lab work
- Let the transplant team know about any changes in your health
- See your dentist every 6 months

Contact Information
The transplant team must know how to get in touch with you 24 hours a day, 7 days a week. The transplant nurse coordinator will have to work quickly to find you when a kidney becomes available. It is essential that you are easy to reach. Many people find that a cell phone makes them easiest to reach. An added help is a list of contact people and phone numbers where you can most often be reached. This includes family members, friends, neighbors, etc., and their numbers. Please give the transplant nurse coordinator or clinical coordinator a list of all of your phone numbers, and update them as necessary, including:
- Home
- Work
- Cell phone
- Close family/friends/neighbors
- Places you frequently attend (e.g., church, school)
The waiting time can be a time of hope, uncertainty and stress for you and your family. Keep yourself busy. You may want to get involved with one of the transplant support groups to meet with others going through the same experience. The transplant social worker can help you with this.

There may be times you no longer meet the transplant center’s criteria. You would then become what we call Status 7 (inactive or on hold). Reasons for this might include:

- Uncontrollable infection
- Abuse of drugs or alcohol
- New complications such as a heart attack, stroke or treatable cancer
- Lack of follow-up with dialysis treatments
- Missing 2 months of blood samples being sent to the Gift of Hope
- Not getting your evaluation updates done as required

While you are inactive on the kidney transplant wait list, you will not receive any kidney offers, but your waiting time will keep accruing.

A person with a status of 7 may need all or part of the evaluation done again before it is decided if they can go back to active status on the transplant wait list. Sometimes it is decided that the person is no longer a candidate and is removed from the waitlist. We will always notify you if we change your status on the waitlist.

Planning Ahead
Even though we cannot know how long you will wait for your transplant, you can still make plans that will make things easier when you do receive “the phone call.” It is a good idea to let your employer know when you become a transplant candidate. Complete any needed leave of absence papers in advance. Also, consider how you will get to the hospital when the time comes. Who will take care of your family and home?

Many people find that having a living will and power of attorney gives them peace of mind. The transplant social worker can help. You can reach the social workers at 312-695-0828.

After transplant surgery you will need transportation to and from the hospital for follow-up clinic visits. These arrangements also should be made ahead of time. The timing of the visits will vary. At first they will be frequent. As you are getting better, the clinic visits will decrease. Eventually, you should need to see the transplant nephrologist and transplant nurse coordinator no more than once a year. But you always will need to have your blood drawn frequently. Your transplant nurse coordinator, nurse practitioner or doctor will let you know how often you need to have your blood drawn. The blood draws can be done with your local doctor but the results need to be shared with the transplant center. This way we can monitor your kidney function. You will learn more about this after your transplant.
Making the Most of Your Waiting Time

**Short Term:**
- Make healthy diet choices.
- Put yourself on a schedule that allows for exercise and rest.
- Make sure it is easy to find you by phone at all times.
- Call your transplant team contact as soon as there is a change in your health.
- Complete all tests, procedures and blood work as requested by your doctor, transplant nurse coordinators and clinical coordinators.
- Make sure your monthly samples go to Gift of Hope.
- If you have not started dialysis yet, call us every month with your creatinine level or when you start dialysis.

**Every 6 Months:**
- Have your teeth cleaned and checked. Your doctor or dentist may want you to take antibiotics before and after your dental treatment. Check on this before your appointment.

**Long Term:**
Arrange for your time away by planning for:
- An extended absence
- Care for your children or other family members, pets, etc.
- Upkeep of your home or apartment
- Mail pick-up
- Financial matters (bill paying, banking, etc.)

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**Staying in Touch**
You and your family will need to be physically and mentally ready for the transplant. Please feel free to call the transplant team if you or your family has any questions. The transplant nurse coordinators, doctor, social workers, transplant financial liaison and dietitian are more than willing to answer your questions and listen to your concerns.

As you wait for a transplant your health may change. It is important to keep the transplant team aware of how you are doing. Let us know of any changes in your medical condition and if you have had to go to the hospital for any reason.

Kidney offers can happen at any hour of the day or night. You and your family need to be ready to come to the hospital.

**The Phone Call**
You will receive a phone call when a suitable donor is found. The organ bank asks the pre–kidney transplant nurse coordinator to find you and make sure that you are healthy and ready for surgery. The transplant nurse coordinator will talk to you about the donor organ, including any special circumstances. Then you will have all the information you need to accept or reject the organ that is offered (informed consent). The doctor also will join the call to answer any questions you may have. If you choose not to accept the kidney, you will not lose your place on the waiting list. We can only tell you our best estimate of your chances to get another offer soon.
The transplant nurse coordinator will tell you how to get ready for the transplant. You may be told to come to the hospital right away or to come in a few hours. In most cases, our procurement team will go out to get the donor kidney. The kidney is checked carefully to make sure it is okay for transplant. While the donor’s kidney is being checked, you will be in the hospital waiting for the results. As soon as we know that the organ is okay, you will be taken to surgery. If the kidney is not okay, you will be sent home to wait for another offer. If this happens, you will still keep your place on the waiting list.

To avoid significant parking fees, please DO NOT PARK OVERNIGHT in the Northwestern Memorial Hospital Huron/Superior parking garage located at 222 E. Huron Street. If you get admitted to the hospital, please speak with a family member, friend or caregiver to arrange transportation to Northwestern Memorial or ask them for assistance moving your automobile from the parking garage.
Chapter 4: The Transplant

The Surgical and Medical Hospital Staff
It is helpful to know that during your hospital stay you will meet many members of the healthcare team. Some of the staff includes:

Anesthesiologists and the critical care team will monitor your care during surgery and in the ICU (intensive care unit).

Respiratory therapists will help you with your breathing exercises and breathing treatments.

Physical and occupational therapists will help you increase your physical activity and strength.

Dietitians will work with you and the doctors to create the best diet for you – for your healing and for the long term.

Social workers, case managers and discharge planners will assist you with your insurance needs and help you prepare to go home.

Staff nurses who are specially trained in transplantation will help you learn about your post-transplant care and medications.

Patient care technicians (PCTs) assist staff nurses in meeting your daily care needs.

Pharmacists will help you learn about your medications and how to take them.

Attending physicians, resident physicians, interns, fellows, physician assistants (PA), nurse practitioners and transplant nurse coordinators will follow your progress closely.

The inpatient transplant nurse coordinators are very important transplant team members. You will get to know them well as they work with you through all phases of your hospital care. They review your chart every day, monitor your lab results, assist you in obtaining your discharge medicines and help plan your care with the medical staff. These nurses work with the doctors and the entire transplant team to coordinate your care.

The medical staff includes the transplant surgeons and nephrologists. These attending physicians supervise the fellows, residents, interns and medical students who will give you the attention and care that you need. They work together to:
- Talk about your specific needs
- Develop a plan of care just for you
- Monitor your progress
- Change your plan of care based on your needs
Before Surgery
After your admission to 11 East Feinberg or Same Day Surgery (if you have a living donor), you will have blood tests, a chest X-ray and an electrocardiogram (EKG) done. You will put on special stockings to help prevent blood clots in your legs. A doctor will explain the surgery, including possible risks. You will then be asked to sign a consent form.

You will go to the pre-operative waiting area. Your family can come with you. At this point an anesthesiologist will come in to talk with you, start an IV (into the vein) line and give you medicine to relax you. Then you will be taken into the operating room (OR). In the case of a living donor transplant, you will be taken into the OR when we know the kidney is okay.

During Surgery
Anesthesia given through your IV line will cause you to fall asleep quickly. Then you will have a:
- Small tube in your mouth and throat for breathing. The tube is called an ET or endotracheal tube.
- Nasogastric (NG) tube placed into your nose and to your stomach
- Catheter (tube) in your bladder to monitor your urine output.

The transplant surgeon will make an incision low on either the left side or right side of your abdomen. (See Figure 2.)

![Figure 2](image)

Your “old” kidneys are not taken out. The new kidney is sutured in place (See Figure 3). A small plastic tube (stent) is inserted in ureter where it connects to the bladder. Then the incision is closed with staples. If needed, a small tube (JP) may be inserted to drain blood or fluid from the incision.
The surgery usually takes about 3 to 4 hours. Your family and friends can wait at the surgical waiting area on the 7th floor of the Feinberg Pavilion. At least 1 family member or friend needs to be in the waiting area at all times to talk with the surgeon. A member of the transplant team will come out or call directly from the OR to provide updates on your progress during the surgery.

After Surgery
From the OR, you will be taken to the recovery room located on the 5th floor of the Feinberg Pavilion. You will stay in the recovery room for a few hours or overnight. When you first arrive in the recovery room you might still have your ET, although it often is removed before you get there. Nursing staff and members of the transplant team will closely monitor you throughout your stay.

The head of the bed will be raised to help ease your breathing. You will be connected to a heart and blood pressure monitor.

A catheter in your bladder will drain your urine. You will have an IV that is used for medicines and fluids.

You will not remember the first hours after the transplant. The anesthesia used during the surgery will still be in your body. Gradually you will become more alert and responsive. You will feel weak, tired and sore after the surgery. The nursing staff will be at your bedside often to check on you and keep you comfortable.

Your comfort is very important. It is common to have pain during the first few days after your surgery. Tell the nurse if you are having pain. Rate your pain on a scale of 0 to 10, with 0 meaning “no pain” and 10 the “worst pain you could imagine.” It is best to take your pain medicine before the pain becomes severe. Once it becomes severe, pain is more difficult to relieve.

To keep your lungs expanded and healthy, the nurse will have you begin coughing and deep breathing exercises right away. This includes using a hand-held device called an incentive spirometer. The spirometer allows you to see how deeply you are breathing. Deep breathing is very important to:
- Keep your lungs clear of fluid and mucus build-up
- Guard against pneumonia.

As you continue to improve, you will be transferred to the Transplant Unit on 11 East Feinberg for the rest of your hospital stay.
Transplant Unit
On the 11 East Feinberg Transplant Unit, you still will have your urine catheter and an IV. You will continue with deep breathing exercises and the incentive spirometer.

When your stomach starts working, you can have small amounts of fluids to drink. As you are able, you gradually will be able to eat a normal diet.

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

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

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

Your stay on the Transplant Unit will be about 2 days. The goal is to have you out of the hospital 2 days after surgery, depending on your progress.

Keep in mind that there are times when the kidney does not work at all or does not work well enough to keep you well right after surgery. In those cases you still may need dialysis.
Chapter 5: Preparing for Home

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

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

Arrangements for a home health nurse can be made if needed.

If you live far from the hospital (at least one hour drive in normal driving conditions) and need frequent clinic visits, we may be able to arrange for you and a caregiver, based on availability, to stay together at the nearby Residence Inn by Marriott, 201 E. Walton Place (about 6 blocks from the hospital). One of the conditions for you to stay at The Residence Inn is that you need to have a family member or friend stay with you as a caregiver.

The room has a queen-sized bed, a pull-out sleeper sofa and a fully equipped kitchen. If other family members need hotel rooms, discounts at other hotels can be coordinated by calling 312-926-ROOM.

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

You will learn more about your post-transplant appointments and your responsibilities after your transplant. Your staples usually are removed in the transplant clinic about 3 weeks after your surgery.

About 6 weeks after your transplant, the stent (the small plastic tube in the ureter of your new kidney) will need to be taken out. This is done by the urologists in their clinic. Your appointment with the urologists will be made before you leave the hospital. Be sure to keep this appointment. If the stent remains in place too long, it may cause problems.

To take the stent out, the urologist inserts a small scope into your urethra (urine opening). This helps locate the stent so it can be gently removed. This takes only a few minutes.
Transitions after Transplantation

The first few months after your transplant will be a big change in your life. You will have frequent blood tests and several visits to the transplant clinic. Approximately three months after your transplant, or when your transplant team feels you are ready, your care will transition back to your referring kidney doctor (nephrologist) and primary care doctor.

The focus of the transplant team after your transplant is making sure your organ is working well. The focus of your kidney and primary care doctor is to provide care for any non-transplant medical issues such as diabetes, cholesterol and gout. Many times your physician who sent you to Northwestern for transplant will be able to manage your care after transplantation. There may be a situation that your physician may want you to continue receiving your care at the Northwestern Memorial Hospital transplant clinic after your kidney transplant. If this is the case, you will need to make sure you schedule your follow-up appointments prior to leaving each clinic visit.

The transplant team will always be available if you have questions or concerns. We will continue to provide your transplant specific medications and follow your laboratory test results. Additionally, we will work closely with the kidney and primary care doctors to help coordinate your care.

**Important Phone Numbers**

<table>
<thead>
<tr>
<th>Service</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-Kidney Transplant Team (7 days a week, 24 hours a day)</td>
<td>312-695-0828</td>
</tr>
<tr>
<td>Patient Financial Liaison</td>
<td>312-695-6322</td>
</tr>
<tr>
<td>Transplant Social Workers</td>
<td>312-695-0828</td>
</tr>
<tr>
<td>Patient Representatives</td>
<td>312-926-3112</td>
</tr>
</tbody>
</table>
Medications

Overview
You will take a combination of different anti-rejection medicines. These drugs work together to help your body accept your new kidney. They lower your body’s normal immune response to the new kidney. Without these medicines, your body will reject your transplanted kidney.

Commonly Used Anti-Rejection Medicines include:
- Tacrolimus (Prograf®, Hecoria®)
- Cyclosporine (Neoral®, Sandimmune®, Gengraf™)
- Mycophenolate (Myfortic®, CellCept®)
- Sirolimus (Rapamune®)
- Everolimus (Zortress®)
- Prednisone (Deltasone®)

- Alemtuzumab (Campath®)
- Thymoglobulin®
- Rituximab (Rituxan®)
- Basiliximab (Simulect®)
- Methylprednisolone (Solu-medrol®)
- Belatacept (Nulojix®)

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

Prograf®, Neoral®, Rapamune®, Zortress® and sometimes Myfortic® or CellCept® doses are adjusted to maintain a certain drug level in your blood. For example, if the drug blood levels are too high, the dose of medicine may go down. If the blood levels are too low, the medicine dose may go up. You will have frequent lab tests to monitor these blood levels, it is important that you wait to take you anti-rejection medicine until after the blood is drawn on the lab test days.

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

Some important facts about your medicines:
- Most medicines are taken 1 to 2 times a day. A few medicines may need to be taken 3 or 4 times a day

- Never stop taking your anti-rejection medicines. If you do, you risk transplant rejection.

- Never double the dose of any medicine. If you forget to take a dose, follow these guidelines.

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

But remember, taking the right dose of your medicines at the right time is very important!
The following anti-rejection medicines are the most commonly used. If you have any questions please ask your transplant nurse coordinator.

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

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

**How to Take**

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

**Possible Side Effects**

**Diarrhea**

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

**Decreased White Blood Cell (WBC) Count**

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

**Nausea/Vomiting**

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

**Anemia**

Your blood count will be checked closely for any decrease in your red blood cell (RBC) count. If you feel more tired or fatigued talk to a member of your Transplant Team at a clinic visit.
Important Safety information for Women who take
Mycophenolate (Myfortic®, CellCept®)

Your doctor will give you the Mycophenolate REMS Overview & Your Birth Control Options booklet and discuss with you the risks of taking mycophenolate.

**Important things to remember:**

- If you get pregnant while taking mycophenolate or within 6 weeks after you stop, there is:
  - A higher risk of losing the pregnancy (miscarriage) in the first 3 months
  - A higher risk that the baby will have birth defects

- You will have pregnancy tests before you start and during mycophenolate treatment.

- Your doctor will talk with you about acceptable forms of birth control. It is also recommended that you inform your routine OB/GYN doctor about taking this medicine. Information about your birth control options is provided in the Mycophenolate REMS Overview & Your Birth Control Options booklet.
  - Unless you choose not to have sexual intercourse with a man at any time (abstinence), You will always use acceptable birth control
    - During your entire treatment with mycophenolate
    - For 6 weeks after you stop taking mycophenolate

- If you are thinking about having a baby during your mycophenolate treatment, you should talk with your doctor right away.

- You should tell your doctor right away if you get pregnant during your mycophenolate treatment or within 6 weeks after you stop.

- Your doctor will report any pregnancies to the Mycophenolate Pregnancy Registry.
Tacrolimus (Prograf®, Hecoria®)

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

How to Take: Doses are taken at the same time each day, in the morning and evening about 12 hours apart (e.g. 9:00 a.m. and 9:00 p.m.). Take this medicine the same way, with or without food, for every dose. Exception: On those days you when your blood tests are done, take this medicine right after your blood is drawn. Do not eat grapefruit or drink grapefruit juice while taking this medicine.

Possible Side Effects:

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

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

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

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

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

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

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

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

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

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

<table>
<thead>
<tr>
<th>Medication</th>
<th>Use/Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ganciclovir (Cytovene®)</td>
<td>Treat or prevent CMV (cytomegalovirus) infection or other viral infections</td>
</tr>
<tr>
<td>Valganciclovir (Valcyte™)</td>
<td>Reduce stomach acid and help prevent ulcers. Depending on your insurance coverage, you may purchase these over the counter.</td>
</tr>
<tr>
<td>Acyclovir (Zovirax®)</td>
<td>Prevent or treat fungus infection (candida, also called thrush) in your mouth</td>
</tr>
<tr>
<td>Valacyclovir (Valtrex®)</td>
<td>Prevent urinary tract infections</td>
</tr>
<tr>
<td>Lansoprazole (Prevacid®, esomeprazole (Nexium®), pantoprazole (Protonix®), omeprazole (Prilosec®), or famotidine (Pepcid®)</td>
<td>Prevent a certain type of pneumonia called pneumocystitis pneumonia</td>
</tr>
<tr>
<td>Nystatin or clotrimazole (Mycelex® troche)</td>
<td>Help keep your blood magnesium level normal</td>
</tr>
<tr>
<td>SMX-TMP (Bactrim SS®) or another antibiotic if you are allergic to sulfa</td>
<td>Treat BK virus</td>
</tr>
<tr>
<td>Atovaquone (Mepron®) or SMX-TMP, (Bactrim SS®)</td>
<td>Blood thinner to prevent clotting and for long term cardiovascular health</td>
</tr>
<tr>
<td>Magnesium oxide</td>
<td>Prevent re-infection with hepatitis B</td>
</tr>
<tr>
<td>Cidofivir</td>
<td></td>
</tr>
<tr>
<td>Aspirin</td>
<td></td>
</tr>
<tr>
<td>Hepatitis B immunoglobulin (H-BIG) [if you had hepatitis B before the transplant] and lamuvudine (Epivir®), entecavir (Baraclude®), or tenofovir (Viread ®)</td>
<td></td>
</tr>
</tbody>
</table>

Your Transplant Team will explain these and other medicines in more detail as they are prescribed to you. If you have any questions, please ask.
APPENDIX A: Stress, Emotions and the Transplant Process

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

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

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

Depression
Everyone, at some point in time, feels sad or down. That is normal and typically this sadness decreases soon after the transplant. If sadness lasts more than two weeks and affects the way you function, it may be a sign of a more serious illness such as clinical depression.

Clinical depression is not the same in everyone. But it often includes feeling sad and/or a loss of interest in most activities. One person may have a hard time concentrating, feel irritable, sleep poorly and have no appetite or energy. Another may feel tearful and hopeless, guilty and ashamed and feel no joy. No matter what the signs are, depression is distressing and it makes it difficult to live a normal life.
Having some or all of the symptoms that are listed in this chart, when felt for 2 weeks or longer, may be a sign of depression.

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

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

If you or your loved ones notice signs of depression, call your transplant team. It is important to look at your specific symptoms and feelings and work with the transplant psychiatrist, social worker or transplant nurse coordinator. Treatment depends on what you need, but may focus on:
- Improving your mood
- Helping you cope with stress
- Adjusting to what is happening to you

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

**Anxiety**

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

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

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

Fear and anxiety can be caused by fear of the “unknown” or when:
- The worst-case scenario is assumed
- You feel you have little or no control

As a transplant patient, there are many aspects of your health and recovery that you cannot control. But there also are many things that you can and need to control. To ward off anxiety, try to remain focused on what you can control:
- Keep your follow-up appointments
- Follow medication guidelines
- Exercise and eat a healthy diet
- Maintain a positive outlook
- Be an active partner in your care

Another way to remain in control is having the information you need to understand:
- What is happening and why
- What is the best thing you can do to help

If you or your loved ones notice signs of anxiety, call your transplant team. Ask questions so that you have accurate information.

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

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

Physically you might feel tense muscles, upset stomach, headaches and/or changes in sleep or appetite. People often feel “butterflies” in their stomach, a fast heartbeat, sweating or tingling in their fingers during a stressful event. Some may cry, shout, walk away or abuse drugs or alcohol. Everyone responds differently to stress, even to the same stressful situation. For example, what causes anxiety and insomnia in one person might cause diarrhea and an upset stomach in another. One person may become angry when under stress, while another tends to be tearful and sad.

People also vary in how they view a situation. If you believe that you can cope with or overcome the challenges that face you, then you are likely to feel less stress.
Chronic stress can greatly strain body systems and damage them over time. When you have a weakened immune system, it is especially important to limit the amount of stress in your daily life so that the physical effects of stress will not harm your new organ.

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

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

### Ideas to Help Reduce Stress

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

### Coping

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

There is no “right way” to cope. The best way is for you to identify coping strategies that work for you and make you feel more comfortable and at peace with the events you face. It can be hard, especially when you already have had to cope with your illness, but think about what works for you. Some ideas are described in greater detail below. Your transplant team also can help you learn new ways to cope.
Gathering information: It often helps to gather as much information as you can about your medical condition, what to expect during the transplant process and what your responsibilities are throughout that process. Knowledge helps you establish more realistic expectations, which often can help lessen stress. Since stress, depression and anxiety can make it harder to concentrate and remember things, it often helps if you bring someone with you to your appointments. You also may bring a notebook to keep track of the information you receive. You should write down your questions before your appointments and then write what you learned during that appointment. Also, feel free to visit Northwestern Memorial’s Health Learning Center, a state-of-the-art health information library on the third floor of the Galter Pavilion. Health educators are available there to help you gather information about medical topics at no charge. For more information, contact the Health Learning Center at 312-926-LINK (5465) or by e-mail at HLC@nmh.org. The Alberto Culver Women’s Health Learning Center also is available in Prentice Women’s Hospital.

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

Distraction: While some people like to actively confront a situation, others prefer to distract themselves. Distraction can be particularly helpful during a hospital stay, when you have a lot of time to dwell on stress and worries. You can keep yourself busy in the hospital or while recovering at home by engaging in various activities. For example, you can watch television or movies, read, play games such as cards or checkers, talk with others, knit, do crossword puzzles, walk, invite people over to visit, write about your experience, draw, use the computer or write to friends. Ask for help to make sure the activities that you would like to do are available to you.

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

Humor: Laughter and a sense of humor are related to a better quality of life and better physical health. Laughter can improve sleep and mood and even reduce pain. It can help you relax your breathing and improve your heart rate and blood pressure. You can help improve your spirits by looking for the humor in your situation whenever possible or by making time to read funny things or watch television shows that make you laugh.
Communicating with Family and Friends about Your Transplant
You should not have to be on this journey by yourself. Share your concerns, questions, feelings and emotions with others. Tell them what you need and ask for help. For example, let family and friends know whether you want them to visit you in the hospital, to call more often or less often, to bring your favorite foods or magazines to the hospital, to let others know about your condition or just to be there for support. Loved ones usually feel more comfortable if you give them some direction.

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

How Should I Feel?
There is no particular way that you should feel. There is much that is happening before and after a transplant. Both your physical and emotional health can change quickly, independent of your plans or behaviors. Resources are available to help you deal with your reactions.

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

The transplant team is available to help family members cope with the emotions, stresses and responsibilities associated with caregiving, or can refer you to other professionals if that is what you need. Always feel free to ask for help.

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

- Practice healthy coping strategies.
- Surround yourself with family and friends.
- Focus on the parts of the situation that you can control.
- Establish realistic expectations and priorities.
- Plan ahead.
- Communicate effectively with your family, friends and transplant team.

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

For most individuals, receiving a new organ is a joyous time filled with celebration, hope and a renewed appreciation for life.

We wish you all the best throughout your transplant journey.
APPENDIX B: Frequently Asked Questions for the Social Worker

I have only Medicare. How are my transplant medicines paid for?
Medicare Part B pays 80% of the cost of the anti-rejection medications for 3 years after your transplant. The 20% that you have to pay runs about $400 to $600 per month just for the anti-rejection medications. Drug stores will require the 20% co-payment when you pick up the medications.

There is very little help from community groups to assist with these co-payments. Medicare Part D will provide some coverage for your other transplant medicines.

How long can I keep Medicare after a transplant?
The Social Security Administration expects people to go back to work 3 years after transplant. Should you decide to go back to work during the 3 years, you will keep Medicare benefits as long as you pay the required premiums. However, at the end of 3 years, if you have not returned to work, you will have to prove to the Social Security Administration that you are still disabled. Having a kidney transplant alone is not reason enough to stay on Medicare or receive disability benefits.

Does that mean I can lose my disability benefits, too?
Yes, 3 years after the date of the transplant, you will lose these benefits if you:
- No longer need dialysis
- Have no other disability and
- Are not of retirement age

I also have Medicaid. Will it help with the transplant?
Yes. Medicaid reimburses for kidney transplantation, but the amounts vary. Your social worker and the Illinois Department of Public Aid can assist. The Illinois Department of Public Aid can be reached at 1-800-252-8635.

I don’t have Medicare. How can I get it?
Medicare is an insurance that people pay into through payroll taxes and is automatically offered at the age of 65. To be eligible for Medicare, if you are not of retirement age, you have to have paid into Medicare for 40 quarters (10 years). To qualify, you also have to be on dialysis or have had a transplant. You can apply for Medicare by speaking to your dialysis social worker if on dialysis, or with a transplant patient financial liaison once you have had a transplant. If you have private insurance, you should consider applying for Medicare as a secondary insurance.
**If I have more than 1 insurance company, which pays the bills first?**
If you have 2 private insurances (yours and your spouse’s), your insurance would be billed first. Your spouse’s insurance would be billed second.

If you have Medicare and private insurance, there is a special arrangement between Medicare and the insurance companies. The private insurance will be your primary carrier for the first 30 months of Medicare eligibility. After that, Medicare becomes the primary insurance and your private insurance becomes your secondary carrier.

*It is important to keep your private insurance even after Medicare becomes your primary insurance.*

**I have a managed-care plan (HMO). Do I need to do anything special?**
Yes, you will need to obtain referrals from your primary care doctor to be evaluated by our program and for all follow-up care (post-transplant clinic visits and blood work).

**The insurance through my job has a prescription plan. Do I need to do anything?**
The prescription plan through your insurance company may have flat co-pays for generic and brand medications. Some plans are based on a percentage. Others will pay only for medications at designated pharmacies. It is important to know with which pharmacies your plan participates. After transplant, many patients need:
- 2 anti-rejection medications, which you must take for the rest of your life
- 2 medications to prevent viral and bacterial infections, which are taken for 3 to 6 months
- Some medicines you were on before transplant

**What happens if I have no prescription coverage or need assistance to afford my medications?**
It is *very important* for you to contact your social worker or transplant nurse coordinator for various resources that might be available to help with your medication expenses. We can help you in the application process for indigent programs with the pharmaceutical companies. The National Transplant Assistance Fund (1-800-642-8399) and the National Foundation for Transplants (1-800-489-3863) can guide you in how to do fundraising to help with some of your medical expenses.
Northwestern Memorial offers a range of financial assistance programs to ensure that quality healthcare is accessible to everyone, including those who are least able to afford it. Our financial counselors can help you further understand whether you qualify for any of the programs. They can assist you with the application process.

**It is important that you understand what your insurance does and does not cover. It will allow you to make an informed decision about whether transplantation is right for you.**

**Can I work after transplant?**
You can work unless your doctor tells you that you should not work after transplantation. You usually can return to work within 4 to 12 weeks after the transplant. This will depend on your recovery and your job and its demands. If you are interested in another line of work, you may be eligible for free job training (including certificate programs, computer classes, college-degree programs and vocational training programs). Your social worker can assist.

**Is there reimbursement for parking for the clinic visits?**
No, but with a voucher from the clinic, your parking ticket can be validated at any of the information desks on the second floor for a discounted rate.

**Can my family sleep in my room?**
Since Northwestern Memorial has only private rooms, overnight guests are allowed to stay in your hospital room unless you are in the ICU.

Special hotel arrangements are made at the Residence Inn for you and 1 family member if you:
- Have had your transplant and are discharged from the hospital
- Live a great distance from the hospital

Patients and families also can call 312-926-ROOM to get a list of discounted hotels near the hospital. If you need further help with lodging, please contact the transplant social worker.

**What is the average hospital length of stay for kidney transplant patients?**
For a kidney transplant recipient, the average length of stay in the hospital is 2 days. Patients should expect to be discharged within this time frame and should have the necessary support system in place to allow for their transition home.
Will I need help at home after the transplant?
It is important to arrange for help at home after your transplant, as you will need time to recover. If you anticipate that you will need help other than that provided by family and friends, the social worker has a list of private-duty homemakers/caregivers. However, these services are **not** covered by insurance. If you have Public Aid or have less than $10,000 in assets, you are eligible to receive a homemaker/caregiver through the Illinois Department of Rehabilitation/Department of Aging.

During the first month, your appointments will be more frequent. Unless you have Public Aid or have ADA Para Transit, there is little assistance available to you for transportation. You should not take public transportation right after surgery due to the high risk for developing an infection.

Will I need a home health nurse when I go home?
**In most cases,** a home health nurse is not needed. You will be closely monitored in the clinic after your transplant. If you are in need of home care, the discharge planner/nurse will set up these services before you go home, using the home care agency of your choice.

What else can the social worker provide help with?
In addition to answering your questions regarding Medicare and Medicaid coverage, making referrals to local support groups, referring patients to non-profit fundraising organizations to assist with transplant-related costs not covered by insurance and providing assistance with applications for indigent medication programs, transportation and homemaker/caregiver needs, your social worker always is available to provide supportive counseling related to your adjustment to illness.

If you have any questions about any of this information, please feel free to call 312-695-0828 and ask for your social worker. For specific insurance-related questions, please ask for your transplant financial liaison.
APPENDIX C: Resources

AMERICAN ORGAN TRANSPLANT ASSOCIATION
For information, education and support
Phone: 281-261-2682
e-mail: aota@pdg.net

CENTERS FOR MEDICARE AND MEDICAID SERVICES
www.cms.hhs.gov

MEDICARE
www.medicare.gov

NATIONAL COUNCIL ON PATIENT INFORMATION AND EDUCATION
For information and education
Phone: 202-347-6711
e-mail: ncpie@erols.com

NATIONAL FOUNDATION FOR TRANSPLANTS
For fundraising information and short-term financial assistance
Phone: 800-489-3863
e-mail: natfoundtx@aol.com
www.transplants.org

SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS
Phone: 877-970-SRTR
Email: srtr@srtr.org
www.srtr.org

TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION (TRIO)
For information, education, networking and support
Phone: 800-874-6386
www.trioweb.org

UNITED NETWORK FOR ORGAN SHARING
Phone: 888-894-6361
www.unos.org

ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK (OPTN)/Health Resources and Services Administration (HRSA)
For general information
Phone: 888-ASK-HRSA (888-275-4772)
Email: ask@hrsa.gov
http://optn.transplant.hrsa.gov
APPENDIX D: Blood Tests

A CBC (Complete Blood Count) with platelets tells if the body is “making” enough blood. It also gives important information about:
- Blood volume (hematocrit or Hct)
- Blood count (red blood cells or RBCs)
- The blood’s ability to carry needed oxygen to all parts of the body (hemoglobin or Hgb)
- The blood’s ability to clot (platelets or Plt)
- The body’s ability to fight or prevent infection (white blood cells or WBCs)

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

Creatinine Clearance is a urine collection (you collect and save your urine for 24 hours) that helps tell how well your kidneys are removing creatinine from the blood.

CMV Antibody is a blood test to check for exposure to the cytomegalovirus (CMV). This is done before you get your transplant to find out your risk of CMV disease post-transplant.

CMV PCR Quantitative is a blood test to look for and measure the amount of CMV in your blood. It is very important to get this test and NOT the antibody test after transplant.
Hemoglobin A1-C is done if you have diabetes. It is a blood test to see how well your blood sugars have been controlled over the last 2 to 3 months.

Quantiferon TB Gold detects any previous exposure to tuberculosis.

Liver Function Tests (LFTs) provide a good picture of your liver’s condition:
- **Albumin** is a protein that is made by the liver. When the liver cannot make enough albumin, fluid leaks out of your blood vessels and into your tissues. This is one cause of edema.
- **Alpha-fetoprotein (AFP)** levels help monitor the growth of any liver tumors.
- **Bilirubin** is a byproduct of hemoglobin breakdown. High bilirubin levels may cause jaundice and/or mean that you might have:
  - Liver injury
  - Blood flow problems to the liver (i.e., ischemia and blood clots)
  - Blockage of the bile ducts
- **GGT (gamma glutamyl transpeptidase)** is made in the bile duct. High levels indicate:
  - Duct blockage
  - Decreased blood flow
- **SGOT/AST (serum glutamic oxaloacetic transaminase/aspartate aminotransferase)** is an enzyme found in the liver. A high AST signals injury to the liver, kidney, heart, red blood cells or muscles.
- **SGPT/ALT (serum glutamic pyruvic transaminase/alanine aminotransferase)** is another enzyme found in the liver. High levels may mean liver injury.
- **Prothrombin time (PT), partial thromboplastin time (PTT) and international normalization rate (INR)** give information about how fast your blood clots. Medication, liver disease and certain foods can increase or decrease the clotting time.
APPENDIX E: Diagnostic Tests

Some of the following tests may be part of your evaluation. Your nurse will provide more detailed information about any of these tests if they are ordered for you.

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

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

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

A colonoscopy is an exam used to detect disease of the lower digestive tract for early signs of colon and rectal cancer. These include polyps that can, over time, develop into cancer. It also is helpful in finding the cause of diarrhea, bleeding or changes in bowel habits. The test takes about 30 minutes. During the exam, a small, flexible tube is inserted into the rectum and to the colon. At the end of the tube is a tiny video camera with a light. This test may be more helpful than X-rays alone since the doctor may:

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

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

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

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

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

A 2-D echocardiogram uses high-frequency sound waves (ultrasounds) to look at how the various parts of the heart work.
An **upper endoscopy** (also called an **EGD**, gastroscopy or esophagogastro-duodenoscopy) is an exam that can detect diseases of the esophagus, stomach and duodenum (top part of the small intestine). An EGD is used to find the cause of:
- Persistent nausea or vomiting
- Heartburn or stomach pain
- Ulcers or bleeding
- Swallowing problems

The test takes about 15 to 30 minutes. During the exam, a small, flexible tube is inserted into the mouth, down the throat and into the stomach and duodenum. At the end of the tube (endoscope) is a tiny video camera with a light. This exam may be more helpful than X-rays alone since the doctor may:
- Actually view the area
- Take a small tissue sample (biopsy)

**Endoscopic Retrograde Cholangiopancreatography (ERCP)** is a test used to study the ducts (drainage paths) of the liver, pancreas and gallbladder. It uses a thin, flexible tube (endoscope) with a tiny video camera and light. The tube is inserted into the mouth and to the stomach. The doctor is able to see the small openings to the common bile duct and pancreatic duct. The exam lasts about 1 hour. ERCP is helpful in detecting diseases of the pancreas, bile ducts, liver and gallbladder. It also can allow the doctor to:
- Place a stent (tube) to open a blockage
- Repair narrowed ducts
- Obtain tissue biopsies
- Remove stones or sludge in the ducts
- Decide the need for surgery

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

The test takes about 15 minutes. During the exam, a small, flexible tube (sigmoidoscope) is inserted into the rectum and to the descending colon. At the end of the tube is a tiny video camera with a light. This exam may be more helpful than X-rays alone since the doctor may:
- Actually view the area
- Take a small tissue sample (biopsy)
A **kidney ultrasound** looks at both the kidneys and bladder. The test uses sound waves to project an image. This allows the doctor to view organs and areas within the body. A small, hand-held device called a transducer is placed on the skin over the area to be examined. The sound waves from the transducer are reflected off the internal organs back to the transducer. The sound waves create an image on a video screen. The images are viewed and captured in real time, showing movement. The exam, done in the Ultrasound department, takes about 30 minutes.

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

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

**Pulmonary Function Tests (PFTs).** A **Full PFT** is a group of tests that check lung function, such as:
- How easily the air moves in and out of the lungs
- The amount of air your lungs can hold
- How much oxygen (O2) the lungs send to the heart.

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

Every MRI patient needs to be screened to ensure that certain safeguards are in place. If you have any metal inside your body, please tell your doctor before the exam. This may include:
- Pacemaker
- Aneurysm clip
- Ear or eye implant
- Joint or bone rods or clips
- Metal plate
- Bullets or shrapnel

It also is helpful to talk with your doctor if you:
- Cannot lie flat for about an hour
- Have claustrophobia (are uncomfortable with closed-in spaces).
There are specialized MRIs:

**MRA (magnetic resonance angiography):** To look at your arteries

**MRV (magnetic resonance venogram):** To look at your veins

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

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

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

- **KUB** is an X-ray of your abdomen with a focus on your kidneys, ureters and bladder.
- **CXR** is a chest X-ray.
- **Panorex** is an X-ray of your teeth and gums.
APPENDIX F: Special Donor Circumstances

ECD-Kidney
This is what will be read to you when kidney donation from an expanded criteria donor (ECD) is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

ECD - Expanded Criteria Donor
Some donors meet the criteria known as an Expanded Criteria Donor organ. An ECD is a deceased donor:
- Older than 60
  or
- A deceased donor older than 50 who has 2 of the following:
  - High blood pressure
  - Stroke as the cause of death
  - Elevated creatinine

Kidneys from an ECD often have less than ideal kidney function. But every donor is different. Some ECD kidneys have good kidney function.

We usually obtain a biopsy from ECD kidneys. A small piece of tissue (biopsy) taken from the kidney is closely examined. If the quality of tissue is good, we believe that the kidney will work well.

A biopsy was taken of the ECD kidney that is being offered to you. The biopsy results showed that the kidney should be a good fit for you.

*If the doctor believes there are additional factors you should know about the donor that could add other risks, he/she will discuss these with you as well.*

You are being offered this organ because your doctor believes that the benefits of accepting this organ outweigh the risks.

The final decision to accept the organ is yours.

If you decide not to accept this organ you will not lose your place on the list. Your doctor will give you his/her best estimate of getting another offer for you.
DCD – Kidney
This is what will be read to you when kidney donation after cardiac death (DCD) is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

DCD – *Donation after Cardiac Death*

Most kidneys used for transplant are obtained from a donor who has died but whose heart continues to beat (brain-dead, heart-beating donor).

The organ you are being offered is different. The donor died (heart stopped beating) just a short time before the kidneys were removed. This is a *Donation after Cardiac Death.*

Kidneys that do not work well right after transplant are called “sleepy” kidneys. Kidneys from DCD donors are 2 times more likely than kidneys from brain-dead, heart-beating donors to be “sleepy” kidneys. On average, 20% of kidneys from brain-dead, heart-beating donors are “sleepy” compared to 40% from DCD.

It is important to know that:
- If you have a “sleepy kidney,” you may have to stay on dialysis for a short time.
- Most of these “sleepy” kidneys will wake up within days or weeks after transplant.
- Findings confirm that at 1, 3 and 5 years post-transplant, the DCD kidneys work just as well as standard donor kidneys.

*If the doctor believes there are additional risks, he/she will discuss these with you as well.*

You are being offered this organ because your doctor believes that the long-term benefits with this DCD kidney should be similar to the benefits you would get with a brain-dead, heart-beating donor kidney.

The final decision to accept the organ is yours.

If you decide not to accept this organ you will *not lose* your place on the list. Your doctor will give you his/her best estimate of getting another offer for you.
Hepatitis B core antibody

This donor tested positive for hepatitis B core antibody. This means that donor was exposed to the hepatitis B virus at some point. We know you have antibodies to protect you from this virus because of certain lab results we have received from you. Because you have antibodies, your risk of getting infected with Hepatitis B from this donor is very low. There is still a very small risk of infection, but it is less than 1.1%. If you accept this organ, hepatology will be consulted to determine if you need further follow-up. As with all of your transplant care, your health insurance will be billed for any follow-up visits or treatment.

You are being offered this organ because your physician thinks that the benefit of accepting this organ outweighs the potential risks. The final decision to accept the organ is yours.

If you decide to turn this organ down, you will not lose your place on the list. However, your doctor believes your chances of getting an offer next few months are:

**Kidney/SPK/Pancreas**
- Excellent – Top of list with a PRA < 20%
- Poor – PRA between 20%-80% or not included in top 5
- Very Poor - PRA > 80% or low on list

**Liver**
- Excellent – Calculated or Assigned* Meld > 25 or a status one
- Poor – Calculated or Assigned* Meld 20-24
- Very Poor – Calculated or Assigned* Meld < 20 or HCC out of Milan Criteria

*If a patient has cancer (HCC) there is a chance your cancer will progress and that you will no longer be eligible for extra points. In that case your chance of getting an organ will be decreased.
Hepatitis C Antibody

This is what will be read to you when a donor kidney that is positive for Hepatitis C antibody is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

You are being offered an organ from a donor who tested positive for Hepatitis C antibody. At some point in the donor’s life, the donor was exposed to the Hepatitis C virus.

You also have been exposed to the Hepatitis C virus.

Several research studies have shown that using organs from donors with the Hepatitis C antibody in patients who also have the Hepatitis C antibody has the same results as using organs from donors who do not have the antibody. We have experienced the same results in the Northwestern Memorial Hospital Transplant Program. We believe this type of transplant is safe and should not make any difference in the results of your transplant.

If the doctor believes there are additional risks, he/she will discuss these with you as well.

You are being offered this organ because your doctor believes that the benefits of accepting this organ outweigh the risks. You will not need any additional treatments if you accept this organ.

The final decision to accept the organ is yours.

If you decide not to accept this organ you will not lose your place on the list. Your doctor will give you his/her best estimate of getting another offer for you.
CDC Increased Risk Donor

This is what will be read to you when a kidney from a high-risk donor is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

You are being offered an organ from a deceased donor that the Centers for Disease Control’s (CDC) guidelines defines as being at increased risk for transmitting infections, such as HIV, HBV, and HCV. The increased risk does not affect how well the organ works. Instead, we mean that this donor engaged in behaviors before their death that increase their chances of having an infection. The risk factor(s) for this donor is (are):

LIST
This donor has already had two types of screening for infections. They had required testing for HIV, hepatitis B, and Hepatitis C. They also had special testing for HIV and Hepatitis C. All of these tests results were negative. Even with negative test results, there is still a very small chance that this donor has an infection such as HIV or hepatitis. We feel that transplanting you with this organ outweighs the very small risk. Otherwise we wouldn’t offer the organ to you.

Based on information on similar donors with the same behaviors and negative test results, your risk of getting: (only read statistics pertaining to this donor’s specific behavior)

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>HIV Rate</th>
<th>HCV Rate</th>
<th>Compared to HD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men who have sex with men</td>
<td>0.034%</td>
<td>0.038%</td>
<td>10 times</td>
</tr>
<tr>
<td>Injection drug user</td>
<td>0.053%</td>
<td>0.378%</td>
<td>Same</td>
</tr>
<tr>
<td>Hemophiliac</td>
<td>0.002%</td>
<td>0.005%</td>
<td>700 times</td>
</tr>
<tr>
<td>Prostitute</td>
<td>0.012%</td>
<td>0.115%</td>
<td>3 times</td>
</tr>
<tr>
<td>Sex partner with any of the above</td>
<td>0.011%</td>
<td>0.135%</td>
<td>3 times</td>
</tr>
<tr>
<td>Exposed to HIV through blood</td>
<td>0.005%</td>
<td>0.023%</td>
<td>15 times</td>
</tr>
<tr>
<td>Incarceration</td>
<td>0.006%</td>
<td>0.073%</td>
<td>5 times</td>
</tr>
</tbody>
</table>
For patients on HD: You should also know that there is also a risk (0.34%) of developing hepatitis C per year while on dialysis. You should also consider your risk of death if you stay on dialysis instead of accepting this offer. Your risk of death per year of dialysis is:

<table>
<thead>
<tr>
<th>Age</th>
<th>Risk of Death</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;65 years old</td>
<td>3.8%</td>
</tr>
<tr>
<td>66 – 69 years old</td>
<td>4.2%</td>
</tr>
<tr>
<td>70 – 74 years old</td>
<td>5.0%</td>
</tr>
<tr>
<td>75 – 84 years old</td>
<td>7.3%</td>
</tr>
</tbody>
</table>

Your doctor has carefully looked at information about this donor. She/he recommends that you accept this organ. In his/her opinion, the potential benefit of accepting the organ outweighs the risk of getting an infection from this donor. If you decide to accept this organ, you will be seen by our Transplant Infectious Disease team after your transplant. The Transplant Infectious Disease team will monitor you to be sure that you did not get an infection. If you get an infection, there are treatments available. The infectious disease doctors will treat you, if needed. As with all of your transplant care, your health insurance will be billed for these visits, labs, and, if necessary, treatments.

We believe that the risk of getting an infection is extremely small. That is why we suggest that you accept this organ. The decision to accept this organ is yours. If you decide to not accept the organ, you will not lose your place on the waiting list. However, your chances of getting another organ offer in the next few months are:

**Kidney/SPK/Pancreas**
- Excellent – Top of list with a PRA < 20%
- Poor – PRA between 20-80% or not included in top 5
- Very poor – PRA >80% or low on list

**Liver**
- Excellent – Calculated or Assigned* Meld > 25 or a status one
- Poor – Calculated or Assigned* Meld 20-24
- Very Poor – Calculated or Assigned* Meld < 20 or HCC out of Milan Criteria

*If a patient has cancer (HCC) there is a chance the patient’s cancer will progress and that that patient would no longer be eligible for extra points. In that case, the chance of getting an organ will be decreased.
Donor with Other Risk Identified

This is what will be read to you when a kidney from a donor with other risks is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

Every transplanted organ has a chance of transmitting disease from the donor to the recipient.

The doctor will tell you about whatever risk(s) this donor may have.

You are being offered this organ because your doctor believes that the risks from this donor are very small and that the benefits of accepting this organ outweigh the risks. Because of these risks, you will be monitored post-transplant with blood tests and for signs or symptoms of related illness. No special testing is required other than routine post-transplant care.

The final decision to accept the organ is yours.

If you decide not to accept this organ you will not lose your place on the list. Your doctor will give you his/her best estimate of getting another offer for you.

Para asistencia en español, por favor llamar a el departamento de representantes para pacientes al 312-926-3112.

Northwestern Memorial is an equal opportunity employer that welcomes, respects and serves with dignity all people and does not discriminate, including in hiring, or employment, or admission, or access to, or treatment in its programs or activities on the basis of race, color, gender, national origin, religion, disability, handicap, age, Vietnam or other veteran status, sexual orientation or any other status protected by relevant law. To arrange for TDD/TTY, auxiliary aids and foreign language interpretation services, or for issues related to the Rehabilitation Act of 1973, call the Patient Representative department at 312-926-3112, TDD number 312-926-6363.
What are the OPTN and UNOS?
The Organ Procurement and Transplantation Network (OPTN) links all of the professionals involved in the nation's organ donation and transplantation system. The OPTN also strives to make more organs available and increase patient access for transplants. The United Network for Organ Sharing (UNOS) is a non-profit organization that operates the OPTN under a contract from the federal government.

The OPTN and UNOS continuously review new advances and research and use this information to improve organ transplant policies to best serve patients needing transplants. All transplant programs and organ procurement organizations are members of the OPTN and agree to follow its policies.

How am I listed for a transplant?
If you have a condition leading to organ failure, your doctor may recommend you for an organ transplant. To become a transplant candidate, you must be evaluated and accepted by a transplant hospital. It is up to each center to decide whether or not it will accept someone as a transplant candidate.

How am I considered for organs from deceased donors?
You are considered for available organs based on a combination of medical facts entered into a computerized matching program. These factors include blood and tissue type, medical urgency, body size, distance between the donor and transplant hospital and time spent waiting for a transplant.

The distance between the donor and transplant hospital is important because the less time the organ must be preserved outside the donor's body, the better the chance that it will function when transplanted. There are three levels considered:

- **Local.** This is usually the area served by the local organ procurement organization (OPO) where the donation occurs. There are 58 OPOs nationwide. These areas are often statewide but can be smaller (such as a large city or part of a state) or larger (a multi-state area). Your transplant center can tell you what your local area is.

- **Region or zone.** If there are no suitable local matches, organs are offered to patients at transplant centers in a wider area. Kidneys, livers, pancreases and intestinal organs are first offered within one of 11 regions of the United States. Heart and lung offers are considered for candidates within 500 miles of the donor site, then 1,000 miles, then 1,500 miles.

- **Nationwide.** If there are no matches in the local area or region, organs will be offered to anyone in the United States who is a potential match.
**What is multiple listing?**
Multiple listing involves registering at two or more transplant centers. Since candidates at centers local to the donor hospital are usually considered ahead of those who are more distant, multiple listing may increase your chances of receiving a local organ offer.

**Could multiple listing shorten my waiting time for a transplant?**
Some studies suggest multiple listing can shorten the average waiting times of kidney transplant candidates by several months. This does not guarantee that every multiple-listed patient will have a shorter waiting time.

Many factors affect how long you might wait for a transplant. Of course, not enough organs are donated each year to meet everyone’s needs. Everyone in the transplant community shares the goal of increasing organ donation to save and enhance more lives.

Other waiting time factors include how urgent the patient is and how closely the donor and candidate match on body size and blood type. Some kidney and pancreas candidates have a “highly sensitized” immune system because of earlier transplants, pregnancy or multiple blood transfusions. Highly sensitized patients will only be good matches for a limited number of organ offers, so they often wait longer than non-sensitized candidates.

**Are there any restrictions?**
OPTN policy allows multiple listing. It will still be up to the individual center to decide whether to accept you as a candidate. You probably would not benefit from listing at multiple centers in the same local allocation area (which is usually the OPO). This is because waiting time priority is first calculated among candidates at all hospitals within the local donation area, not for each hospital individually.

Some transplant programs may not accept multiple-listed patients. Others may set their own requirements for multiple-listed candidates. If you are considering multiple listing, you should ask the transplant team how they handle such requests.

**What is involved in multiple listing?**
As with any transplant listing, you must be considered and accepted by a transplant center. This involves completing an evaluation and agreeing to meet any conditions set by the program (for example, ability to come to the hospital within a certain time if you are called for an organ offer).

You might check with your insurance provider to see if they will reimburse the cost of additional evaluations. You should also consider other costs associated with listing that insurance may not cover. For example, you may need to pay for travel and lodging if the center is further from your home. You should also find out whether your post-transplant medical care will be provided at the center.
or can be transferred to a facility closer to your home. In addition, you would need to maintain current lab results and contact information for each transplant program where you list. Each program will need current information should they receive an organ offer for you. Through the OPTN database your center can know if you are multiple-listed but may not know the other hospital(s) where you are listed.

If I list at more than one center, how is my waiting time considered?

As soon as a center accepts you as a transplant candidate, your “waiting time” begins. Depending on the organ you need, waiting time may be a factor in matching you for an organ offer. Waiting time is a more important factor for certain organ types such as kidney and pancreas. It is less of a factor with heart, liver, and intestinal organs. For these organs more priority is given for factors such as medical urgency.

If you are a lung transplant candidate age 12 or older, waiting time will not be used at all in matching you with organ offers. Lung transplant priority is given for a combination of medical urgency and expected post-transplant survival. Waiting time is a factor for lung transplant candidates age 11 and younger.

The longest amount of time you have waited at any center is called your primary waiting time. If you list at multiple centers, your waiting time at each center will start from the date that center listed you. OPTN policy allows you to transfer your primary waiting time to another center where you are listed, or switch time waited at different programs. (For example, if you have waited 9 months at Center A and 6 months at Center B, you could switch your time to have 6 months at Center A and 9 months at Center B.)

You are not allowed to add up or split your total waiting time among multiple centers. (Again, assume you have waited 9 months at Center A and 6 months at Center B. You could not assume you have 15 total months of waiting time and assign 5 months to Center A and 10 months to Center B.)

Any request to transfer or switch waiting time must be approved by the transplant center(s) involved. Most transplant programs require a written request to swap or transfer waiting time, which will then be considered by the transplant team.

If I do not multiple-list but transfer my care to another hospital, what happens?

If you want to end your listing at one program and transfer to another, your primary waiting time can be transferred as long as you coordinate with both programs. The new transplant program will probably ask you to request in writing to transfer the waiting time. Keep in mind that if you end your listing at one program before another program formally accepts you, you may risk losing all previous waiting time.
Sometimes a transplant program may inactivate for a period of time (for example, to replace a key member of the transplant team who leaves) or close its operations. If this happens, the OPTN requires that the program contact you and provide for your continuing care. If the inactivation is short-term you may choose to remain listed until the program becomes active again, but you will not receive organ offers during that time. If the program closes, the staff will work with you to arrange care at another center without loss of your primary waiting time.

Where can I get additional information?
You should first contact the staff of the transplant program where you are listed or want to be listed. They will have the most specific information about how they handle requests for multiple listing and/or waiting time transfer. They will also make any needed arrangements with UNOS.

UNOS maintains a web site, Transplant Living, which contains extensive information for transplant candidates and recipients as well as their family members. The address is www.transplantliving.org. You may also wish to visit the OPTN web site at www.optn.org.

UNOS also maintains a toll-free phone information line for transplant candidates, recipients and family members. The number for Patient Services is 1-888-894-6361.
The UNOS mission is to advance organ availability and transplantation by uniting and supporting its communities for the benefit of patients through education, technology and policy development.
**Note to transplant candidates/family members:**

In accordance with OPTN Policy 3.2.3, your transplant center is required to provide you with written information about multiple listing and transferal of waiting time. Your signature below confirms that your center provided you this booklet. Your center will keep this form on file to document compliance with this policy.

I have received the booklet **Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer.**

__________________________________________  __________________________________________
Signature of Transplant Candidate/Family Member  Printed Name of Transplant Candidate

__________________________________________  __________________________________________
Date Received  Signature of Transplant Center Staff Member Providing Booklet
Early testing and treatment can prevent the spread of HIV/AIDS.

Human Immunodeficiency Virus (HIV) Testing

What is HIV?

HIV is a virus that:
- Damages the way the body protects itself against illness.
- If not treated, can lead to AIDS (Acquired Immune Deficiency Syndrome).

What is AIDS?

AIDS causes the body to lose its natural protection against infection. A person with AIDS is more likely to become ill from infections and unusual types of pneumonia and cancer that healthy persons most often can fight off.

How does someone get HIV?

HIV is found in the blood and body fluid (semen and vaginal secretions) of infected persons. The virus is spread from the infected person to others:
- During sex – vaginal, anal or oral.
- While sharing needles/devices used for injecting drugs or tattooing.
- By passing the virus from an HIV-infected woman to her baby during pregnancy and birth, or by breastfeeding.

How is HIV diagnosed?

A person with HIV may look and feel healthy. Many are often unaware they have HIV and can infect others. Only an HIV test can tell if you have been exposed to the virus. If you have, your immune system makes proteins called antibodies. It takes most people up to 12 weeks after exposure before the antibodies can be detected (“window period”). But in some cases, it may take as long as 6 months.
If your test is positive for HIV antibodies, it means you are infected and can infect others. If the test is negative, it usually means you are not infected. You should, however, be tested again if, in the 6 months prior to the test, you engaged in behavior that could transmit the virus.

An HIV antibody test can be done in 1 of 2 ways:
- Blood test.
- Mouth swab.

Early testing and treatment can:
- Prolong life and keep people out of the hospital.
- Prevent the spread of HIV/AIDS.

Where is testing done?

HIV testing is done at Northwestern Memorial Hospital. You can arrange to be tested by your own doctor. Many local health departments and community agencies offer anonymous or private counseling and testing services. For help, call the toll-free AIDS/HIV and STD Hotline at 1-800-243-2437.

How can HIV be prevented?

Never share needles or injection equipment. Practice “safe sex:”
- Use latex condoms correctly every time you have vaginal, anal or oral sex. This can greatly lower your risk of infection. The only sure way to prevent HIV is not to have anal, vaginal or oral sex.
- Do not impair your judgment with drugs or alcohol.

How can I obtain more information about HIV?

Call the free and anonymous AIDS/HIV and STD Hotline at 1-800-243-2437 or TTY (hearing impaired use only) 1-800-782-0423 to learn more about:
- Your risk.
- HIV or other sexually transmitted diseases (STDs).

Illinois Department of Public Health (IDPH) www.idph.state.il.us
Centers for Disease Control and Prevention (CDC) www.cdc.gov/std/
CDC-INFO Hotline (24 hours, 7 days a week)
- 1-800-232-4636 (English and Spanish).
- 1-888-232-6348 (TTY).
Northwestern Memorial Hospital is one of the country’s premier academic medical centers and the primary teaching affiliate of Northwestern University’s Feinberg School of Medicine. The hospital which is located near the medical school on the Northwestern Campus, serves as a regional and national referral center as well as a local hospital for the community.

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

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

Para asistencia en espanol, por favor llamar al Departamento de Representantes para Pacientes al 312.926.3112.

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