

Kovler Organ Transplantation Center

## Kidney/Pancreas Transplantation

A Patient Handbook

## Welcome

Welcome to the Kidney/Pancreas Transplant Program at Northwestern Memorial Hospital. A kidney/pancreas transplant can help patients with end stage kidney disease and Type 1 diabetes live better and longer.

This handbook will help you understand:

- What is involved in the kidney/pancreas transplant process
- What it means to live with a transplanted organ
- The risks and benefits of a kidney/pancreas transplant
- Your role in taking care of yourself and your new kidney/pancreas 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/pancreas transplant.

This handbook provides you and your family with important information about your 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 may be other treatment choices for you. You have the right to know what those are. Perhaps you may choose a treatment other than transplant or continue with your present treatment. 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 both your decisions and your care. The team will provide the best care possible for you before and after your kidney/pancreas transplant. Your transplant team is a group of health care professionals who have special training and experience in transplantation. The team includes:

- 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 surgeon and doctor 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 an hour away from the hospital

**Opportunities for Your Feedback**

At Northwestern Memorial Hospital, our belief and commitment is *Patients First*. This means that 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. We welcome your comments and look forward to receiving your survey.
- You can always 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: 1-888-894-6361.

Kovler Organ Transplantation Center

## KIDNEY PANCREAS TRANSPLANTATION: A Patient Handbook

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## Chapter 1 - The Pancreas and the Kidney

### The Pancreas

Your pancreas is found in your abdomen behind your stomach. (see figure 1)

It has two main functions:

- Makes and releases fluids (enzymes) into your intestine to help with digestion
- Releases insulin and glucagon (hormones) to maintain a steady blood glucose (sugar) level

Insulin is secreted by the *islets of langerhans* which are found in the pancreas. Insulin controls our blood sugar level within a narrow range to keep us healthy. When the islets do not work properly:

- There is not enough insulin to control the blood glucose
- Blood glucose levels rise
- This may result in diabetes mellitus

In *Type 2* diabetes the pancreas secretes insulin but the body becomes resistant to the insulin. The insulin does not work as well and the blood sugar level is then poorly controlled. Patients with *Type 2* diabetes are not pancreas transplant candidates. These patients are treated with diet and medicines.

### *Symptoms / Complications of Pancreas Failure*

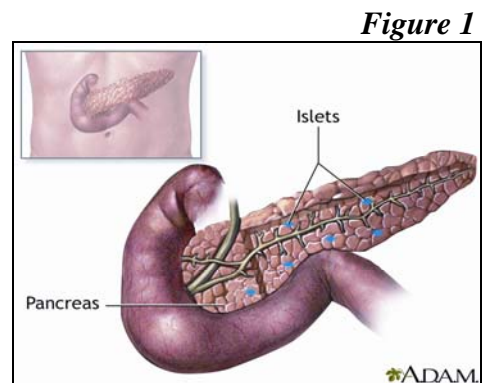
In *Type 1* diabetes, the pancreas does not make any insulin Patients with *Type 1* diabetes must take insulin to live. Over time, diabetes can cause complications such as:

- Kidney Failure
- Neuropathy (problems with nerves – numbness, pain)
- Poor circulation (may result in amputation)
- Retinopathy (decreased vision – blindness)
- Hypoglycemic unawareness (low blood sugars that you do not realize are low)
- Earlier onset of heart disease
- Gastropathy (digestive problems)

*Type 1* diabetes is diagnosed by a blood test called C-Peptide. A very low to absent C-Peptide level usually means that you have *Type 1* diabetes. Only patients with *Type 1* diabetes can be considered for a pancreas transplant.

Pancreas transplantation restores the functions of the pancreas.

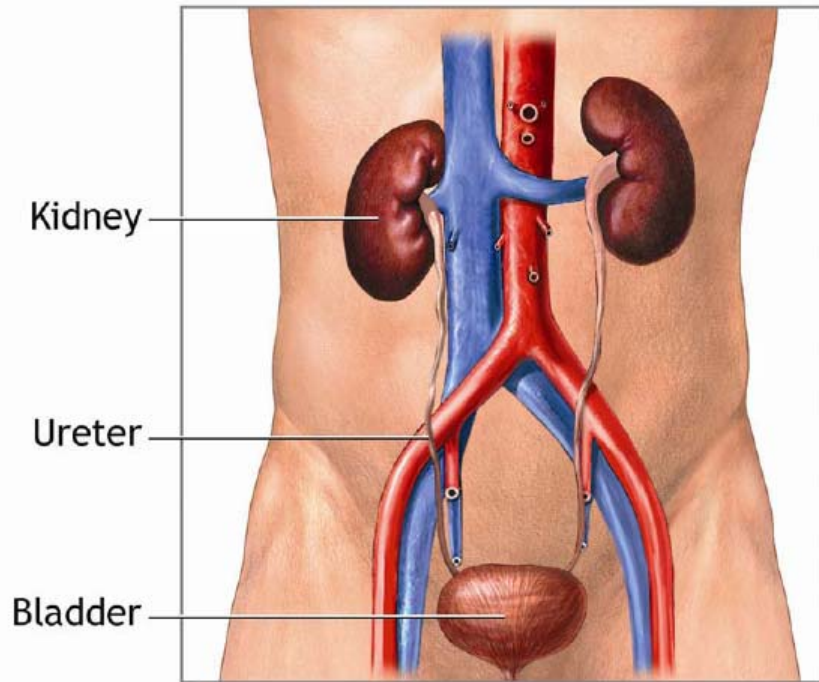
- Patients no longer need insulin
- Diabetes-related problems are slowed down



## The Kidney

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

*Figure 2*



Normally, the kidneys help your body:

- Maintain a balance of water and chemicals (electrolytes)
- Filter the body's waste products out of the blood (which then exit 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). Your kidneys failed because of diabetes.

**Symptoms and Complications of Kidney Disease**

Kidney Disease can cause:

- Fluid overload
- Swelling (edema) of hands and legs
- Anemia – low red blood cell (RBC) count
- Chronic fatigue (weakness and muscle loss)
- Osteoporosis

See Table 1 for more details about possible complications of diabetic kidney disease. Remember, the risk and complications differ with each patient.

**Table 1: Complications of Diabetic Kidney Disease**

<p><i>Anemia:</i> decreased number of red blood cells (hemoglobin) can cause:</p> <ul style="list-style-type: none"> <li>▪ Fatigue</li> <li>▪ Shortness of breath</li> <li>▪ Dizziness</li> <li>▪ Headache</li> <li>▪ Difficulty sleeping</li> <li>▪ Faster heart rate</li> <li>▪ Lower blood pressure</li> </ul> <p><i>Cardiac Disease:</i> because of its affects on blood vessels, diabetes can lead to and earlier onset heart disease and heart attacks. The fluid overload and hypertension of kidney disease may also damage the heart.</p> <p><i>Digestion problems:</i> because of poor circulation to the digestive system and neuropathy.</p> <p><i>Fatigue:</i> being tired all the time, even after you rest.</p>	<p><i>Fluid Overload and Edema:</i> the kidneys are not able to rid the body of enough water.</p> <p><i>Hypertension:</i> high blood pressure.</p> <p><i>Hyper (too high) or hypo (too low) glycemia (blood sugar):</i> Risk of confusion, coma, death</p> <p><i>Hypoglycemia unawareness:</i> when you don't know that your blood sugars are low.</p> <p><i>Neuropathy:</i> pain and numbness at your nerve endings, especially in the legs and feet.</p> <p><i>Osteoporosis:</i> with kidney disease there is a calcium imbalance in the blood and this can weaken the bones.</p>	<p><i>Poor circulation:</i> risk of cellulitis and infection, especially in the legs. Risk of amputation.</p> <p><i>Retinopathy:</i> damage to the blood vessels in your eyes. Risk of blindness.</p> <p><i>Sexual:</i></p> <ul style="list-style-type: none"> <li>▪ Loss of sex drive (libido)</li> <li>▪ Menstrual cycles may stop in women</li> <li>▪ Men may suffer impotence</li> </ul> <p><i>Psychosocial/Financial:</i></p> <ul style="list-style-type: none"> <li>▪ Inability to work due to dialysis schedule.</li> <li>▪ Inability to get health, life or disability insurance because of chronic illness</li> <li>▪ Child care issues because of your dialysis schedule</li> </ul>
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When kidneys completely stop working, treatment is needed. Your options include dialysis or a possible kidney transplant. Dialysis filters, or cleans, your blood. This prevents 'waste' 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 for you several things need to be considered. These include work, lifestyle, other medical conditions, and your 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 should have a better quality of life.

**Indications for Kidney/Pancreas Transplantation**

You can be considered for a kidney and/or pancreas transplant if:

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

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

Criteria for acceptance as a kidney transplant candidate are:

- A kidney/pancreas 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/pancreas 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

Patients who have hypoglycemia unawareness and other serious complications of diabetes and have no kidney failure may be candidates for a pancreas transplant alone.

\* See the Insurance/Financial Support section found on page 17.

**Contraindications for Kidney/Pancreas Transplantation**

A kidney/pancreas transplant is *not* an option for the patients who have:

<ul style="list-style-type: none"><li>▪ Severe, untreatable heart or lung disease</li><li>▪ Active or uncontrollable cancer</li><li>▪ Untreatable mental illness</li><li>▪ Alcohol or drug addiction</li><li>▪ Severe neurologic deficit</li><li>▪ Severe peripheral vascular disease (PVD)</li><li>▪ Uncontrollable infection that will not go away with a transplant</li></ul>	<ul style="list-style-type: none"><li>▪ Uncontrolled HIV infection with AIDS despite optimal medical therapy</li><li>▪ Irreversible brain disease or damage</li><li>▪ Failure of other organs that will not improve with a transplant</li></ul>
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Other conditions that may also disqualify you from getting a kidney/pancreas transplant include:

- Age greater than 65 with other serious illnesses
- Obesity (BMI greater than 32)
- Chronic active Hepatitis B
- Hepatitis C

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

**Results of Kidney and Pancreas Transplantation**

About 90% of transplanted kidneys and about 85% of the transplanted pancreases still “work” 1 year after surgery. Patient survival following Simultaneous Pancreas Kidney transplantation is between 95 and 97% at one year.

For patients getting a pancreas alone, the pancreas survival rates at one year are between 80% and 85% and patient survival is over 97%.

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](http://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/Pancreas Transplantation**

The transplant process includes a complete evaluation. This includes various blood tests and exams. The transplant team will review all the screening and test results. If they recommend 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/pancreas 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/pancreas transplantation can occur early (in the first 30 days) or later on (after 30 days).

**Early complications can include:**

- Primary non-function (the kidney and/or pancreas never work)
- Delayed organ function (the kidney and/or pancreas do not work right away)
- Bleeding (that requires added surgery)
- Clotting of major blood vessels to the kidney
- Rejection (usually in first 3 months)
- Infections
- Diabetes

**Late complications can include:**

- Rejection
- Infections (different types, including CMV; and BK virus in the kidney transplant)
- Recurrent disease or diabetic complications continue to progress
- Kidney disease and other side effects of anti-rejection medications
- Certain types of cancer
- Type 2 Diabetes
- High blood pressure

Table 2 below lists some of the complications that may happen after a kidney/pancreas transplant.

**Table 2: Potential Complications of Kidney/Pancreas Transplant Surgery**

<i>Surgical</i>	<i>Medical</i>	<i>Psychosocial / Financial</i>
<ul style="list-style-type: none"> <li>▪ Death</li> <li>▪ Bleeding</li> <li>▪ Infection</li> <li>▪ Pain</li> <li>▪ Hernia</li> <li>▪ Complications of general anesthesia, including brain damage or death</li> <li>▪ Need to stop the surgery</li> <li>▪ Need to return to the operating room, for reasons such as:                             <ul style="list-style-type: none"> <li>- Bleeding</li> <li>- Wound breakdown</li> <li>- Bowel perforation</li> <li>- Infection</li> </ul> </li> <li>▪ Need for blood products during surgery                             <ul style="list-style-type: none"> <li>- Risk of blood-borne viral infection</li> </ul> </li> <li>▪ Need to be on a ventilator</li> <li>▪ Surgical scars at the incision site</li> <li>▪ Damage to the nerves in your legs (often short-term)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Fatigue</li> <li>▪ Nausea and vomiting</li> <li>▪ Heart attack, stroke or major blood clot(s)</li> <li>▪ Cardiac arrhythmias and cardiovascular collapse</li> <li>▪ Pneumonia</li> <li>▪ Damage to other organs and organ failure</li> <li>▪ Failure of the new kidney and/or pancreas to work</li> <li>▪ Rejection of your transplanted kidney and or pancreas</li> <li>▪ Primary or recurrent cytomegalovirus (CMV) or BK virus</li> <li>▪ Need for re-transplantation</li> <li>▪ Blood clots causing the kidney and/or pancreas to stop working</li> <li>▪ Unidentified donor-related risks, for reasons such as:                             <ul style="list-style-type: none"> <li>- Unreported illnesses by donor family</li> <li>- Unknown viral or bacterial infection</li> <li>- Unknown cancer</li> </ul> </li> <li>▪ Chronic rejection</li> <li>▪ Medication side-effects</li> </ul>	<ul style="list-style-type: none"> <li>▪ Post-surgical depression related to coping with complications of:                             <ul style="list-style-type: none"> <li>- Surgery</li> <li>- Medications</li> <li>- Life changes</li> <li>- Feeling that you are a burden</li> <li>- Body image</li> <li>- Family tensions</li> </ul> </li> <li>▪ Loss of work or inability to do work due to:                             <ul style="list-style-type: none"> <li>- Illness</li> <li>- Evaluation testing</li> <li>- Surgery</li> <li>- Recovery time</li> </ul> </li> <li>▪ Financial and emotional concerns due to loss of work</li> <li>▪ Inability to obtain future employment or afford health, life or disability insurance</li> <li>▪ Inability to afford medication</li> <li>▪ Financial risks or child-care costs due to the need for follow-up care</li> </ul>

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/pancreas. 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* which harm your new kidney/pancreas.

- *Acute* rejection often happens in the first several months after transplant. But rejection can occur at any time (that is why you must always take your medicines to prevent 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 to years. It can be hard to treat.

**Infection.** Anti-rejection medicines also 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 be a life-threatening illness. You may need anti-viral medications either to prevent or to 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.** Because of the medicines that weaken your immune system you are at more risk to develop certain kinds of cancers, such as skin cancer. You will learn how to protect yourself from cancer risks.

There are also potential *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 after the transplant; and might feel worried or anxious about their health.

You may feel anxious about depending on others for help and even guilty. 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**

Pancreas and kidney transplantation is not the best option for every patient. You and your family may decide that you do not want a pancreas and/or kidney transplant. There are other treatment options besides transplant. You can continue to treat your diabetes with insulin and you have the option to stay on dialysis. Of course, you may also choose not to have any treatment. We will support your decision, no matter what you decide.

Some patients may decide to have just a kidney transplant and continue to manage their diabetes with insulin. **Living donor kidney transplantation** is an option for those patients who have a family member or friend who is willing to donate a kidney. This option is discussed in detail in the Kidney Transplant patient education handbooks.

### **Pancreas and Kidney Sources**

The person giving the organs is known as the *donor*. The person who receives the new organ(s) is the *recipient*.

*Pancreas transplant alone* or a combined *kidney/pancreas transplant* are almost always done from deceased donors.

*Kidney transplants* can come from two sources:

- Deceased (non-living) donors
- Living donors

No matter where they come from, all organs are carefully screened for disease or damage before being considered for transplant.

### **Getting an organ from a deceased donor is based on your:**

- Blood type
- Tissue type matching (a blood test)
- Wait time (how long you have been on the transplant waitlist).

There are two main types of deceased organ donors. The most common is from donors whose heart is still beating but whose brain does not function. These donors cannot survive without life support (e.g., a ventilator). These donors are known as DBD donors (*Donation after Brain Death*).

The second type is from donors who die when their heart 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 will also be told of any added risks if you accept it.

All organs from deceased donors are carefully screened by the organ bank and by the transplant center. Only organs that meet our transplant center’s criteria are used for transplant. The donor’s medical history, cause of death, and organ function are 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 disease or infection. Some of these are listed in Table 3:

**Table 3: Risks from the Donor**

<p><b><i>Infections</i></b></p> <ul style="list-style-type: none"> <li>▪ Infections of the central nervous system             <ul style="list-style-type: none"> <li>- Encephalitis (bacterial, fungal or viral)</li> <li>- Meningitis</li> </ul> </li> <li>▪ JC virus (causes progressive multifocal leukoencephalopathy)</li> <li>▪ Hepatitis A, B and C</li> <li>▪ West Nile virus</li> <li>▪ Cryptococcal and other fungal infections</li> <li>▪ Creutzfeldt-Jacob disease</li> <li>▪ Cytomegalovirus (CMV)</li> <li>▪ Herpes</li> <li>▪ Epstein-Barr virus (EBV or mononucleosis)</li> <li>▪ Human Immunodeficiency Virus (HIV)</li> <li>▪ (HTLV) I/II</li> <li>▪ Trypanosoma cruzi, Leishmania, Strongyloides, Toxoplasmosis</li> <li>▪ Tuberculosis (TB)</li> </ul>	<ul style="list-style-type: none"> <li>▪ Severe Acute Respiratory Syndrome (SARS)</li> <li>▪ Syphilis</li> <li>▪ Rabies</li> </ul> <p><b><i>Malignancies (Cancers)</i></b></p> <ul style="list-style-type: none"> <li>▪ Melanoma, Merkel cell (including Kaposi’s sarcoma)</li> <li>▪ Hodgkins disease and non-Hodgkins lymphoma</li> <li>▪ Multiple myeloma</li> <li>▪ Leukemia</li> <li>▪ Aplastic anemia agranulocytosis</li> <li>▪ Other carcinomas (cancers)</li> </ul> <p><b><i>Other</i></b></p> <ul style="list-style-type: none"> <li>▪ Any new potentially communicable (spreadable) diseases identified by the Centers for Disease Control and Prevention (CDC)</li> </ul>
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## 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 or pancreas 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

Organs from an EC donor often have less than ideal function. But every donor is different. For example, 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 or pancreas 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 waitlist 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 has:

- The highest PRA
- And a negative crossmatch
- And has been on the wait list for the longest time

### 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



*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 (“sees”) tissue or blood from another person. This can also happen with pregnancies and with blood transfusions. When you have these antibodies in your bloodstream and are exposed to human tissue (such as the kidney or pancreas) 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. The test is called a Percent Reactive Antibody (PRA). 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 organs right away. The test between donor tissues and your stored blood sample is called a *crossmatch*. The crossmatch must be **negative** for the kidney and/or pancreas to be offered to you.

**Types of Pancreas and Kidney Transplants**

Your doctor and transplant surgeon will recommend the type of transplant that is best for you. The decision is based on:

- Your medical condition
- Your overall health
- Your pre-transplant evaluation
- The availability of organs

Transplant options include:

***Simultaneous*** (at the same time) **Pancreas/Kidney (SPK) Transplant** is done for those who:

- Have ESRD from Type 1 diabetes
- Need both a kidney *and* a pancreas

Kidney-pancreas transplant candidates may be on dialysis or will need dialysis soon. The kidney and the pancreas both come from the *same* deceased donor. After an SPK transplant, the new kidney ends the need for dialysis and the new pancreas produces insulin so that you no longer need insulin.

**Pancreas after Kidney (PAK)** Transplant is for patients with Type 1 diabetes who already had a kidney transplant (that is still working)

The kidney transplant may have come from a deceased donor or from a living donor. Some people who have a living donor may choose to have a kidney transplant first and then have the pancreas transplant at a later time. Others have already received a kidney transplant from a deceased donor and are now ready for a pancreas transplant from a different deceased donor.

A **Pancreas Transplant Alone (PTA)** is for patients who have severe diabetes but do not need a kidney transplant.

**Research Studies**

*Northwestern Memorial Hospital is affiliated with Northwestern Medical School. You may be asked to participate in a 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.*

**Islet Cell Transplantation** is still experimental. It involves taking the islet cells from a deceased donor pancreas. These cells are then injected into the liver where they *engraft* (take hold) and begin to make insulin. Most patients need two infusions of islet cells. This replaces the need to transplant an entire pancreas. Islet cell transplants can be done two ways:

- An **Islet Cell Transplant Alone (ITA)** may be an option for patients with uncontrolled diabetes that:
  - Causes repeated hospital stays
  - Interferes with their daily lives
- An **Islet Cell Transplant after a Kidney Transplant (IAK)** might be done for someone with Type 1 diabetes who already has a working kidney transplant

Talk to the transplant team to see if islet cell transplantation is an option for you. Your transplant nurse coordinator can put you in touch with a research nurse who can talk to you about this.

One of your choices might be a pancreas/kidney transplant. There is much to learn about getting a pancreas/kidney transplant, including:

- The potential benefits
- Your role before and after the transplant
- Potential risks

Your transplant team is ready to help you through the whole process. Know that you can change your mind about getting a transplant at any time.

Much of the information in this patient education handbook is also true for pancreas transplant alone.



## Chapter 2 - Evaluation and Listing Process

### Medical Evaluation Process

Your first clinic appointment starts the process of learning about kidney/pancreas 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 will also tell you how to get to the Kovler Organ Transplantation Center and have directions for discount parking.

In 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 is also very helpful to send any recent medical tests to the transplant program before your first appointment. This way the doctors can review your health history before they meet with you.

Your appointment starts with an 1-hour group session. The transplant surgeon or doctor will talk about kidney/pancreas 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 what kinds of positive changes a kidney/pancreas 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 have time to speak privately with the doctor and 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's assistant* 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.

Diabetes is a major risk factor for heart disease, even if you are feeling well, so all patients with diabetes will be seen by a cardiologist (heart doctor). As part of the cardiac evaluation you will be scheduled for an EKG and imaging studies that will look at your heart function.

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* to address your 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 kidney/pancreas transplant, you will need a complete medical evaluation. The evaluation tests are done to:

- Identify the extent of your kidney damage
- Identify how diabetes has affected your body
- See if kidney/pancreas 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
- Hemoglobin A1-C
- C-peptide
- Screening for certain infections

These chemistry values need to be in balance 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, other testing may be ordered.

The transplant clinical coordinators will help you arrange for any tests or procedures that will be done at Northwestern Memorial Hospital. If insurance coverage permits, some exams may be able to 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 you need to follow. Some of these tests are described in Appendix E.

### **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/pancreas 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 **always 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.**

#### **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 GOH.
- If you are not on dialysis, the tubes will be mailed to your home. You can go to any nearby hospital or doctor's office to have the blood drawn. You are then responsible for mailing the tubes back to GOH in the box provided.
- You will start getting these tubes one month after your name has been added to the transplant list.
- If you move or change dialysis center you should notify us immediately so we can let 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 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 can also 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 your dialysis appointments
- Work to keep your blood sugars under control
- 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, seven days a week**. The Transplant Nurse Coordinator will have to work quickly to find you when a kidney and/or pancreas become 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 phone numbers where you can most often be reached and a list of contact people. 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 or 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 reasons that come up when you no longer meet the transplant center's criteria. You would then become what we call a status 7 (inactive or "on hold" status).

Reasons for this might include:

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

When you are inactive on the kidney/pancreas transplant wait list you will not receive any kidney/pancreas offers, but your waiting time **will** keep adding up.

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 or 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 end up waiting 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, and 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 a living will and power of attorney gives them peace of mind. The transplant social worker can help. You can reach the social worker at 312-695- 0828.

After transplant surgery you will need transportation to and from the hospital for follow up clinic visits. These arrangements should also be made ahead of time. The timing of the visits will vary. At first they will be very often. As you are getting better the transplant clinic visits are less frequent. But you will *always* 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 and pancreas 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 call us when you start dialysis.

#### ***Every Six Months***

- Have your teeth cleaned and checked. Your doctor or dentist may want you to take antibiotics before and after your dental treatment, so check on this before your appointment.

#### ***Long Term***

Arrange for your time away by planning for:

- An extended absence away
- 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.)

### **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, doctors, 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/pancreas offers can happen at all hours 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 becomes available. The organ bank asks the pre-kidney/pancreas Transplant Nurse Coordinator to find you and verify that you are healthy and available for surgery. The Transplant Nurse Coordinator will talk to you about the donor organs, including any special circumstances, so that you will have all the information you need to choose to accept or turn down the organ(s) that is (are) offered (informed consent). The doctor will also join the call to answer any questions you may have. If you choose not to accept the kidney/pancreas, you will not lose your place on the waiting list. We can only tell you our best estimate of your chances of getting another offer soon.

The Transplant Nurse Coordinator will tell you how to prepare for the transplant. You may be told to come to the hospital right away or to come in several hours. In most cases, our procurement team will go out to obtain the donor kidney and pancreas. The organs are checked carefully to make sure they are suitable for transplant. While the donor's kidney and pancreas are being checked, you will be in the hospital waiting for the results. As soon as we know that organs are okay, you will be taken to surgery. If the organs are not okay, then you will be sent home to wait for another offer. If the donor organs are not suitable, you will still keep your place on the waiting list.



## 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 include:

*Anesthesiologists and the critical care team* will monitor your care during surgery and in the ICU.

*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 get ready 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's assistants, 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 laboratory 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 (kidney specialists). 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 (the Transplant Unit) (or Same Day Surgery if you have a living donor), you will have blood tests, a chest X-ray and an EKG. You 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 the consent form.

You and the transplant team will wait until the condition of the donor kidney and pancreas are checked. When the organs are confirmed as acceptable 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).

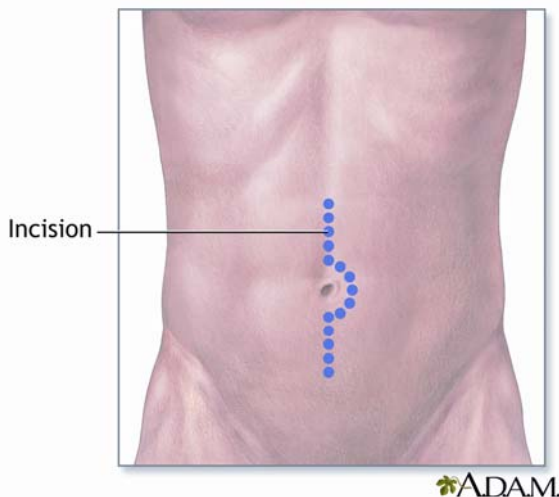
### During Surgery

Anesthesia given through your IV line will quickly cause you to fall asleep. While in the OR, you will:

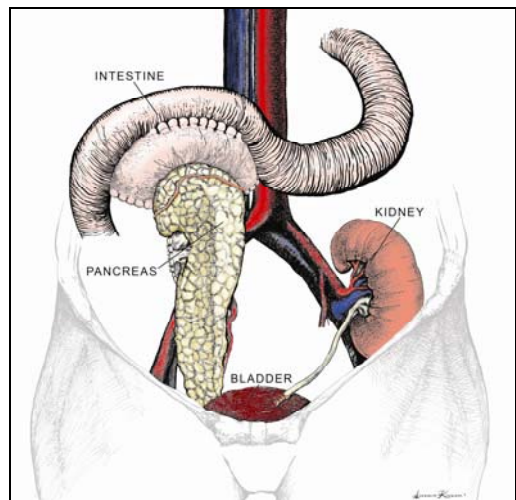
- Receive medications to keep you in a deep sleep
- Have a small tube in your mouth and throat for breathing. The tube (ET or endotracheal tube) is put in after you are asleep
- Have a catheter (tube) in your bladder to monitor your urine output. This tube is put in after you are asleep
- Have lines placed to monitor your temperature and your heart
- Have a tube (NG or nasogastric) placed down your nose to your stomach

The transplant surgeon will make a single incision in the middle of the abdomen. The new pancreas and the new kidney can both be placed through that single incision. (*see figure 3*)

**Figure 3**



**Figure 4**



Your "old" pancreas and kidneys are not removed. Once the new organs are in place (*see figure 4*), the incisions are closed with staples.

Small plastic tubes (JP drains) may be inserted to drain blood and fluid from the incision(s). Additionally, a plastic stent is placed in the ureter where it connects to the bladder.

The SPK surgery usually takes about 6 hours. A pancreas transplant alone takes about 3 to 4 hours. Your family/friends can wait at the Surgical Waiting Area on the 7<sup>th</sup> floor of the Feinberg Pavilion. At least one family member or friend needs to be in the waiting area at all times so the surgeon can talk to that person. A member of the transplant team will come out or call directly from the OR to update your family/friend on your progress during the surgery.

### **After Surgery**

From the OR, you will be taken directly to the Cardiothoracic and Transplant Intensive Care Unit (CTICU) located on the 7<sup>th</sup> floor of the Feinberg Pavilion. You will likely stay in the CTICU for one day. But your stay depends on your surgery and how sick you were before the transplant. Nursing staff and members of the transplant team will closely monitor you throughout your stay.

As you are waking up from surgery, you will be very groggy. As a gentle reminder, we place soft wrist restraints on you to keep you from pulling out any of your tubes, drains, or catheters. (It is normal to try to remove unfamiliar objects while you are groggy). The restraints are taken off as soon as you become more awake and understand what is going on around you.

The head of the bed will be raised to better help you breathe. You will be connected to a heart and blood pressure monitor.

The ET-tube may be in place to help you breathe. It is removed when you can breathe deeply on your own.

A catheter (tube) in your bladder will drain your urine. JP drains will be in place to collect fluid at the incision site. You will have a special three-way IV line on the side of your neck covered with a dressing. This IV is used for needed medicines and fluids. You may need to keep this line in for a few days after you go home.

Some patients have an upset stomach or a bloated feeling. To prevent this, you will still have the NG to keep your stomach empty.

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.

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 mucous build-up. Without deep breathing your lungs could become congested which could lead to pneumonia.

In the CTICU you will begin taking your anti-rejection medicines, first through your IV and then by mouth (orally) after your NG tube is removed.

As you continue to improve you will be transferred to the 11E Feinberg Transplant Unit for the rest of your hospital stay.

### **Transplant Unit**

On the 11East Feinberg Transplant Unit, you still will have your urine catheter, an IV and the JP drains. You will continue with the deep breathing exercises and the incentive spirometer.

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

The nurses 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 doing 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 0-10.

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 and pancreas always retain their 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.)

Depending on your progress, your stay on the 11E Feinberg Transplant Unit will be about 3 to 4 days. Our goal is to have you out of the hospital by the fifth day after surgery.

Keep in mind that there are times when the kidney and/or pancreas do not work at all or do not work well enough after surgery. In those cases you may still need dialysis and/or insulin for a while.

## Chapter 5 - Preparing For Home

### Guidelines

Before you go home the nurse will show you how to care for yourself. You may go home with an IV for about a week to help make sure you get enough fluids. You will have written instructions and your nurse will go over them with you in detail.

These might include:

- Wounds and drain care
- Care of your IV line
- How to give fluids via the IV
- Medicine instructions
- Signs of infection and rejection
- Activity and diet guidelines
- Follow-up doctor visits
- Lifestyle changes
- Who to call with questions
- Important contact phone numbers

The incision staples are removed either in the hospital or in the transplant clinic after you are discharged from the hospital.

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

If you live far from the hospital, rooms may be available at a nearby Residence Inn by Marriott. It is at 201 East Walton Place, about six blocks from the hospital. The Residence Inn offers a free place to stay after the transplant for patients and a caregiver, until they are ready to go home.

The room has a queen-sized bed, a pull-out sleeper sofa and a fully equipped kitchen. Rooms are limited, and they are only available to newly transplanted patients and donors. 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.

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.

The transplant team will be primarily responsible for your care for about 3 months. At that time, if your condition is stable, your routine care will be transferred to your nephrologists and primary care doctor.

**Important Phone Numbers**

Pre-kidney/pancreas Transplant Team (7 days per week, 24 hours a day)	312-695-0828
Transplant Financial Liaison	312-695-6322
Transplant Social Workers	312-695-0828
Patient Representatives	312-926-3112



## 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.

- |  |  |
|--|--|
| <ul style="list-style-type: none"><li>▪ Sadness, tearfulness or crying spells</li><li>▪ Loss of interest in activities that you used to like</li><li>▪ Feeling tired and having a lack of motivation</li><li>▪ Feelings of guilt, helplessness and hopelessness</li><li>▪ Forgetfulness or changes in concentration</li><li>▪ Body aches and pains, such as headaches or upset stomach</li></ul> | <ul style="list-style-type: none"><li>▪ Irritability or anger</li><li>▪ Decreased sexual desire</li><li>▪ Changes in appetite or weight</li><li>▪ Increased or decreased sleep patterns</li><li>▪ Decreased self-esteem level</li><li>▪ Withdrawing from others</li><li>▪ Altered perceptions</li><li>▪ Recurrent thoughts of death or wanting to harm oneself</li></ul> |
|--|--|

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](mailto: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 care giving, 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 only have 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 help with these co-payments. Medicare Part D will provide some coverage for your other transplant medications.

### **How long can I keep Medicare after a transplant?**

The Social Security Administration expects people to go back to work 3 years after a kidney/pancreas 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/pancreas transplant 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 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 and pancreas transplantation. However, this is a difficult question since there are a lot of different programs (Medicaid HMO, Medicaid and QMB, and Medicaid with a spend-down) within the Illinois Department of Public Aid (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 either be on dialysis or have a kidney 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 kidney transplant. If you have private insurance, it would be in your best interest to consider applying for Medicare as a secondary insurance.

**If I have more than one 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 primary.*

**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 for 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 a flat co-pay 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 go home on:

- 2 anti-rejection medications, which patients must stay on for the rest of their lives
- 2 medications to prevent viral and bacterial infections (for 3 to 6 months)
- Some medicines they 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 Hospital offers a range of financial assistance programs to ensure that quality healthcare is accessible for 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 available programs and can assist you with the application process.

*It is important that you understand your insurance coverage and gaps. 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 the doctor tells you that you should not work after transplantation. You can usually 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 for a discounted rate at any of the information desks on the second floor.

### **Can my family sleep in my room?**

Since there are only private rooms, overnight guests are allowed to stay in the hospital room at Northwestern Memorial Hospital unless you are in the intensive care unit.

Special hotel arrangements are made at the Residence Inn for you and one family member if you:

- Have had your transplant and are discharged from the hospital
- Live a great distance from the hospital

Patients and families can also 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/pancreas transplant patients?**

For a kidney transplant recipient, the average length of stay in the hospital is 2 days. For pancreas alone transplant patients the typical length of stay is 4-5 days. For a SPK transplant, the average length of stay in the hospital is 7 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. These 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 group, 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 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  
281-261-2682  
[aota@pdq.net](mailto:aota@pdq.net)

### CENTERS FOR MEDICARE AND MEDICAID SERVICES

[www.cms.hhs.gov](http://www.cms.hhs.gov)

### MEDICARE

[www.medicare.gov](http://www.medicare.gov)

### NATIONAL COUNCIL ON PATIENT INFORMATION AND EDUCATION

for information and education  
202-347-6711  
[ncpie@erols.com](mailto:ncpie@erols.com)

### NATIONAL FOUNDATION FOR TRANSPLANTS

for fundraising information and short-term financial assistance  
800-489-3863  
[natfoundtx@aol.com](mailto:natfoundtx@aol.com)  
[www.transplants.org](http://www.transplants.org)

### SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS

[www.srtr.org](http://www.srtr.org)

### TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION (TRIO)

for information, education, networking and support  
800-874-6386  
[www.trioweb.org](http://www.trioweb.org)

### UNITED NETWORK FOR ORGAN SHARING

888-894-6361  
[www.unos.org](http://www.unos.org)

## 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:

- **Blood urea nitrogen (BUN):** A by-product of protein breakdown. A BUN test helps to assess kidney function.
- **Calcium (Ca):** Important for muscle function, normal heart rhythm, blood clotting and for healthy bones and teeth.
- **Carbon dioxide (CO<sub>2</sub>):** A gas that is a natural waste product of the body. Changes in the CO<sub>2</sub> 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):** Is another of the body’s waste products.

**Creatinine Clearance:** is not a blood test. It 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) virus. This is done before you get your transplant to help us know your risk of CMV disease after transplant.

**CMV PCR Quantitative:** is a blood test to look for and measure the CMV virus 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 blood tests 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 by-product 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 bone mineral loss, 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. This includes polyps which 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 of looking inside your body. The images produced are cross-sectional planes taken from a part of your body, much like slices taken out of 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 special steps to be taken both prior to 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 (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, 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 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
- Can 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 one hour. ERCP is helpful in detecting diseases of the pancreas, bile ducts, liver and gallbladder. It can also 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 seen and captured in real time, showing movement. The exam, done in the Ultrasound department, takes about 30 minutes.

A **heart ultrasound** looks at the heart. The test uses sound waves to project an image. This allows the doctor to view the heart 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 seen 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 heart beat (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 will often note changes in how the heart muscle contracts.

Although Dobutamine is the most common drug for this test, other drugs may be used instead. Thus, 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 which checks 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 (O<sub>2</sub>) 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 of 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 is also 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 1st set is taken when you are at rest. The 2nd 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 2 radioactive tracers to show the blood flow (perfusion) to the heart muscle. The amount of radiation used in this test is small and well within limits that are not harmful. Your total test time is 3 to 3½ hours.

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

- **KUB:** is an X-ray of your abdomen with a focus on your kidneys, ureters and bladder.
- **CXR: is a chest C-xray**
- **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.

### **DCD - Pancreas**

**This script must be read, as written, to the patient during the organ offer. The patient must verbally confirm that he/she is accepting this offer. The coordinator will document your response as required.**

#### **DCD – Donation after Cardiac Death**

Most pancreas organs 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 differs. It is a Donation after Cardiac Death (**DCD**). DCD refers to organs obtained from donors who have died (heart stopped beating) just a short time before their kidneys and pancreas were removed.

Compared to brain-dead, heart-beating donors, DCD kidney- pancreas recipients may have:

- A longer hospital stay
- The same outcomes at one, 3 and 5 years post-transplant (patient survival and organ function)

We carefully select organs from DCD donors that we believe are safe for pancreas transplantation.

*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 pancreas should be similar to a brain dead, heart beating donor pancreas.

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 positive

**This is what will be read to you when a donor kidney that is positive for Hepatitis B 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.**

The donor tested positive for *Hepatitis B core antibody*. At some point in the donor's life:

- They were exposed to the Hepatitis B virus
- or
- The donor has had a recent infection with Hepatitis B virus and has not yet made antibody.

You also have been exposed to Hepatitis B **or** have had immunization shots and have antibody to protect you from the virus. But there still is a slight risk that you could get a Hepatitis B infection. To prevent infection, we will treat you with the antiviral medications.

*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.

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 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 High-Risk (for transmission of HIV) 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.**

### **High-Risk Donor**

You are being offered an organ from a deceased donor who is considered to be high risk for transmitting certain infections. The Centers for Disease Control (CDC) considers donors to be “high risk” if they participated in certain high-risk behaviors, such as:

- Prostitution
- IV (into the vein) drug use
- Homosexuality

We do not accept organs from such donors unless we feel that the benefits far outweigh the risks.

*The doctor will talk to you about the specific risks this donor has. 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.*

The blood tests so far show that this donor is *not* infected with viruses such as HIV, Hepatitis B or Hepatitis C. But, while rare, false negative results can occur. From available data from organ, tissue and blood donors, we know there is a small chance (between 1 in 60,000 and 1 in 2 million) that an infectious agent could be transmitted from the donor to you.

You are being offered this organ because your doctor believes that the risk of turning this organ down and waiting for another organ is much greater than the risk of accepting this organ.

If you accept this organ, you will be referred to the Transplant Infectious Disease group. They will monitor you for several months after your transplant. There are treatments for most of the recognized infections you might possibly get from your donor, so if transmission occurs, the Infectious Disease doctors will arrange for treatment.

We believe that the risk of accepting this organ is extremely small or we would not suggest that you accept it. 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.

## 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.*

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