

Kovler Organ Transplantation Center

## Living Kidney Donation

A Patient Handbook

## Welcome

Welcome to the Kidney Transplant program at Northwestern Memorial Hospital. Being a kidney donor is an important decision. Donating a kidney to someone in need can make a very positive change in that person's life, but there are risks for you. We want to make sure that you have all of the information you need to make an informed decision. It is a decision that only you can make. This handbook will help you understand what it means to donate one of your kidneys. You need to know what to expect, both in the short term and the long term. You also need to understand the risks involved.

This handbook describes:

- The screening, evaluation and matching process
- Potential risks and benefits
- The hospital experience
- Preparing for home and recovery
- The role of the Independent Donor Advocate

The entire multidisciplinary transplant team (referred to as “transplant team” in this handbook) is here to help you with both your decisions and your care. We will provide the best care possible for you before and after your surgery. This team is a group of health care professionals who have special training and experience in transplantation and includes:

- Transplant surgeons
- Transplant nephrologists
- Psychiatrists
- 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.

## Opportunities for Your Feedback

At Northwestern Memorial Hospital, our belief and commitment is *Patients First*. We want every patient to receive the best care and service. To provide the best possible care, 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* found in the waiting area in our outpatient clinic.
- A *Patient Satisfaction Survey* will be mailed to your home after your hospital stay. 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.

## Being a Kidney Donor

It is important to know that it is *your choice* to donate. You must not feel pressured or that donating is something you “have to do.” This is a decision you need to make for yourself. You have the right to change your mind at any time. Your reasons for doing so will remain confidential. We will support you no matter what you decide.

As a potential donor you will go through a very thorough evaluation to make sure there are no medical or psychosocial problems that would prevent you from being a donor.

Every donor is assigned an *Independent Donor Advocate*. The Independent Donor Advocate is involved **only** with *your* well-being and is not involved with the recipient. The advocate gives you information about the donation surgery as well as about possible risks to both you and the recipient.

As with all patient information, please know that all of your medical information and anything that you discuss will remain confidential, subject only to authorized release. Any decisions you make, including your reasons to donate or not to donate, will remain private. No one but you can call and ask about your medical evaluation or for any information. You may change your mind and withdraw from the program at any time.

KOVLER ORGAN TRANSPLANTATION CENTER

LIVING DONOR KIDNEY: A Patient Handbook

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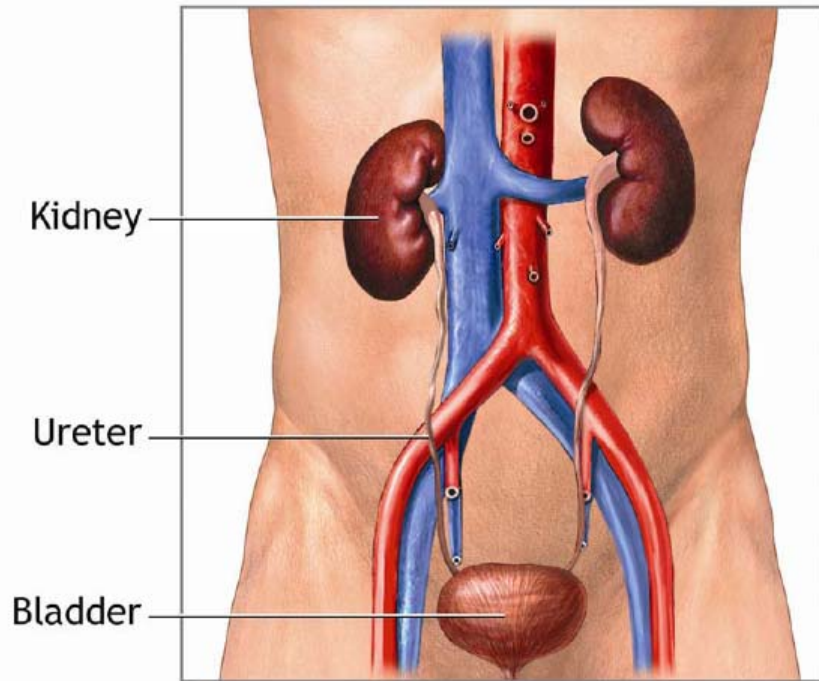
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## The Kidney

### Chapter 1: The Kidney

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

*Figure 1*



The kidneys help your body:

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

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

When nephrons stop working, this is called end-stage renal disease (ESRD). There are many causes of ESRD.

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

Kidney transplantation restores the functions of the kidney. With a new kidney, a patient should not need dialysis any longer and should have a better quality of life.

### **Living Donor Kidney Transplantation**

In organ transplantation, the person who receives an organ is called the recipient. The person giving the organ is called the donor.

All potential living donors must:

- Be in good health
- Undergo a thorough evaluation process
- Understand and accept the surgery and its risks, including medical, psychosocial, and financial implications
- Volunteer to be a transplant donor
- Understand and accept that the outcome of the transplant may not be as expected
- Be able to tell the team clearly their reasons for donating once they are aware of all of the benefits and risks

As a possible donor, you may come to a group educational meeting to learn all about living donation. If you are still interested, we will provide you with a screening Health Questionnaire, or you can call us and we will send you one. You will have a blood test done to find out your blood type. If your blood type is compatible with the recipient's blood type, you will have more testing to make sure that you are medically able to donate. (In some cases, donors who do not have a compatible blood type may also be considered.) The transplant team works very carefully to make sure there are no medical or other issues that may increase the risk to you as a donor, either at the time of the operation or in your future.

#### *Screening*

You will have a blood test done to find out what your blood Type is. The four blood Types are:

O, A, B, AB

If your blood type is compatible with the recipient's blood type OR your recipient can be treated to accept your blood type, you can begin the next phase of the evaluation.

#### Usually:

- Blood group O can donate to blood groups O, A, B, AB
- Blood group A can usually only donate to blood groups A or AB
- Blood group B can usually only donate to blood groups B or AB
- Blood group AB can usually only donate to blood group AB

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Before being considered for donation, a careful screening or *evaluation* process takes place. This helps make sure that the best possible care and outcome happen for both you and the recipient. The screening process looks at your health and your ability to donate. The phases of this evaluation process are described below and will be explained to you.

The tests will include:

- Medical history
- Psychosocial history
- Diagnostic tests
- Evaluation of the kidney's size and shape
- Evaluation of the kidney's blood vessels and ureters

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

## Chapter 2: Evaluation Process

The donor evaluation process begins when you are identified as a possible donor and continues until the time of the transplant or if the tests show you can no longer be considered as a donor.

Remember that the goals of the evaluation are to make sure you are:

- Healthy enough to donate
- Comfortable with your decision

<p><i>We welcome your questions at any time</i></p>
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### *Phase 1*

As a potential donor, you begin the evaluation process by contacting the Independent Donor Advocate (IDA). The IDA will:

- Explain the four phases of the evaluation
- Talk about the risks of donating a kidney
- Answer any questions that you have

At this time the IDA will also ask you about your health history. You can come to listen to a donor talk at this time or an information packet can be mailed to you. In the packet, you will fill out a Health Questionnaire that comes with your donor packet. This form will be reviewed by one of our doctors to see if you can be a potential donor.

To be a kidney donor, a person should:

- Be at least 18 years old and be able to make informed decisions
- Have no history of long term (chronic) illnesses such as cancer, diabetes or heart disease
- Be willing to donate; and not feel obliged or pressured to do so
- Be able to comply with needed follow-up care
- Have a personal physician
- Have health insurance

During the evaluation process, know that **at anytime, in any phase**, you can:

- Ask questions
- Change your mind and withdraw from the program. ***Any reasons for doing so will remain private.***

If the evaluation shows that you have a medical problem, we will refer you back to your own doctor for further testing. At this point your evaluation as a donor stops until the problem is resolved.

It is important to know that there are other treatments options for recipients. They could

- Choose another donor
- Wait for a deceased donor
- Be treated with dialysis



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### Behavioral Risk Questions

Any time that blood, tissue, or organs are transplanted from one person into another, there is a risk of passing on hidden disease or infections. Most of the time, if there are any problems, they are found during the evaluation. Sometimes, though, they are not.

Although our main concern is your health and well-being, we also need to make sure the recipient will not get sick from any hidden disease or infections you may have.

Some behaviors put people at risk for certain diseases or infections. We will ask **all** potential donors about their lifestyle. Just like all of your health information, these answers are kept private. If you tell us about a high-risk behavior you may still be able to donate, but you will need some special testing. Since there might be a very small risk of passing that illness to the recipient, we have to let him or her know that there is that specific risk.

You can withdraw from the program at anytime.

***Reasons for doing so will remain private.***

If you do not want the recipient to know this information you would not be able to donate. We will simply tell the recipient that you are unable to donate for health reasons.

### **The Donor Talk:**

You are welcome to come to a donor talk and learn about donation. At this education meeting you will spend about 1-2 hours with the transplant team learning about donation.

You will need to understand the:

- Screening process
- Steps in the evaluation process
- Types of donations
- Potential psychosocial issues which could affect success of recovery
- Surgery, including the possible risks and benefits
- Timing of the donor and recipient surgeries
- Recovery process
- Importance of having health and life insurance

If you are still interested in donating, we will draw two samples of your blood (one now and one during phase 4) to see if your blood type is compatible with the recipient's blood type.

Depending on your recipient's circumstances, we may draw another blood sample to see if your recipient's body would immediately destroy your kidney. This blood test is called a *crossmatch*.

We may also do another blood test— this is called *Human Leukocyte Antigen (HLA) typing* or “tissue typing.” This is done to see how closely your tissue matches that of your recipient. You *do not* have to be a perfect tissue-typing match to your recipient.

If your first crossmatch is positive, you may still be able to donate. We have special treatments for the recipient that may still make donating possible.

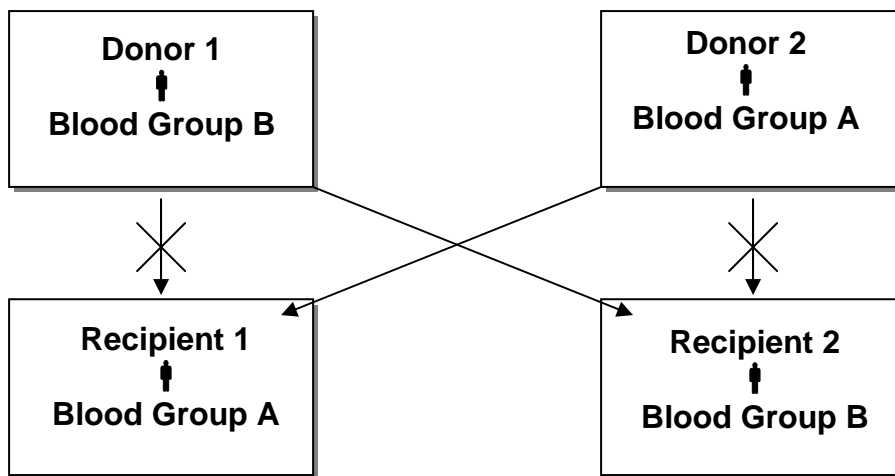
## Paired Kidney Exchange For Living Donor Kidney Transplantation

Sometimes, potential donors are not able to donate to their recipient but still wish to be a kidney donor. *The Paired Kidney Exchange Program* allows you to donate your kidney to another recipient, and that recipient's donor can donate to your recipient. The diagram on this page helps show what this means.

If the special treatments do not work and it is not possible for you to donate to your recipient, there is another option. It is called a "swap" or paired kidney exchange program. Please see the box to the left for more information.

Sometimes we do not do these tests until later in the evaluation. Even if we do the crossmatch test in phase 2, it is repeated in phase 4 to make sure nothing has changed.

## Example of a Basic Paired Kidney Exchange



### What are 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 reacts by forming antibodies against the flu virus. So when the flu germs (the antigens) come to you, these antibodies will destroy them and you will not get the flu.

Your body also makes antibodies when it is exposed to ("sees") tissue or blood from another person. The recipient's body makes antibodies the same way.

This can happen for example, with pregnancies, blood transfusions or previous transplants.

When the recipient has antibodies in his or her bloodstream and is exposed to human tissue (in this case your kidney) with a similar genetic code, the recipient's body will attack it just as it does the flu germs.

Sometimes, if the recipient has antibodies against your antigens, you cannot be the donor. Other times we can give the recipient special treatments and it may still be possible for you to be the donor.

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### **Financial and Insurance Issues**

Financial and insurance concerns are also discussed. The recipient's insurance usually covers:

- The cost of the evaluation
- All the tests and doctor visits
- The surgery
- Your hospital stay
- Needed follow-up care

If there are any follow-up tests that we need for our required reports, the recipient's insurance may not pay for them. In this case, the Transplant Program will cover the costs.

Many times the recipient's insurance does not cover travel expenses. You may also be responsible for some out-of-pocket costs. You may need to use your own health insurance for any:

- Follow-up tests you may need if a medical problem was found in your evaluation
- Post-transplant complications that may develop many months later

The transplant social worker or IDA may be able to help you find other ways to deal with any expenses. It is also very important that you make sure you have health and life insurance before you donate. Donating a kidney may make it harder for you to get life or health insurance in the future, so you want to make sure you have both before you donate. If the transplant is not done in a Medicare approved center, it could affect the ability of the recipient to have his/her anti-rejection medications paid for by Medicare Part B.

### ***Phase 2***

Phase 2 includes blood tests to make sure that there are no medical reasons that will keep you from being a donor. These tests include:

- Complete blood count (CBC) with platelets
- Chemistry Panel
- Liver function tests (LFTs)
- Prothrombin Time / International Normalized Ratio (PT/INR)
- Lipid panel

Blood will be drawn to look for diseases such as:

- Hepatitis
- Syphilis (RPR)
- Cytomegalovirus (CMV)
- Epstein-Barr virus (EBV)
- HIV

You will also have:

- A chest X-Ray
- An electrocardiogram (ECG)

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Several urine tests will be done to check the health of your kidneys. These will include:

- Urinalysis (UA)
- Urine culture
- 24 hour urine collection for protein and creatinine clearance

### ***Research Studies***

*Northwestern Memorial Hospital is affiliated with Northwestern University Feinberg School of Medicine. 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.*

### ***Phase 3***

In phase 3 you will have a general History and Physical (H&P). To make sure that *your* interests come first, the exam is done by a doctor (usually a nephrologist). This exam helps us know if you have any risk, for example, for kidney and heart disease, infection or cancer. If you have a risk for diabetes, you need to know that you are at an increased risk to develop diabetes and perhaps kidney disease in the future.

Based on your H&P, we may do other tests. These might focus on:

- The health of your coronary arteries
- How well your lungs work (for smokers)

We recommend that any cancer screening be done by your own doctors. These tests might include:

- PAP smears for women
- Mammogram
- PSA
- Colonoscopy

In some cases, a more thorough exam by a dentist may be needed. There is a risk for dental injury at the time of surgery if the donor has serious gum disease and/or tooth decay.

It is important to know that some testing and exams will need to be covered by your own health insurance. These include any that are added:

- For your own general health screening
- Because of any abnormal results that may have been found during your evaluation

If these initial exams are okay, you will get a computerized tomography (CT) scan. The CT scan will check for problems with your liver, lymph nodes, adrenal glands (glands on the kidney) and spleen. This will help select which one of your kidneys will be donated.

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You will see a social worker – who is your IDA- and possibly a psychiatrist to review your psychosocial history. You will talk about things like:

- Alcohol intake
- Smoking history
- Substance use and abuse
- History of mental illness and any treatments you may have had
- Behavioral risks

While most donors are confident of their decision to donate, some donors may experience depression and anxiety (no matter what happens). It is important to have support systems at home – people to:

- Help you understand what is happening
- Share your feelings with
- Help you understand what you need to do
- Help you get treatment if you need it

After all of the testing is done, we will let you know if there are any health issues that could affect your ability to donate and/or to recover. If you are a suitable donor and decide that you still want to donate, a 7-day “cooling off” period is then required for all living donors. You and a family member(s) are asked to talk about all of the information at home. This allows you time to think about and be sure of your decision.

### **Possible Risks of Kidney Donation**

Remember that the evaluation is done to make sure that you are healthy and the risks of donating are minimal. There are risks to every surgery. The risk is different with every person. The transplant team works to make sure there is the least possible risk to you, either at the time of the surgery or in the future. Some possible risks are listed in the box on page 10.

## Possible Risks of Kidney Donation

### *Surgical*

- Death
- Severe bleeding
- Infections
- Pain
- Organ failure
- Hernia
- Need to stop the surgery to protect you from significant risk or death
- The need for blood products during surgery
  - Risk of viral infection
- Complications of general anesthesia, including:
  - Brain injury or death
  - Need to be on a ventilator
- Surgical scars at the incision site
- Need to return to the operating room, for example for:
  - Bleeding
  - Bowel perforation,
  - Wound breakdown
  - Infection

### *Medical*

- Fatigue
- Nausea and vomiting
- Major blood clot(s)
- Cardiac arrhythmias and cardiovascular collapse
- Pneumonia
- Damage to other organs and organ failure
- Wound infection
- Leg numbness

### *Psychosocial/ Financial*

- Post-surgical depression related to:
  - Complications
  - Feelings of burden
  - Body image (scar)
  - Family tensions
  - Loss of employment
  - Related financial and emotional concerns
- Loss of work or inability to do work due to:
  - Evaluation testing
  - Surgery
  - Recovery time
- Inability to obtain future employment or health, life or disability insurance

## *Phase 4*

### **Pre-Surgery Preparation**

After the “cooling off” period and if you agree to be a donor, surgery is scheduled. One to 2 weeks before the surgery date, both you and the recipient may need to have an updated:

- Physical exam
- EKG
- Chest x-ray
- Blood tests including blood type and final crossmatch

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You will meet with the surgeon and the transplant nurse coordinator who will again review:

- Transplant outcomes
- Risks to you
- Any personal, financial, and psychological impact
- The hospital stay, after care, and at-home care

You will also see a video about the donor surgery.

The doctor and transplant nurse coordinator will answer any questions you may have and review your pre-surgery instructions, which include:

- Where to go on the day of surgery
- What time to be at the hospital
- Bowel preparation

You will give a verbal consent for the donor surgery during this meeting. A signed consent will be obtained on the day of surgery.

It is important not take any aspirin, ibuprofen, or herbal supplements for at least one week before your surgery.

On the day before surgery, do not eat or drink anything after midnight.

As always, you can change your mind at any time.

## CHAPTER 3 - HOSPITAL STAY

### Before Surgery

Early on the morning of the surgery, you are admitted to the Same Day Surgery unit on the 5<sup>th</sup> floor of the Galter Pavilion, 201 East Huron. (The recipient is usually admitted to the Transplant Unit on 11 East in the Feinberg Pavilion.) While you are waiting, two adults may visit.

You will change into a gown and put on special compression leggings (to help prevent blood clots in your legs). A doctor will explain the surgery again, including possible risks. You will be asked to consent to the surgery in writing.

The 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 cause you to fall asleep quickly. Then you will have a:

- Small tube placed in your mouth and throat for breathing. (The tube is called an ET or endotracheal tube).
- Catheter (tube) in your bladder to monitor your urine output

You will likely donate your kidney by *laparoscopy*. The surgeon will make several small port holes on your side (usually the left side) and a 2 to 3 inch incision a little lower to remove your kidney and ureter. Usually the incision will be closed with dissolving sutures. Small white pieces of tape (SteriStrips™) and/or skin glue is used for the port sites.

## OPERATIVE TECHNIQUE

*Figure 2*

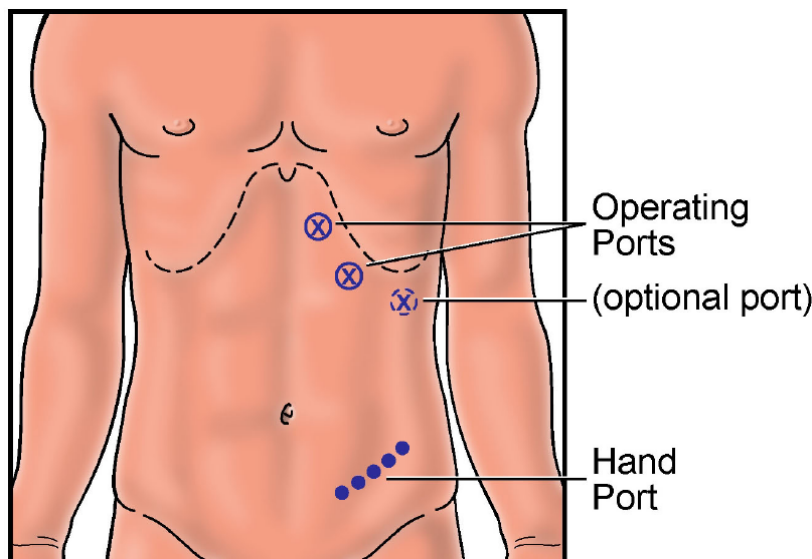


Figure 2 - Illustration provided by © MOVCO Media Productions



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If a laparoscopy is not possible, an open incision along your side will be made. This might happen if problems develop during the laparoscopic surgery and you are at risk for serious complications. Since your safety is the most important thing, we will make the best decision as we need to keep you safe.

Surgery may be stopped if:

- Complications develop in surgery that increase your risk
- Something unexpected happens to the recipient and the transplant cannot be done

While you are in surgery, 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 update your family/friend on your progress during the surgery.

### **After Surgery**

From the OR you will be taken directly to the Transplant Unit (11E) on the 11<sup>th</sup> floor of the Feinberg Pavilion. The nurses and the transplant team will continue to watch you closely.

When you wake up after surgery, you will be very groggy. As a safety measure, you will have soft wrist restraints on to keep you from pulling out any of your tubes or drains while you are waking up. (It is normal to try to remove the unfamiliar objects while you are groggy.) The restraints are taken off as soon as you are awake and understand what is going on around you.

You will feel weak, tired and sore. The nursing staff will be at your bedside often to check on you and keep you comfortable. They will give you medicine for any pain that you might have.

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, it is more difficult to relieve.

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 this medicine is working.

You will be connected to a heart monitor. To ease your breathing, the head of the bed will be raised and the ET tube may be in place. While rare, there is a chance that you may need to be on a ventilator for a while. Once you can breathe deeply on your own, both the ET tube and ventilator will be removed.

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After the ET tube is removed, 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 also lets you see how deeply you are breathing. Deep breathing is important to:

- Keep your lungs clear of fluid and mucous build-up
- Guard against pneumonia

**A catheter in your bladder will drain your urine. It is taken out the first day after surgery.** Most of the time, everything but a simple IV in the arm will be taken out by the next day.

As you are able, your diet will gradually advance and soon you should be eating normal food.

Depending on how well you are doing, you should be able to go home the next day.

Most often, you are discharged from the hospital when you:

- Can tolerate a clear liquid diet
- Can walk without help
- Have bladder function
- Have good pain control

The transplant team members are here to help you. As always, we welcome your questions and those of your family. Knowing what to do will ease your transition home.

### **Going Home**

Your nurse will discuss in detail how to care for yourself and provide important contact phone numbers. You will need to know:

- How to take your medicines
- Signs of infection
- Guidelines for your activity and diet
- Who to call with questions
- Your follow-up appointment schedule/doctor visits

If you live far from the hospital, rooms may be available at a nearby Residence Inn by Marriott, 201 E. Walton Place (about 6 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.

There are a few rooms available and they are offered only 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.

## Chapter 4 - Follow-up Care

### Home Care Guidelines

#### *Activity*

During the day, it is important to vary your activities. Rest when you get tired but do not lie down for long periods of time. Get up and walk every hour while you are awake. Gradually increase the distance you walk every day. Do not resume strenuous exercise until you talk to your doctor at your follow-up visit.

It is important that you do *no heavy lifting* (nothing heavier than a gallon of milk) for 4 to 6 weeks. After 4 weeks, you can gradually increase the amount you lift.

If you had laparoscopic surgery, it is common to feel bloated. You should feel normal in about a week. Walking often helps relieve the pressure. If bloating lasts more than 2 weeks, please call your transplant team.

#### *Diet & Fluids*

There are no diet restrictions when you are home. Keep taking a stool softener to help prevent constipation and straining with bowel movements. It also helps to have more fluid, fruit, raw vegetables, whole grains, and prune juice in your diet.

#### *Bathing, Incision and Drain Care*

Do not take a tub bath until your Steri-Strips™ are off. You can shower or take sponge baths. Allow water to flow over your incision(s). Gently wash the area with a soft, clean cloth and pat dry. There is no need to cover the wound with a dressing.

The Steri-Strips™ offer extra support while your incision heals. Over time, these strips curl up and fall off on their own or they will be removed in the outpatient Transplant Clinic.

#### *Driving/Work*

Check with your doctor or transplant nurse coordinator before you start driving. Often, patients can drive 1 to 2 weeks after surgery. You should not drive while you are taking prescription pain medicine.

Talk to your doctor or transplant nurse coordinator about going back to work. Most patients can return to work in about 4 to 8 weeks. But it depends on your work and its demands.

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### *Medicine*

Be sure to take all of your medicine as directed.

Incision pain and tenderness will lessen over the next 2 weeks. Pain and discomfort can be relieved with your prescribed pain medicine or Tylenol®. You may need to take this medicine regularly, as directed, for the first few days after surgery. This should help control your pain and allow you to be more active. Talk to your doctor if your medicine does not control your pain. To prevent nausea, it helps to take pain medicine with food.

If your pain medicine has acetaminophen or Tylenol® in it, **do not take more than 4,000mg of acetaminophen or Tylenol® in a 24-hour period.**

*Note: Northwestern Memorial Hospital policy, as well as state and Federal laws, states that we cannot under any circumstances, take back any unused medications or supplies.*

### *About Sex*

You can resume normal relations as soon as you feel ready. However, during the first month avoid positions that cause discomfort or might strain your incision site. Please feel free to talk to your doctor or transplant nurse coordinator if you have any concerns or questions.

### **Appointments**

Before you leave the hospital, we will make an appointment for you to see the surgeon in one week. As always, please call if you have questions before that time.

You will have a follow-up appointment with the doctor and the IDA at 6 months after your donation surgery and again at 1 year and 2 years after your surgery. Please keep these appointments, even if you are feeling well. If you live a great distance from the hospital, you may be able to have your 6 month, one year and two year follow-up visits with your own doctor.

### **When to Call the Doctor**

Notify your surgeon at 312-695-0828 if you have any of the following:

- A temperature above 101.0°F
- Chills
- An increase in the temperature of your skin
- Swelling, inflammation (redness) or tenderness around your incision
- Bloating in your abdomen for more than 2 weeks

### **Important Phone Numbers**

Transplant Office	<b>312-695-0828</b> , 24 hrs a day, 7 days a week.
Donor Transplant Nurse Coordinator	312-695-0828
Independent Donor Advocate	312-695-0828
Transplant Social Workers	312-695-0828
Transplant Clinic	312-695-8900

### **APPENDIX A: Stress, Emotions, and the Transplant Process**

It is common and even healthy for organ donors and their loved ones to experience a variety of emotions throughout the donation process. These feelings will vary from person to person and everyone's responses are different and unpredictable. They may range from positive to negative, often within a very short period of time. This is all a normal part of the decision making process. It is important to understand some of the reasons for your stressors and how to successfully manage them.

During the evaluation period, organ donors often express feelings ranging from hope and resolve to guilt or anxiety. The evaluation period can be long and stressful, and sometimes marked with setbacks—both medical and emotional. It is common for emotional distress (often manifested in sadness and frustration) to increase during times when the physical discomfort or medical symptoms are worse and improve when you are feeling better. After donating you may continue to experience changes in mood as you recover from surgery and return to your daily life. It is impossible for anyone to predict your emotions or feelings of stress throughout the donation journey, but we can share with you some common experiences to help you prepare yourself for changes and think of ways to deal with them. Remember, most patients adjust well to the different phases of the donation journey—in their own way and on their own time.

#### **Depression**

Sadness is a healthy emotion and should not be confused with clinical depression. Everyone, at some point in time, feels sad or down. These emotions typically resolve in a short time. For some people, though, feelings of sadness may last more than two weeks. People may experience a host of other symptoms that affect the way the body functions. This is clinical depression and is looked at differently. Clinical depression can look different in different people, but it always includes feelings of sadness and/or a loss of interest in most activities. For example, one person with clinical depression may have difficulty concentrating, feel down, and have less energy, poor sleep and less of an appetite. Another person may feel unmotivated, have little enjoyment in activities, and have feelings of guilt, self-blame and shame. They may feel hopeless and tearful. No matter how each person experiences depression it is distressing and can interfere with quality of life and normal activities of daily living.

Having some or all of the following symptoms, when experienced for two weeks or longer, may indicate depression:

- Sadness, tearfulness or crying spells
- Loss of interest in activities that were once enjoyable
- Lack of motivation and increased fatigue
- Feelings of guilt, helplessness and hopelessness
- Forgetfulness or changes in concentration
- Body aches and pains, such as headaches or upset stomach
- Irritability or anger
- Decreased sexual desire
- Changes in appetite or weight
- Increased or decreased sleep patterns
- Decreased self-esteem level
- Withdrawing from others
- Altered perceptions
- Recurrent thoughts of death or wanting to harm self

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Depression can occur before surgery, soon after surgery or even a long time after you donate. Depression can cause a slower recovery and can have an effect on your social relationships, your desire and capacity to be productive, your ability to follow medical recommendations and your will to live.

If you have signs of depression or if your loved ones notice them in you, call the Transplant Nurse Coordinator or your Independent Donor Advocate. It is important to look at your specific symptoms and design a treatment course that will help you. Treatment depends on what you need. It might focus on improving your mood, helping you cope with stress, and adjust to what is happening to you. Treatment can help teach you how to relax and ways to help your sleep and mood. Sometimes medication for depression is needed. By monitoring your symptoms, communicating, and possibly receiving individual counseling and/or medication, your depression can often be manageable and short lived.

### **Anxiety**

You may also experience anxiety, worry and fear during this process.

Remember, emotions that are fleeting and do not cause significant distress are normal, healthy and appropriate. Many patients express fear, anxiety and worry, for example, about whether the kidney will work or if it will be rejected, and about how donating a kidney will affect them. 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 us to think ahead, plan for future setbacks and solve problems.

When anxiety, worry and fear become overwhelming and consume your thoughts throughout the day, then worry is no longer productive. Patients may then have difficulty sleeping, trouble concentrating, increased irritability and excitability, muscle tension and sometimes even panic attacks. Anxiety is treatable and can often be helped by talking to a professional to help you name your anxiety, develop problem-solving skills, become more comfortable with your medical situation, learn relaxation techniques and find more appropriate and productive ways of coping with stress. You may also be referred for individual counseling.

Fear and anxiety are often the result “of the unknown” or when the worst-case scenario is assumed. They can often be lessened when patients have the information they need to help them understand what is going on with them, both emotionally and physically. Be sure to talk to your Independent Donor Advocate and any members of the transplant team so that you can get the information you need. Make sure you understand what is happening and what the most likely course of action or the most likely outcome will be.

To ward off anxiety, try to remain focused on things that you can control. For example, you can (and should) control keeping your appointments, exercising and eating a healthy diet, maintaining a positive outlook and being an active participant in your care. Take comfort in knowing that you are doing everything in your power to make a situation better.

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### **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 may include sadness, frustration, anger or depression.

Physical responses might include muscle tension, stomach upsets, headaches and/or changes in sleep or appetite. People often feel “butterflies” in their stomach, a rapid heartbeat, sweating or tingling in their fingers during a stressful event. Behaviorally, some individuals may cry, shout, walk away or engage in substance abuse. Everyone responds differently to stress, even to the same stressful situation. For example, what causes anxiety and insomnia in one person may 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 less likely to feel overly stressed.

Chronic stress can greatly strain body systems and damage them over time. It is especially important for those with weakened immune systems to limit the amount of stress experienced in their daily lives so that the physical effects of stress will not harm their new organ.

It is important to take a good look at your ability to cope with difficult situations. You will likely realize that you can cope with almost anything. The donation process might not be easy, but know that you have many resources to help you through the tough times and to help make them more manageable. While it is realistic to anticipate physical changes and emotions when you donate, including stress, believe in yourself and your ability to persevere 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, of course, is to take care of yourself, both mentally and physically. Some ideas are listed in the table on 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 counteract or comfort themselves in the face of stress. Not all coping strategies are healthy. For example, some people use nicotine, alcohol or illicit drugs to help them cope with stress. While these behaviors may seem to bring some immediate relief, they can eventually be the source of harm. It is important that you use healthy coping strategies to help you get through difficult situations while minimizing distress.

There is no "right way" to cope. The best way is for you to identify a variety of coping strategies that work for you, that help you feel more comfortable and at peace with the events you face. Some ideas to help you learn new ways to cope:

***Gathering information:*** It often helps to gather as much information as possible about your medical condition, what to expect during the donation process and what your responsibilities are throughout that process. Increased knowledge helps you establish more realistic expectations, which can often help lessen stress. Since stress, depression and anxiety can impair concentration and memory, it often helps if you bring someone with you to your appointments, or bring a small notebook for note taking, writing down your questions before your appointments and writing what you learned during your 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 in the Center 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 you consider faith to be an important part of coping, consider talking with someone at your religious institution, or at Northwestern Memorial, who can offer support or guidance, or working with a prayer group for example. To speak with someone at Northwestern Memorial Pastoral Services, please 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 hospitalization when you often 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 being creative, maybe watching television or movies, reading, playing games such as cards or checkers, talking with others, knitting, doing crossword puzzles, walking, inviting visitors, writing about your experience, drawing, using the computer or writing to friends, etc. Ask for help to make sure the things that you would like to do are available to you.



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**Relaxation:** Relaxation techniques can often help counter the physical and emotional effects of stress. Learning new ways to breathe, meditate or engage in imagery can 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. Engaging in leisure activities that you like to do 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:** Research tells us that 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 decision to donate:** You should not have to be on this journey by yourself. Sharing your concerns, questions, feelings and emotions with others, telling them what you need, asking for help when you need it. Loved ones usually feel more comfortable if you give them some direction.

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

### **How Should I Feel?**

There is no particular way that you *should* feel. Know that both your physical and emotional health can roller-coaster, independent of your plans or behaviors. There is much that is happening before and after you donate—it is okay to experience emotions when they appear. Resources are available to help you deal with your reactions.

### **Summary**

The donation process, while exciting and full of hope, can trigger emotions such as depression, anxiety and increased stress.

There are many ways to minimize the stress, including practicing healthy coping strategies, surrounding yourself with family and friends, focusing on the aspects of the situation that you can control, establishing realistic expectations and priorities, planning ahead and communicating effectively with your family, friends and transplant team. Monitor your emotional symptoms, discuss them, and seek help from the psychological, behavioral and educational resources that are available to you.

*For most individuals, donating an organ to a loved one is a rewarding decision,  
filled with celebration, hope and a sense of having made a difference.  
We wish you all the best throughout this journey*



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Northwestern Memorial Hospital is one of the country's premier academic medical centers and the primary teaching affiliate of Northwestern University's Feinberg School of Medicine. The hospital which is located near the medical school on the Northwestern Campus, serves as a regional and national referral center as well as a local hospital for the community.

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

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

*Para asistencia en español, por favor llamar al Departamento de Representantes para Pacientes al 312-926-3112.*

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