

Kovler Organ Transplantation Center

Living Liver Donation

A Patient Handbook

Welcome

Welcome to the Liver Transplant program at Northwestern Memorial Hospital. Being a liver donor is an important decision. Donating a part of your liver to someone in need can make a very positive change in that person's life, but there are risks for you. We want to be 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 a part of your own liver.* 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 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” throughout the rest of 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
- Hepatologists
- 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
- Pharmacist

* 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* that are 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: 312-695-0870
 - 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 Liver 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 and transplant nurse coordinator 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 LIVER: A Patient Handbook

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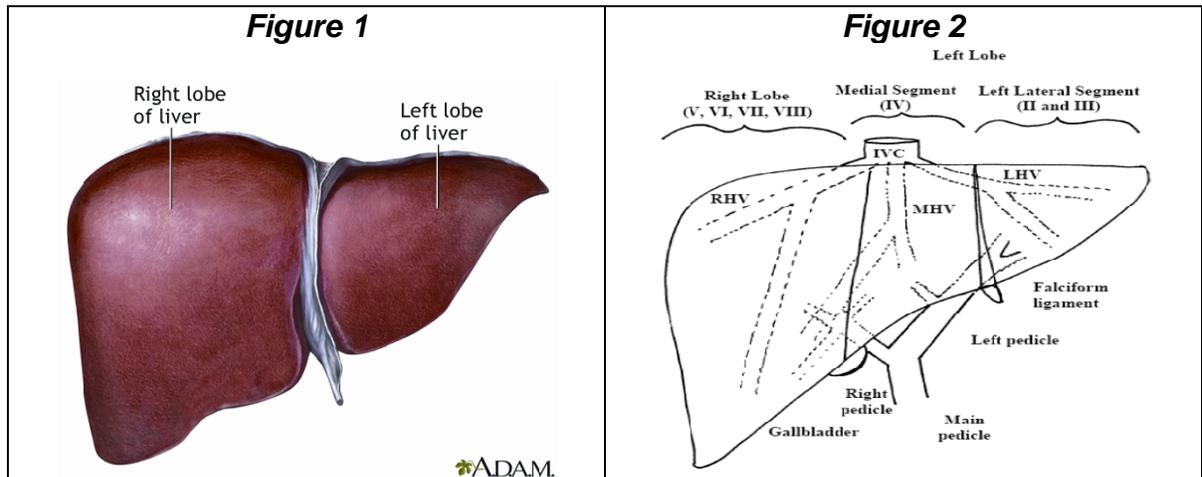
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Chapter 1: The Liver

Structure and Function

The liver is the largest organ in your body. It is about the size of a football. It has two main lobes (sections). The right lobe is larger than the left lobe. The liver is found in your abdomen, just under your right rib cage. Most of the time you cannot feel your liver.



The liver works in many ways to sustain life. Your liver helps:

- Make clotting factors that prevent bleeding
- Filter chemicals and “wastes” out of the blood (e.g., medicine, alcohol, etc.)
- Aid digestion
- Make muscle out of proteins (nutrients)
- Store extra nutrients for later use

The liver is a sturdy organ. Often, a damaged liver can heal itself. Even if almost 70% of the liver is damaged, it can still work. A healthy liver can regenerate (grow back) after it is damaged or after part of it is removed. It is the only organ in the body that can do this.

Living Donor Liver Transplantation

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

In the United States, living donor liver transplants were first done with children. The left lobe of the liver (or a section of it) from a living adult donor was given to children in liver failure. As this procedure became successful, surgeons began using right lobe donations for adults in liver failure. It is now an accepted practice for many patients, both children and adults.

Many people ask what happens to the liver when half of it is removed. After the surgery, the rest of the donor's liver will stay healthy and will meet the needs of the donor. Over 2 to 3 months, the donor's liver will grow to within 90 to 100% of the original size. Most donors can expect to return to a normal lifestyle with no changes in health, life expectancy, or the ability to have children.

Still, taking out a part of a person's liver is major surgery and has significant risks.

All potential living donors must:

- Be in good health
 - Undergo a thorough evaluation
 - Understand and accept the surgery and its risks (medical, psychosocial, and financial)
 - **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
-
- Return (early post-transplant or years later)
 - Injure the new liver

Some of the diseases that might come back are listed in the box on the right.

If the disease comes back in the donated liver we may treat it with medicines or surgery. In some cases another liver transplant is needed.

To learn about being a liver donor, call the living donor Transplant Nurse Coordinator.

The Transplant Nurse Coordinator will give you the information you need to decide if you want to be tested to be a donor.

Risk of Recurrent Disease

- Hepatitis C
- Non-alcoholic Steatorrheac
- Hepatitis (NASH)
- Primary Biliary Cirrhosis (PBC)
- Primary Sclerosing Cholangitis (PSC)
- Autoimmune Hepatitis (AIH)
- Hepatitis B
- Hepatoma
- Cholangiocarcinoma

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 you can begin the 1st phase of the evaluation.

Usually:

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

Before being considered for donation, a careful *evaluation* takes place. 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. This screening process looks at your health and your ability to donate.

The tests include:

- Medical history
- Psychosocial history
- Diagnostic tests
- Evaluation of the liver's size
- Evaluation of the liver's blood supply and bile ducts

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

We welcome your questions at any time

Potential Donor

As a potential donor, you begin the evaluation process by contacting the donor Transplant Nurse Coordinator. The nurse will:

- Ask you about your health history
- Explain the four phases of the evaluation

To be a liver donor, a person should

- Have had no major abdominal surgery
- Have no history of long term (chronic) illnesses such as cancer, diabetes or heart disease
- Be between 18 and 55 years old
- Be able to make informed decisions
- Be willing to donate (not feel obligated or pressured to donate)
- Be able to comply with needed follow-up care
- Not be overweight

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. While 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. 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.

You can withdraw from the program at anytime. ***Reasons for doing so will remain private.***

Phase 1:

In the first phase of the evaluation you will spend about 3 hours, or longer if needed, in the transplant clinic. You will learn about donation. You will also have a physical exam. To make sure that *your* interests come first, this exam is done by a doctor (usually a gastroenterologist) who is not involved in the care of the recipient.

The Transplant Nurse Coordinator will review the evaluation process and explain the surgery.

You will learn about the:

- Screening process
- Types of donations
- Surgery, including the possible risks and benefits
- Timing of the donor and recipient surgeries
- Recovery process
- Steps in the evaluation process

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. 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 post-transplant complications that may develop many months later. The transplant social worker or Independent Donor Advocate 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 part of your liver may make it harder for you to get life or health insurance in the future, so you want to make sure you have them before you donate. If the transplant is not done in a Medicare approved center, it could affect your ability to have your anti-rejection medications paid for by Medicare Part B.

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 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)
- Hepatitis Serologies
- HIV

You will see a licensed social worker or psychiatrist to review your psychosocial history. While most donors are confident about 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
- Help you understand your responsibilities
- Help you get treatment if needed

Your Independent Donor Advocate will also see you at this point and is a good resource for help.

Phase 3

If you complete Phase 2 and wish to continue with the evaluation, you will start Phase 3, often on the same day. Some of the tests you will need include:

- An **MRI** (Magnetic Resonance Imaging). This test looks closely at your liver itself, including the bile ducts and the blood vessels going to and from your liver.
- A **Liver biopsy** may be done at a later date if, your MRI or blood tests show that you might have excess fat deposits in the liver.

The Transplant Nurse Coordinator will explain any other tests that might be needed.

The surgeons will review all of the findings to see if the size and structure of your liver are right for donation. You would not be able to donate if:

- The blood vessels branch in a way that would make surgery risky
- The liver is too small
- There are too many fat deposits in the liver

Phase 4

In this final phase, we will talk to you about your test results. 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, a meeting is scheduled. You and any family members are invited to talk with the surgeon, Independent Donor Advocate and Transplant Nurse Coordinator. Details of the surgery are reviewed along with:

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

Potential Risks

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 below.

Possible Risks of Liver Donation

<i>Surgical</i>	<i>Medical</i>	<i>Psychosocial/ Financial</i>
<ul style="list-style-type: none"> ▪ Death ▪ Severe bleeding ▪ Infections ▪ Pain ▪ Organ failure ▪ Bile leaks ▪ Hernia ▪ The use of blood products during surgery <ul style="list-style-type: none"> - Risk of viral infection ▪ Complications of general anesthesia, including <ul style="list-style-type: none"> - Brain injury or death ▪ Need to be on a ventilator ▪ Surgical scars at the incision site ▪ Need to return to the operating room for reasons such as: <ul style="list-style-type: none"> - Bleeding - Bile duct leakage - Bowel perforation - Wound breakdown - Infection - Hernia 	<ul style="list-style-type: none"> ▪ Fatigue ▪ Nausea and vomiting ▪ Major blood clot(s) ▪ Cardiac arrhythmias and cardiovascular collapse ▪ Pneumonia ▪ Damage to other organs and organ failure ▪ Arm numbness ▪ Wound infection 	<ul style="list-style-type: none"> ▪ Post-surgical depression related to: <ul style="list-style-type: none"> - Complications - Feeling that you are a burden - Body image (scar) - Family tensions - Loss of employment - Related financial and emotional concerns ▪ Loss of work or inability to do work due to: <ul style="list-style-type: none"> - Evaluation testing - Surgery - Recovery time ▪ Inability to obtain future employment or health, life or disability insurance

Although it has never happened at Northwestern Memorial, there are rare cases where, after donating, your liver doesn't grow enough to replace the section you donated. In these rare cases, the donor is placed at the top of the national waiting list for an emergency liver transplant.

You and a family member are asked to talk about this information at home. A 14-day "cooling off" period is required for all living donors. This allows them time to think about their decision. (This cooling off period may not be possible if the recipient is suddenly in liver failure and needs a transplant very quickly.)

Pre-Surgery Preparation

Once the "cooling off" period is over, surgery can be scheduled. Two to three days before surgery, both you and the recipient will have an updated:

- Physical exam
- EKG
- Chest x-ray
- Blood tests

The Transplant Nurse Coordinator will review pre-surgery guidelines. The doctor, Independent Donor Advocate and Transplant Nurse Coordinator will answer any questions you may have. Do not take any aspirin, ibuprofen or herbal supplements for at least a week before your surgery.

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

The transplant nurse will provide more details about what to do.

Chapter 3: Hospital Stay

Before Surgery

Early on the morning of the surgery, both you and the recipient are admitted to the Same Day Surgery (SDS) Unit on the 5th floor of the Galter Pavilion, 201 East Huron. While you are waiting, two adults can visit there.

You will change into a gown and put on special stockings (to help prevent blood clots in your legs). A doctor will explain the surgery, 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), 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 in your mouth and throat for breathing. (The tube is called an ET or endotracheal tube).
- Nasogastric (NG) tube placed into your nose and to your stomach
- Catheter (tube) in your bladder to monitor your urine output

Surgery may be done in one of two ways.

Open Incision

An open incision is the most common method. The surgeon will make an incision one of 2 ways: An incision from your chest to your upper abdomen. It will look like an upside down letter “Y” (figure 1) or an alternate incision that looks like a hockey stick (figure 2). The incision will be closed with dissolving sutures and sterri strips.

Figure 1

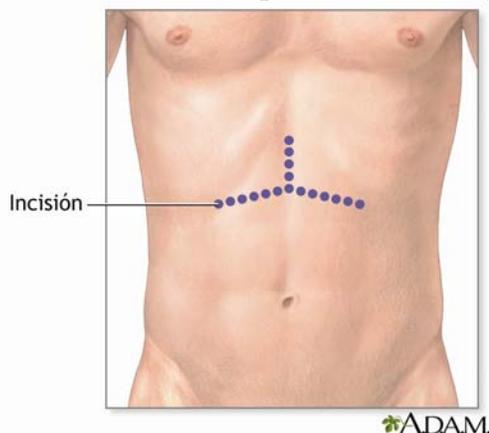
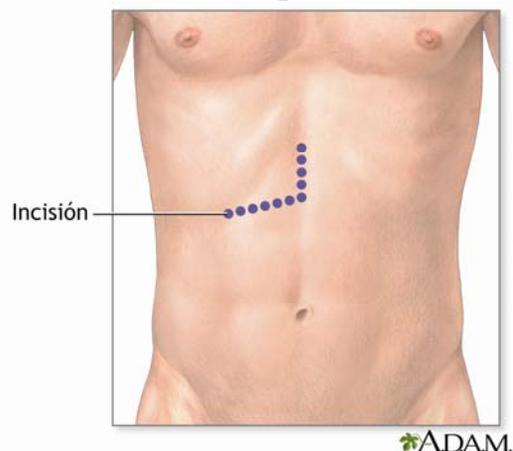
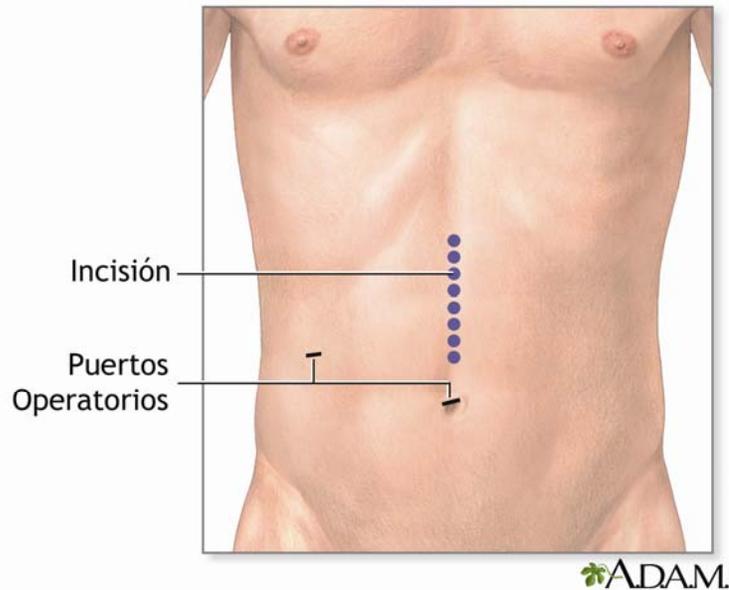


Figure 2



Laparoscopic Surgery

This surgery also involves an incision from your chest to your upper abdomen. But the incision is much shorter than with the open method. The surgeon will also make a series of small incisions in your abdomen. This is done to insert the camera scope and the laparoscopic instruments.



For each method, your gallbladder and the right lobe of your liver will be removed. (If the person you are donating to is a child, the right *or* left lobe may be removed, depending on the size of the child).

The donor surgery can take anywhere from 4 to 6 hours.

In some cases surgery may be stopped due to:

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

Every effort is made to coordinate the procedures so that the chances of these happening are minimal.

Your family/friends can wait at the Surgical Waiting Area on the 7th floor of the Feinberg building. At least one family member or friend needs to be in the waiting area at all times so that 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

CTICU

From the OR you will be taken directly to the Cardiothoracic Intensive Care Unit (CTICU) on the 7th 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 take out 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 after the surgery. 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.

You will be connected to a heart monitor. A catheter in your bladder will drain your urine. To assist 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.

After the ET tube is removed, your nurse will have you begin deep breathing and coughing exercises (10 breaths every hour while awake). To be sure you are taking deep breaths you will use an incentive spirometer. Your nurse will show you how to do this and how to support your incision with a pillow when coughing. This, along with turning in bed, helps prevent mucus and fluid buildup in your lungs and avoid complications such as pneumonia.

You will have a small tube (a JP drain) on the right side of your abdomen to remove any blood or fluid that may build up near your incision. You also will have a special three-way IV line on the side of your neck covered with a dressing. This is used for the medicines and fluids you will need.

You will be given antibiotics if you need them.

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 0-10, 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.

An NG tube will keep your stomach empty. This prevents an upset stomach or a bloated feeling and vomiting. After the first day, or when your stomach starts working again, the NG tube is taken out and you will be able to drink small amounts of fluids.

To improve circulation and prevent blood clots, you will wear elastic stockings and/or sequential compression devices (SCDs). SCDs gently squeeze your calves every so often to copy the muscle movement that happens when you walk. The nurses will also get you out of bed and into a chair or walking as soon as possible.

Most of the time, everything but a simple IV in the arm and 1 or 2 abdominal drains will be taken out the next day.

After about 24 hours in the CTICU you will be transferred to the Transplant Unit for the rest of your hospital stay.

Transplant Unit

The Transplant Unit is on the 11th Floor of the Feinberg Pavilion. Depending on how well you are doing, your stay on the Transplant Unit should be about 2 to 3 days.

As you grow stronger, you will increase your activities each day. You will eat solid food, shower and walk in the hallways 3 to 4 times per day. You will continue to wear elastic stockings or the SCDs.

Medicines may be given through your IV, orally (by mouth) or by injection (a shot). Continue to take your pain medicine. Many patients find it helpful to take pain medicine before walking or other activities that may trigger pain. Be sure to let your nurse know how your pain medicine is working. Rate your pain on a scale of 0 to 10. The pain will lessen over the next few days.

Blood tests are done to check your liver function and overall progress.

Most often you are discharged from the hospital when you:

- Can eat solid foods
- Can walk without help
- Have normal bowel and 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 when you get home will ease your transition.

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 care of your JP drain and wounds
- 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

The incision staples are removed 7 to 10 days after your surgery, either in the hospital or during a follow-up outpatient transplant clinic visit. Most patients go home with the JP drain in. Your nurse will show you how to care for the drain. It can be removed quickly during one of your clinic 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.

The room has a queen-sized bed, a pull-out sleeper sofa and a fully equipped kitchen. 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 8 to 10 weeks. After 4 weeks, you can gradually increase the amount you lift. Wear your elastic stockings as directed.

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.

So your liver can heal, it is important not to have *any* alcohol for at least 3 to 4 months after surgery. **Talk** to your transplant doctor or Transplant Nurse Coordinator *before* you start drinking any alcohol.

Bathing, Incision and Drain Care

Do not take a tub bath until your staples and JP drain are out. 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.

If you have staples closing your incision the transplant surgeon or Transplant Nurse Coordinator will take them out at your follow-up visit.

You may have Steri-Strips™ (little white pieces of tape) on your incision. These 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.

If you have a JP(s) in place, measure and record all that comes out of the drain (your “output”). Your nurse will show you how to do this. If you note any change in color of the drainage, contact the transplant clinic. Once the drain is removed, you might see a little bit of fluid come out of the site. To protect your clothing, place a dry cotton gauze dressing over the area. Once the site has scabbed over, leave it uncovered.

Driving/Work

Check with your doctor or Transplant Nurse Coordinator before you start driving. Often, patients can start driving 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 go back to work in about 8 weeks. But it depends on your work and its demands.

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. But 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 and donor transplant nurse in one week. As always, please call if you have questions before that time. You will have a follow-up appointment with the donor transplant nurse coordinator, and independent donor advocate at 6 months after your donation surgery and again at 1 year and 2 years after you donate. 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 and one year follow-up visits with your primary doctor.

When to Call the Doctor

Notify your surgeon at 312-695-0870 if you have any of the following:

- A temperature above 101.0°(F)
- Chills
- Changes in the color, odor, or amount of incision drainage
- Change in color of the JP tube drainage, (i.e., clear to cloudy or blood-tinged)
- An increase in the temperature of your skin, swelling, inflammation (redness) or tenderness around your incision
- Yellowing of the skin
- Light-colored stool

Important Phone Numbers

Transplant Office	312-695-0870 , 24 hrs a day, 7 days a week.
Donor Transplant Nurse Coordinator	312-695-0870
Independent Donor Advocate	312-695-0870
Transplant Social Workers	312-695-0870
Transplant Clinic	312-695-8900

APPENDIX A: Stress, Emotions, and the Donation 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

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 liver will work or if it will be rejected, and about how donating a liver 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.

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. 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.

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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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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