

Northwestern Medicine Organ Transplant Center

Liver Transplantation

A Patient Handbook



Welcome

Welcome to the Liver Transplant Program at Northwestern Memorial Hospital. A liver transplant in patients with end stage liver disease is a lifesaving operation.

This handbook will help you understand:

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

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

This handbook provides you and your family with important information about your liver transplant.* It describes:

- The evaluation and listing process
- Your time on the waiting list
- Your hospital stay
- How to take care of yourself at home after the transplant

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

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

- | | |
|----------------------------------|--|
| ▪ Hepatologists | ▪ Psychiatrists/Psychologists |
| ▪ Transplant Surgeons | ▪ Licensed Clinical Social Workers (LCSWs) |
| ▪ Transplant Nurse Coordinators | ▪ Transplant assistants |
| ▪ Nurse Practitioners | ▪ Patient Financial Liaisons |
| ▪ Staff Nurses | ▪ Physical Therapists |
| ▪ Registered Dietitians | ▪ Occupational Therapists |
| ▪ Licensed Social Workers (LSWs) | ▪ Pharmacists |
| | ▪ Staff Nurses |

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

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

During and after your hospital stay, the transplant team welcomes any questions you may have. Please contact us at 312-695-8900.

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

Transplant Physician and Surgeon on Call

On-Call means

Available to you...

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

Opportunities for Your Feedback

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

There are several ways for you to provide feedback.

- Please feel free to take one of the *Patient Comment Cards* that are found in the waiting area in our outpatient clinic.
- A *Patient Satisfaction Survey* will be mailed to your home after you leave the hospital. 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.

Liver Transplantation: A Patient Handbook

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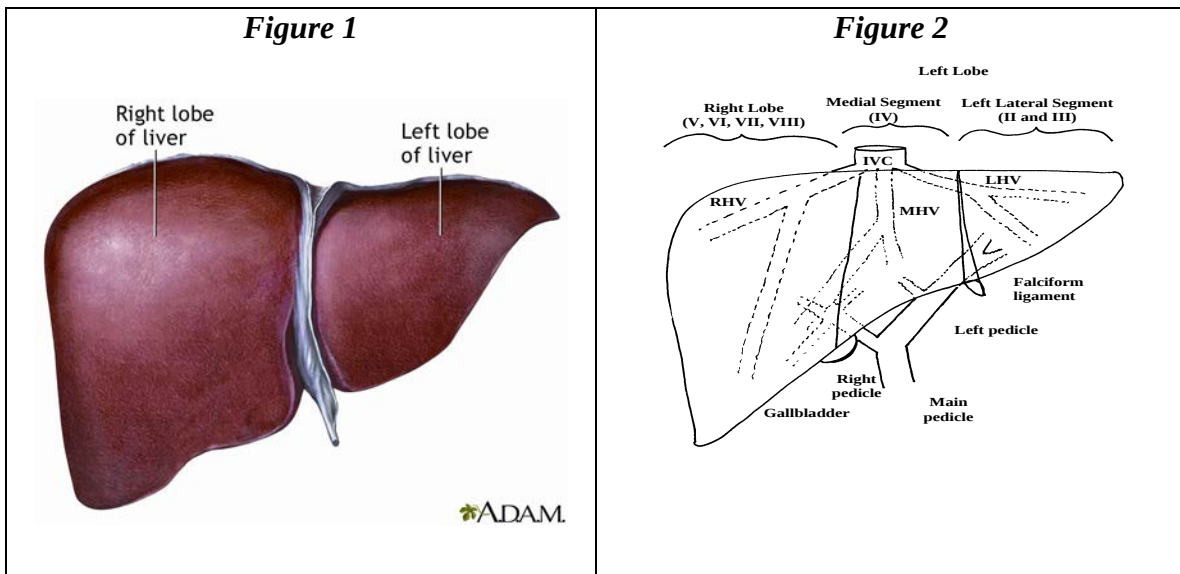
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Chapter 1: The Liver

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. (See Figure 1 & 2)
The liver is found in your abdomen, just under your right rib cage. Most of the time you cannot feel your liver.



The liver has many functions that are needed 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. However, liver disease still causes damage that makes it harder for the liver to do “its job.”

There are many causes of liver disease, e.g.

- Cancer
- Alcohol abuse
- An inherited condition
- Infection, or an injury
- Autoimmune diseases (your immune system can “attack” your liver and cause damage)
- Certain drugs if not taken properly

When disease or damage causes liver failure, the liver can no longer repair itself and forms scar tissue known as cirrhosis.

Figure 1 – Illustration provided by © A.D.A.M. Inc., 2008

Figure 2 – Illustration provided by © Michael Abecassis, MD 2008

Symptoms and Complications of Liver Failure

Cirrhosis seriously limits how well the liver can do its work. Scarred tissue, no matter what the cause, simply does not work. This may cause many health problems. The most common symptoms of liver failure are:

- Fluid build-up in the abdomen (ascites)
- Swelling (edema) of hands and legs
- Confusion and forgetfulness (encephalopathy)
- Constant itching (pruritis)
- Yellow skin and eyes (jaundice)
- Bleeding
- Chronic weakness
- Infection
- Muscle loss

See Table 1 for more details about other possible complications. Remember that the risk and types of complications differ with each patient.

Table 1: Potential Complications of Liver Failure

Anemia: decreased number of red blood cells (hemoglobin) can cause ▪ Fatigue ▪ Shortness of breath ▪ Dizziness ▪ Headache ▪ Difficulty sleeping ▪ Faster heart rate ▪ Lower blood pressure. Asterixis: a tremor that causes flapping of the hands. This is due to the build-up of ammonia. Cholangitis: inflammation or infection of the bile duct. Cholestasis: slowed or stopped bile flow from the liver. Cirrhosis: scarring of the liver.	Coagulopathy: blood clotting problems; increased risk of bleeding from even simple wounds. Fatigue: tiredness all the time, even after you rest. Gastrointestinal (GI) bleeding: bleeding from anywhere, from your esophagus to your large intestine. Ulcers, irritations or varicose veins in your GI tract can cause the bleeding. Hepatitis: inflammation of the liver cells. Palmar erythema: redness of the palms of your hands. Sepsis: infection in your blood stream that can lead to serious illness and even death.	Spontaneous Bacterial Peritonitis (SBP): the ascites (abdominal fluid) becomes infected, for no obvious reason. Spider angiomas (telangiectasia): tiny blood vessels that can be seen on your skin. Thrombocytopenia: decreased number of platelets. Your spleen can also enlarge. Thrombosis: formation of a blood clot in a blood vessel. Varices: enlargement of blood vessels throughout your gastrointestinal (G.I) tract (like varicose veins) due to increased pressure.
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When the liver fails, the pancreas has to work harder and sometimes it also fails. This may result in high blood sugar levels or **diabetes**. (In diabetes, the pancreas does not make enough insulin to keep a steady blood sugar level to meet the body's needs.)

Hepatocellular Carcinoma (Liver Cancer)

Metastatic Cancer

You cannot be a liver transplant candidate if your cancer has spread to other organs or metastasized. The post-transplant medicines will weaken your immune system and allow the cancer to grow and spread.

Localized Cancer

If the cancer has not affected any other organs, treatment options may include with or without transplantation:

- *Surgery* to remove (resect) the area of the liver that has the tumor. This is done if the rest of the liver is healthy and does not have any cirrhosis or scar tissue.
- *Chemoembolization* as an option for tumors that cannot be removed by surgery because of the location or the numbers of tumors. Using a catheter (tube) inserted into the liver's blood supply, the cancer is attacked in two ways. This is done in the hospital radiology suite.
 - First, it allows chemotherapy drugs (chemo) to be injected directly into the blood supply of the tumor. This gives the drugs more time (and contact with the tumor) to work and destroy the cancer cells.
 - Second, it uses a blocking agent (embolizer) to stop the blood supply to the tumors.

Combining chemo therapy with an embolizer has a more powerful effect than if either were given alone.

- *Radiofrequency ablation (RFA)* which uses energy (heat) to destroy the cancer cells. A thin catheter inserted into the liver tumor directs the energy into the tumor.
- *Y90/TheraSpheres* place radiation beads directly into the liver to kill the tumor. Using Xray to guide them, physicians place the TheraSpheres in the blood vessels feeding the tumor using a small catheter. This is done in the hospital radiology suite.

Some patients may need both chemoembolization and RFA.

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

Indications for Liver Transplantation

You will be considered for a liver transplant if you:

- Have an acute (sudden) onset of liver failure
- Have had liver disease (cirrhosis) for a long time
- Have liver disease that will lead to death or hurt your quality of life
- Had treatments that did not work (and others are not expected to work)

Your transplant team will talk to you about your specific diagnosis.

Liver cancer requires more discussion. Liver tumors are often first detected on routine screenings, such as blood tests or a CT scan, MRI or ultrasound of the liver. When a spot is seen on or in the liver, a biopsy will be done. Tumors are either benign (not cancer) or malignant (cancer). Some examples of benign lesions include liver cysts, a re-growing liver, or scar tissue. If the biopsy is positive for cancer, more tests are done to see if the cancer is found in other parts of the body (metastasized).

If you have cancer, you will be referred to an oncologist (a cancer specialist) for treatment.

Criteria for acceptance as a liver transplant candidate are:

- A liver transplant could improve your quality of life
- You do not have other diseases that cannot be treated **or** are not too sick to likely survive the transplant surgery
- All other medical or surgical treatment options either have not worked **or** are not a good choice for that patient
- You and your support systems (family and friends) understand and accept the risks of having a liver transplant
- You and your support systems are fully committed to and compliant with what is needed before and after the transplant, to make the transplant a success. This would include access to funding for the transplant procedure, post-transplant medicines, and other healthcare costs. The social worker and patient financial liaison may be able to help find other ways to pay for your care.*

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

Contraindications for Liver Transplantation

A liver transplant is not an option for patients who have:

- Current alcohol or drug abuse problems
- Uncontrolled infection that will not go away with a transplant
- Metastatic cancer
- Failure of other organs that will not get better with a transplant
- Uncontrolled HIV infection with AIDS despite treatment
- Irreversible brain disease or damage
- Severe, untreatable heart and lung disease

****See the Insurance/Financial Support section found on page 15.***

Other conditions that may also disqualify you from getting a liver transplant include:

- Hepatopulmonary (liver and lung) disease
- Age greater than 65 with other serious illnesses
- Severe organ disease due to diabetes
- Obesity (BMI greater than 40)
- Chronic active Hepatitis B
- Bile duct cancer
- Portal vein thrombosis
- Hepatorenal syndrome
- Pulmonary hypertension

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

Results of Liver Transplantation

In general, 85% to 90% of transplanted livers still “work” 1 year after the transplant. We can provide the most recent Northwestern Memorial Hospital results as listed in the Scientific Registry of Transplant Recipients (SRTR). You also can go to the SRTR Web site www.srtr.org to view results from Northwestern Memorial Hospital as well as from all other transplant centers in the United States. This database is updated every 6 months.

Risks of Liver Transplantation

As you will learn, the transplant process includes a complete evaluation. This involves a number of blood tests and exams. The transplant team will review all the screening and test results.

If they recommend a transplant for you, it is because they believe you:

- Are likely to do well.
- Have a good chance for a better quality of life afterwards

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

Potential Complications

Complications of liver transplantation can occur early (in the first 30 days) or later (after 30 days). Early complications might include:

- Primary non-function (the liver never works)
- Delayed liver function (the liver does not work right away)
- Bleeding (that requires surgery)
- Clotting of major blood vessels to the liver
- Rejection (usually in first 3 months)
- Infection

Late complications can include

- Rejection
- Infection
- Recurrent disease
- Cancer
- Diabetes
- High blood pressure
- Kidney failure and other side effects of anti-rejection medications

The table below lists some of the complications that may happen after a liver transplant.

Table 2: Potential Complications of Liver Transplant Surgery

<i>Surgical</i>	<i>Medical</i>	<i>Psychosocial / Financial</i>
▪ Death, ▪ Bleeding ▪ Infection ▪ Pain ▪ Organ failure ▪ Bile leaks ▪ Hernia ▪ Complications of general anesthesia, including brain damage or death ▪ Need to return to the operating room for reasons such as: - Bleeding - Bile duct leakage - Bowel perforation - Wound breakdown - Infection ▪ Need for blood products during surgery - Risk of viral infection ▪ Need to be on a ventilator ▪ Surgical scars at the incision site ▪ Damage to the nerves in your arm or leg (often short-term)	▪ Fatigue ▪ Nausea and vomiting ▪ Heart attack, stroke or major blood clot(s) ▪ Cardiac arrhythmias and cardiovascular collapse ▪ Pneumonia ▪ Damage to other organs and organ failure ▪ Failure of the new liver to work ▪ Rejection of your transplanted liver ▪ Recurrence of disease (Hepatitis B or C) ▪ Primary or recurrent cytomegalovirus (CMV) ▪ Need for re-transplantation ▪ Blood clots in the hepatic artery or veins ▪ Unidentified donor related risks such as: - Unreported illnesses by donor family - Unknown viral or bacterial infection - Unknown cancer ▪ Chronic rejection ▪ Medication side effects	▪ Post-surgical depression related to coping with: - Complications of surgery - Medications - Life changes - Feelings that you are a burden - Body image - Family tensions ▪ Loss of employment, and related financial and emotional concerns ▪ Loss of work or inability to work due to: - Illness - Evaluation testing - Surgery - Recovery time ▪ Financial and emotional concerns due to loss of work ▪ Inability to obtain future employment or afford health, life or disability insurance ▪ Inability to afford medication ▪ Financial risks or child care costs due to the need for follow-up care

A few of these complications are more common.

Wound problems. Your incision may not heal easily or it might open. You may need surgery to repair the incision or you might require dressing changes while the wound gradually closes and heals.

Rejection. A major concern after transplant surgery is the risk of organ rejection. Rejection happens when your body stops accepting your new liver. When this happens, your immune system “attacks” your new organ, as if it doesn’t belong in your body. This triggers your body to make *white blood cells* and *antibodies* which harm your new liver.

- Acute rejection often happens in the first several months after transplant. But rejection can occur at any time (that is why you must always take your medicines to prevent rejection). Most acute rejections can be reversed with higher doses of anti-rejection medicines or with other medicines. Treatment often requires blood work and a biopsy to confirm the diagnosis. In some cases you need to come to the hospital for treatment.
- Chronic rejection, if it does occur, usually develops slowly, over months to years. It can be hard to treat.

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

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

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

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

Cancer. Because anti-rejection medicines weaken your immune system you are at more risk to develop certain kinds of cancers, such as skin cancer. You will learn how to protect yourself from cancer risks.

There is also a chance for what we call **recurrent disease**. Sometimes the disease that caused liver damage can:

- Return (early post-transplant or years later)
- Injure your new liver

If the disease comes back and affects your new liver we may treat it with medicines. In some cases another liver transplant is needed.

Some of the diseases that might come back are:

- *Hepatitis C*
 - Hepatitis C Antibody will always be positive even with successful Hepatitis C treatment.
 - About 30% - 40% of patients who have untreated Hepatitis C will develop cirrhosis over decades of active Hepatitis C.
 - About 30% of patients will develop cirrhosis post liver transplant with no treatment with Hepatitis C medications.
- *Non-alcoholic Steatorrheac Hepatitis (NASH)* will come back in some patients a few years after their transplant
- *Primary Biliary Cirrhosis (PBC)* and *Primary Sclerosing Cholangitis (PSC)* rarely reoccur
- *Hepatitis B* rarely reoccurs
- *Autoimmune Hepatitis (AIH)* will come back unless you take prednisone for the rest of your life

There are potential **psychosocial problems** after your transplant. While most patients will have a better quality of life and manage side effects with success, it can be a difficult course. Some patients feel depressed and worry about their health. You may feel anxious and even guilty about depending on others for help. It is important to have support systems at home – people to help you understand what is happening and what your responsibilities are. It helps to have someone you can share your feeling with and to help you get any treatment you may need. Your transplant team members are good resources for help. Please refer to Appendix A, *Stress, Emotions, and the Transplant Process* for more information.

Alternative Treatments

Liver transplantation may not be the best option for every patient. You and your family may decide that you do not want a liver transplant. There may be medical or surgical options that will help your liver function. These are often tried first. You can also choose not to have any treatment. We will support your decision, no matter what you decide.

Liver Donor Sources

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

Livers for transplant can come from two sources:

- Living donors
- Deceased (non-living) donors

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

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

Living Donor

A living donor is an option when family members or friends *volunteer* to donate a **part** of their liver to the recipient.

Once the transplant team determines that transplantation is an option for you, you may want to contact potential donors. Potential donors need to call the donor transplant nurse coordinator to discuss living donation as part of the initial step towards being considered as a potential living donor.

After the phone interview, if the potential donor meets the criteria, a health questionnaire will be sent to the donor for completion and will be scheduled for a full medical evaluation.

The donors will have a blood test done to check their blood type. If they are of a compatible blood type, they will have more testing to make sure that they are medically able to donate. The transplant team is very thorough in making sure it is safe for the donor and the recipient, both at the time of surgery and in their future.

In addition, every donor is assigned an *Independent Donor Advocate*. This person is concerned **only** with the well-being of the donor.

All potential living donors must:

- Be in good health
- Undergo a thorough evaluation process
- Understand and accept the surgery and its risks (medical, psychosocial, and financial risks)
- **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

After the transplant, 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. The recipient's new liver will also meet the recipient's needs and will also grow to a normal size within 2 to 3 months.

Deceased Donor

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

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

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

Risks from the Donor

Any time human tissue, blood or organs are transplanted from one human (living or deceased) to another there is a risk of transferring disease or infection. Some of these are listed in Table 3: *Risks from the Donor*.

Table 3: Risks from the Donor

Infections	
▪ Infections of the central nervous system - Encephalitis (bacterial, fungal or viral) - Meningitis ▪ JC virus (causes progressive multifocal leukoencephalo-pathy) ▪ Hepatitis A, B and C ▪ West Nile Virus ▪ Cryptococcal and other fungus infections ▪ Creutzfeldt-Jacob disease ▪ Cytomegalovirus (CMV) ▪ Herpes ▪ Human Immunodeficiency Virus (HIV) ▪ Epstein-Barr Virus (EBV or mononucleosis) ▪ Human T-Lymphotropic Virus (HTLV) I/II ▪ Trypanosoma cruzi, Leishmania, Strongyloides, Toxoplasmosis ▪ Tuberculosis (TB)	▪ Severe Acute Respiratory Syndrome (SARS) ▪ Syphilis ▪ Rabies
Cancers	
	▪ Melanoma, Merkel cell (including Kaposi's sarcoma) ▪ Hodgkins disease and non-Hodgkins lymphoma ▪ Multiple myeloma ▪ Leukemia ▪ Aplastic anemia agranulocytosis ▪ Other cancers
Other	
	▪ Any new potentially communicable (spreadable) diseases identified by the Centers for Disease Control and Prevention (CDC)

We do everything we can to prevent the transfer of infection or disease, but there is always some risk.

Special Donor Circumstances

If your potential donor is what we call a *high-risk donor*, we will let you know that. You will be informed about the potential risks of that liver. You can decide to either accept the offer or turn it down. Remember, a liver from a high-risk donor is **only** offered to you if your doctor believes that:

- The benefits outweigh the risks for you.
- This is the best option for you at that time.

Some examples of special donor circumstances are listed in Table 4. More details are found in Appendix E.

Table 4: Special Donor Circumstances

<i>Special Donor Circumstances</i> ▪ Donation after Cardiac Death (DCD) ▪ Hepatitis B Core Antibody positive ▪ Hepatitis C antibody ▪ CDC High Risk Donor (for HIV) ▪ Donor with Other Identified Risks ▪ Split or Partial Livers
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Organ Allocation

Organs are given to patients on the waitlist who are in greatest need. This is based on the severity of their illness and on their MELD score (**M**odel for **E**nd-stage **L**iver **D**isease) *see page 16*. As your MELD score goes up, you are moved up on the waitlist. The transplant list is discussed in more detail later in this handbook.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Chapter 2: Evaluation and Listing Process

Medical Evaluation Process

Your first clinic appointment starts the process of learning about liver transplantation.

We ask that you bring friends and/or family members with you to this meeting. This appointment lasts a good part of the day, often up to 6 hours.

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

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

Your appointment starts with an hour-long group slide show presentation given by the transplant nurse coordinator. Then the transplant surgeon or doctor will talk about liver transplantation with you and your family members. There may be other patients and their families at this meeting as well. Your questions are most welcome. We want you to understand the transplant process and what kinds of positive changes a liver transplant can make in your life. It is our job to educate and inform you the best that we can.

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

- Transplant surgeons
- Hepatologists
- Transplant nurse coordinators
- Transplant nurse practitioners
- Clinical coordinators
- Transplant assistants
- Registered dietitians
- Psychiatrists/Psychologists
- Licensed clinical social workers or licensed social workers
- Transplant financial liaisons
- Physical therapists

Evaluation Clinic

The *hepatologist* is a doctor who specializes in liver disease. The hepatologist will manage your liver disease and:

- Often prescribes medicines
- Works closely with all your doctors (including primary care)

You will also meet one of the *liver transplant surgeons*. He or she will explain more about the transplant process, the surgery and answer your questions. The surgeon and the hepatologist will make most of the decisions about the tests you need as part of your transplant evaluation.

The *transplant nurse coordinators* and *transplant assistants* will be your main contacts during the evaluation and until the time of your transplant. They will schedule any tests or procedures you will need at Northwestern Memorial Hospital. They will also talk to you and your family about the transplant process and answer questions you may have. There is a transplant nurse coordinator on call, 24 hours a day, 7 days a week, to help deal with any liver related emergencies.

You will see the *dietitian* to address your specific nutrition needs or if you have weight problems (thin or overweight). Good nutrition is very important to help manage your liver disease, prevent complications and promote good health.

The *transplant physical therapist* will evaluate your physical ability and strength. They will provide you with recommendations regarding exercise and strength building.

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

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

As part of our transplant evaluation, you may also meet with the *transplant psychiatrist* or *psychologist*. This might happen on your 1st visit, or at a follow-up appointment. You can meet with the psychiatrist alone or with your family member(s).

The Plan

After you meet with the doctors, the transplant team will develop your evaluation plan. Based on **your** health status and needs, they will order various tests. Depending on your test results, the initial plan may change. We will also send a letter to your primary care doctor. We tell the doctor that you have met with us and provide a list of the tests you will need. We prefer that you have your testing done at Northwestern Memorial Hospital.

The Transplant Team

- | | |
|---------------------------------|--------------------------|
| ▪ Hepatologists | ▪ Anesthesiologists |
| ▪ Transplant surgeons | ▪ Respiratory therapists |
| ▪ Transplant Nurse Coordinators | ▪ Social workers |
| ▪ Blood bank physicians | ▪ Psychiatrists |
| ▪ Hematologists | ▪ Financial liaisons |
| ▪ Oncologists | ▪ Case managers |
| | ▪ Dietitians |
| | ▪ Pharmacists |

Every week the entire transplant team meets to talk about the plan for all the new liver transplant candidates. The team reviews each patient's test results including:

- The need for other tests or treatments
- Problems that would prevent someone from being a transplant candidate
- Treatment options other than transplant surgery.

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

Diagnostic Tests & Procedures

To become a candidate for liver transplant, you will need a complete medical evaluation. The evaluation tests are done to:

- Confirm that your liver is the main cause of your illness
- Identify the extent of your liver disease
- Evaluate the complications of your liver disease
- Make sure any problems you do have would not be made worse by a transplant

Blood Tests

All evaluations include 5 main types of blood tests.

- Complete blood counts (CBC) with platelets
- Chemistry panel
- Liver function tests (LFTs)
- Prothrombin time/International Normalized Ratio (PTT/INR)
- Alpha-fetoprotein (AFP)

After the evaluation process, these blood tests are done regularly to:

- Monitor your liver function and health status
- Assist in treating complications

Appendix C describes these tests in detail, as well as other blood work that may be done to diagnose or monitor your specific disease.

Blood Type

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

- Blood group O can accept only blood group O
- Blood group A can accept blood group A or O
- Blood group B can accept blood group B or O
- Blood group AB can accept blood groups A, B, O and AB

On rare occasions, such as in life-threatening liver failure, a blood type- incompatible donor might be considered to try to save your life.

Based on your diagnosis and the results of your initial evaluation, other testing may be ordered.

Special tests will focus on your heart, your lungs, and your kidney function. The transplant clinical coordinators will help you arrange for any tests or procedures that will be done at Northwestern Memorial Hospital. If insurance coverage permits, some of the exams may be able to be done near your home. All tests must be done at approved facilities.

Before each test, you will be told what to expect and any special instructions you need to follow. Some of these tests are described in Appendix D.

Liver Biopsy

Sometimes a liver biopsy may be needed. During the biopsy the doctor takes a tiny piece of liver tissue. The tissue is examined to identify the type and extent of your liver damage. A biopsy can also tell if cancer is present. You will be told about the risks before the biopsy is done.

A liver biopsy can be done in two ways:

1. **A percutaneous (through the skin) biopsy** uses the lower right side of the rib cage to gain direct access to the liver. First, the area is injected with a numbing medicine and then a special needle is inserted into your liver to obtain a tissue sample.

After the biopsy, you will be watched carefully for any signs of bleeding. You will need to lie flat on your right side for 2 hours. For the next hour you can lie on your back and then get up when you are ready. You will be able to get up and to go home when the biopsy team is sure there is no bleeding. The whole procedure will take 4 to 5 hours and is done in the GI suite on the 4th floor of the Galter Building.

2. **A transjugular biopsy** takes about 1 hour and is done in the Radiology department. Numbing medicine is injected into the side of your neck. Then a special catheter is placed into the jugular vein in your neck. Guided by x-ray, the catheter is threaded to the liver and a tissue sample is taken. The pressure in the liver's blood vessels is also checked.

After this procedure the nurses will watch you closely until you are ready to go home – usually for about 2 hours

For both types of biopsies, you will need to get a ride home from a friend or family member.

Research Studies

Northwestern Memorial Hospital is affiliated with Northwestern University's 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.

Dental visit

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

Insurance/Financial Support

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

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

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

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

Your transplant social worker can work with you on many transplant issues, including how to make sure you can always get the needed anti-rejection medicines. If the transplant is not done in a Medicare- approved center, it could affect your ability to have your anti-rejection medicines paid for by Medicare Part B.

You can reach the transplant financial liaison at 312-695-6322 or the social worker at 312-695-0870.

Transplant List

After your evaluation and if the transplant team decides that you are a candidate for transplant, you can be placed on the liver transplant waiting list. You will receive a letter verifying this.

When placed on the list you will be given a MELD score
Your MELD score is based on the results of 4 blood tests:

- Total bilirubin
- Creatinine
- INR
- Sodium

The MELD score ranges from 6 to 40 and indicates how urgently you need a liver transplant. Your liver disease and its complications will likely get worse over time. You will be more and more tired. Your ascites, edema and confusion may increase.. You will be less able to do your normal activities or enjoy life. As your need for a liver transplant becomes more urgent your MELD score will go up and you will move up on the waitlist. A patient who is very ill usually has a **high** MELD score. A patient who is not very ill will have a **low** MELD score.

Since your MELD score affects your place on the waiting list, keeping your MELD score up to date is the *only* way you can be sure you are in the best possible place on the wait list. **This means you *must*:**

- **Keep all of your medical and lab appointments**
- **Tell the transplant team if you are hospitalized or unable to keep your appointment.**

Based on your blood test results, we will let you know when your MELD score is going up. The higher your MELD score, the more often you will need to have your blood drawn. **If you do not get your blood work done as directed, your place on the waitlist may be lower than it should be.**

Patients with certain diseases such as hepatocellular cancer might be eligible to get a MELD score upgrade if the liver cancer is caught early enough. This score will be raised in 6 months as long as the ***tumor does not become too large or the cancer does not spread beyond the liver.*** There are other conditions that will allow us to increase the MELD score beyond the one that is calculated from your blood tests.

Some patients may be very ill from liver disease and desperately need a liver transplant, but the blood tests that we use for the MELD calculation may not show this. In these cases, we will recommend living donor transplantation. We may also suggest a liver with additional risks. We will suggest these livers only if we think that the benefit outweighs any risk for you. We will inform you so that you can make your decision. For more details, please see Appendix E.

The length of time you have been waiting on the list, or your “wait time”, is used to “break ties” when there are two or more people with exactly the same MELD score. The person listed longer will be considered first.

To learn more about calculating your MELD score you can visit <http://www.unos.org/resources/meldPeldCalculator.asp>

Liver transplant candidates may also hear the term, “status”:

Status 1: Refers to people without any prior liver disease who are in sudden liver failure and need a liver transplant within 7 days. These people are very ill and will die if they do not get a new liver as soon as possible.

Status 7: A patient’s status will change to a status 7 (inactive or “on hold” status) when the transplant center’s criteria are no longer met. (See page 8 for *Contraindications to Transplant Surgery*) Reasons for this might include:

- Uncontrollable infection
- The patient’s return to drug or alcohol use
- New complications such as a heart attack, stroke, or treatable cancer
- Lack of follow-up with appointments or doctors’ instructions

If your status changes to 7, we would discuss it with you first (if possible) and send you written notice. When you are inactive on the liver transplant wait list you will not have your MELD score updated and will not receive any liver offers.

Status 7 patients may need to redo all or part of the medical evaluation before it is decided if they can go back on the transplant wait list.

[illegible]

Chapter 3: While You Wait for a Transplant

The transplant nurse coordinators will tell you when your MELD score is going up and when you are nearing the top of the transplant wait list. But it is impossible to know how long you will be on the wait list before you are called for your transplant. Many people find it helpful to use this time to get ready for the day they do get called for their transplant.

Ongoing Tests

To remain on the transplant waitlist, all patients must:

- Have routine blood tests drawn along with any other needed tests and procedures
- Follow the care guidelines outlined by the transplant team (including no alcohol, illegal or non-prescribed drugs)
- Keep all clinic appointments

A member of the Transplant team will tell you about your appointments and any tests you will need.

Preventing Infection

There are some simple but important steps you will need to take to help prevent infection:

- Avoid contact with persons who have a cold or flu or other illness
- Practice good hand washing, which means:
 - Wash your hands for 30 to 60 seconds using soap and warm water. Scrub all areas, including between the fingers, under the fingernails, and around the nail beds.
 - Use plain soap and water for visibly dirty hands.
 - You can use alcohol-based hand rubs when your hands are not visibly dirty
 - Use alcohol-based hand-rubs for 20 seconds.
 - Always wash your hands before and after you eat, after you use the bathroom, and when visibly soiled,

Maintaining Your Health

Keep yourself in the best possible health while you are on the liver transplant waiting list. This means making choices so that you:

- Get enough rest
- Exercise and take walks each day (as you are able)
- Take only your prescribed medicines
- Do not take *any* medicines without your doctor's approval (that includes over-the-counter medicines, vitamins, herbs, and supplements)
- Keep up to date on your appointments and lab work
- Let the transplant team know about any changes in your health
- See your dentist every 6 months

Food / Nutrition

Since each liver patient is different, it is important to work with the dietitian to learn what food guidelines are important for **you**. Many times a patient may need to:

- Eat a low salt (2 gram sodium) diet. Read food labels and choose those that have less than 200 mg of sodium in each serving. Do not use table salt in cooking or add salt to any foods you are eating.
- Eat at least 3 meals and a bedtime snack each day. If you find it hard to eat a full meal, eat smaller meals more often to equal 3 meals and a snack. This will help keep your muscles as strong as possible.
- Be on a low-fat diet if they cannot digest fats (due to liver problems) Make sure that you get enough calories from other foods.
- Consider taking diet supplements if you can not take in enough calories with meals and snacks. The dietitian can help you choose the best ones for you.

Medications

The medicines you take will vary depending on your medical condition. Your doctor and transplant nurse coordinator will talk with you about any medications you will need, including:

- Purpose
- Side effects
- How long you will need to take them

Before you take **any** medications, either over-the-counter or prescribed by another doctor, be sure to ask your hepatologist or transplant nurse coordinator. This is important to avoid complications from the side effects of medications. Also, do not take medications that contain aspirin or ibuprofen which may cause bleeding. You can take acetaminophen (Tylenol®) in small doses. **Do not take more 3,000 mg of acetaminophen or Tylenol® in a 24-hour period (and that includes any drugs that have acetaminophen in them, like Vicodin®, Norco®, Tylenol #3®, Percocett® or Darvocet®).**

***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.*

Alcohol and Drugs

Stop drinking alcohol and/or taking illicit drugs! To consider you for transplantation, you and your family or support system must show us a lifetime commitment to sobriety and/or abstinence from illicit drugs which includes a verbal acknowledgement of your addiction problem and commitment to lifetime outpatient group support such as Alcoholics Anonymous or Narcotics Anonymous. We will also have you see an addiction specialist or a psychiatrist and you must agree to comply with random alcohol and drug testing during evaluation and time on the list. Any positive screening will result in you being put on hold status on the waiting list and re-evaluation

Contact Information

The transplant team must know how to get in touch with you **24 hours a day, seven days a week**. The transplant nurse coordinator will have to work quickly to find you when a liver becomes available. It is **essential** that you are easy to reach. A cell phone is helpful along with a list of contact people and phone numbers where you can most often be reached. This includes family members, friends, neighbors, etc. **Please give this list to the transplant nurse coordinator or clinical coordinator**. Update them as necessary, including:

- Home
- Work
- Cell phone
- Close family / friends / neighbors
- Places you frequently attend (e.g., church, school)

Planning Ahead

While we cannot know how long you will wait for your transplant, you can still make plans that will make things easier when you do receive “the phone call.” It is a good idea to:

- Let your employer know when you become a transplant candidate
- Complete any needed leave of absence papers in advance
- Consider how you will get to the hospital when the time comes
- Consider who will take care of your family and home

Many people find a living will and a power of attorney give them peace of mind. The transplant social worker can help. You can reach the social worker at 312-695- 0870.

After transplant surgery you will need transportation to and from the hospital for follow up clinic visits. Consider how you will handle this. These arrangements should be made ahead of time. The timing of the clinic visits will vary. At first they will be very often, daily or every other day. As you are getting better the transplant clinic visits are less often. Eventually, you should only need to come to the transplant clinic once a year. But you will *always* need to have your blood drawn regularly. Your transplant nurse coordinator, nurse practitioner or doctor will let you know how often you need to have your blood drawn. The blood draws can be done with your local doctor but the results need to be shared with the Transplant Center. This way we can monitor your liver function. You will learn more about this after your transplant.

The waiting time can be a time of hope, uncertainty, and stress for you and your family. But there are several things you can do to help yourself.

Making the Most of Your Waiting Time

Short – Term

- Make healthy diet choices
- Put yourself on a schedule that allows for exercise and rest
- Make sure it is easy to find you by phone at all times
- Call your transplant team contact as soon as there is a change in your health
- Consider joining a support group
- Complete all tests, procedures requested by your doctor, transplant nurse coordinators and clinical coordinators

Every 6 Months

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

Long Term

Arrange for your time away by planning for:

- An extended absence away
- Care for your children or other family members, pets, etc.
- Upkeep of your home or apartment
- Mail pick-up
- Financial matters (bill paying, banking etc.)

Staying in Touch

You and your family will need to be physically and mentally ready for the transplant. Please feel free to call the Transplant team with any questions. They are more than willing to answer your questions and listen to your concerns.

General questions, requests for medication refills, and information about tests and procedures can be handled by the Transplant team (312-695-0870). The Pre-liver Transplant office is open weekdays from 8:30am to 5pm.

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

If you note any of the following, please call the transplant nurse coordinator during office hours at 312-695-0870:

- | | |
|---|--|
| <ul style="list-style-type: none">▪ Tarry, dark red, or black stools (indicates bleeding)▪ Jaundice (yellowing of your eyes or skin)▪ Changes in mental condition / confusion▪ Sudden increase in weight (fluid build-up)▪ Severe itching▪ Nose bleeds | <ul style="list-style-type: none">▪ Increase in bruising▪ Dark urine▪ New swelling of your abdomen, hands and legs▪ Severe abdominal pain▪ A temperature higher than 100.5°F |
|---|--|

If you feel the problem cannot wait for office hours, call 312-695-0870 Ask the operator for the pre-liver transplant nurse coordinator on call

- Give your name, phone number, and where you are calling from
- Describe the problem

There is a pre-liver transplant nurse coordinator on call - 24 hours a day, 7 days a week. The operator will page this nurse who will quickly return your phone call. If you do not receive a call back within 20 minutes, please call again. If your problem cannot wait 20 minutes, **call 911**.

Call 911 right away if you have any of the following:

- Bleeding from the mouth, vomiting blood, or bleeding from the rectum (large amounts of red blood)
- Confusion or trouble staying awake
- Severe vomiting or severe diarrhea that lasts more than 12 hours
- Sudden, severe abdominal pain
- Fainting spell or feel lightheaded

Have a friend or family member contact the transplant office after emergency help is given.

The Phone Call

You could be called at *any time, day or night*. Remember, we **must** be able to reach you when a liver becomes available for you, 24 hours a day, 7 days a week. Be sure to give the transplant nurses coordinators a list of phone numbers including your cell phone, pager and *all* of the possible places you may be.

If your MELD score is high and you are going out of town, you must tell the transplant nurse coordinators how to reach you.

You will receive a phone call when a suitable donor is found. The organ bank asks the pre-liver transplant nurse coordinator to find you quickly and make sure that you are healthy and ready for surgery. The transplant nurse coordinator will talk to you about the donor liver, including any special circumstances. Then you will have all the information you need to choose to accept or turn down the liver that is offered. The surgeon will also join the call to answer any questions you may have. If you choose not to accept the liver, you will not lose your place on the waiting list. We can only tell you our best estimate of your chances to get another offer soon.

The transplant nurse coordinator will tell you how to prepare for the transplant. You may be told to come to the hospital right away or to come in several hours. In most cases our procurement team will go out to obtain the donor liver. The liver is checked carefully to make sure it is suitable for transplant. While the donor's liver is being checked, you will be in the hospital waiting for the results. As soon as we know the liver is okay, you will be taken to surgery. If the liver is not okay, you will be sent home to wait for another liver. If this happens you will still keep your MELD score and your place on the waiting list.

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

[illegible]

Chapter 4: The Transplant

The Surgical and Medical Hospital Staff

It is helpful to know that during your hospital stay you will meet many members of the healthcare. Some of the staff includes:

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

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

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

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

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

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

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

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

Attending physicians, resident physicians, interns, fellows, physician's assistants, nurse practitioners, and transplant nurse coordinators will follow your progress closely.

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

The medical staff includes the transplant surgeons and hepatologists. These attending physicians supervise the fellows, residents, interns, and medical students who will give you the attention and care that you need. They work together to:

- Talk about your specific needs
- Develop a plan of care just for you
- Monitor your progress.
- Change your plan of care based on your needs

Before Surgery

After your admission to 11 East Feinberg, the Transplant Unit (or Same Day Surgery if you have a living donor), you will have blood tests, a chest X-ray and an EKG. You will put on special stockings to help prevent blood clots in your legs. A doctor will explain the surgery, including possible risks. You will then be asked to sign the consent form.

You and the transplant team will wait until the condition of the donor liver is checked. When the donor liver is confirmed as acceptable you will go to the pre-operative waiting area. Your family can come with you. At this point an anesthesiologist will come in to talk with you, start an IV (into the vein) line and give you medicine to relax you. From there you will be taken into the operating room (OR).

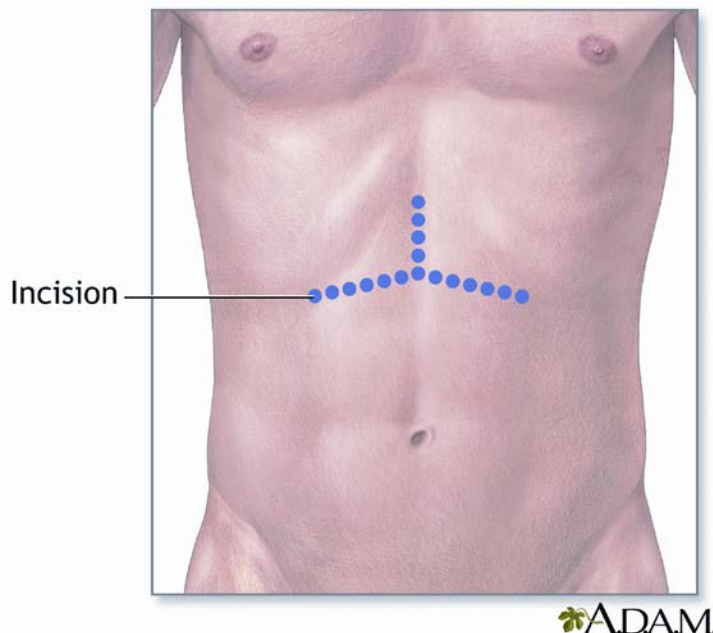
During Surgery

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

- A small tube in your mouth and throat for breathing (called an ET or endotracheal tube)
- Several IVs for your fluids and medicines
- A catheter in your artery for monitoring your heart and blood pressure and for drawing blood samples
- A nasogastric (NG) tube placed into your nose and down to your stomach
- A catheter in your bladder to monitor your urine output

The transplant surgeon will make an upside down letter “Y” or “T” incision. It starts in the center of your chest (just under the breastbone) and extends along your upper abdomen. (See Figure 3)

Figure 3



Both your gall bladder and damaged liver are removed. (Your gall bladder will not be replaced. This is done to avoid future gall bladder problems.)

The surgery can take anywhere from 4 to 24 hours, but usually takes about 5 to 8 hours. The time is longer if you had abdominal surgery before.

In some cases surgery may be stopped due to:

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

During the surgery patients usually need 5 to 6 units of blood and other blood products. This amount varies with each patient.

A member of the transplant team will come out or call directly from the OR to provide updates on your progress during the surgery. A member of the transplant team will come out or call directly from the OR to provide updates on your progress during your surgery.

After Surgery

From the OR you will be taken directly to the CTICU on the 7th floor of the Feinberg Pavilion. The nurses and the transplant team will continue to watch you closely.

The first 24 hours are crucial. Blood tests will be ordered to check how your liver is working. Most of the time your new liver will begin to work right away. If the liver does not work, you will be placed on the liver waiting list with the highest priority, but you could be too sick to get another liver or we might not find another liver for 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. This is repeated 10 times every hour while you are 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 build-up in your lungs and avoid complications, such as pneumonia.

You will have small tube(s), or JP drain (s) 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 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 to 10, with 0 meaning “no pain” and 10 the “worst pain you could imagine.” It is best to take your pain medicine before the pain becomes severe. Once it becomes severe, pain is more difficult to relieve.

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.

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

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

Transplant Unit

On the 11 East Feinberg Transplant Unit, you will continue to take a combination of anti-rejection medicines. These medicines lower your body's normal immune response and help your body accept the new liver and prevent rejection.

You will still have your urine catheter and the IV. You will continue with deep breathing exercises and the incentive spirometer.

If your NG was already taken out you will have fluids to drink. You will gradually be able to eat a normal diet.

The nurses will have you walking as soon as possible. As you grow stronger you will be able to walk in the hallways. Each day you will be able to increase your activities.

Continue to take your pain medicine. 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.

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

Your stay on the Transplant Unit will be about 3 to 4 days. The goal is to have you out of the hospital by the fifth day after surgery, depending on your progress.

[illegible]

Chapter 5: Preparing For Home

Before you go home the nurse will show you how to care for your wounds and drain(s). You will have written instructions and your nurse will review them with you in detail. This will include:

- Care of wounds, drains and tubes
- Medicine instructions
- Signs of infection and rejection
- Activity and diet guidelines
- Follow-up doctor visits
- Lifestyle changes
- Who to call with questions
- Important contact phone numbers

The incision staples are usually removed in the transplant clinic about 3 weeks after surgery. Most often the drain(s) near your incision are removed a few days after the transplant. If you go home with the drains in place, the nurse will show you how to care for them.

Arrangements for a home health nurse can be made if you need one.

If you or another family member need a place to stay, Northwestern Memorial Hospital has negotiated reduced rates at a variety of hotels near the hospital. Please call 312-926-ROOM for assistance.

You will learn more about your post-transplant appointments and your responsibilities after your transplant.

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

Important Phone Numbers

Pre-liver Transplant Team / 7 days per week, 24 hours a day	312-695-0870
Patient Financial Liaison	312-695-6322
Transplant Social Workers	312-695-0870
Patient Representatives	312-926-3112

Medications

Overview

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

Commonly Used Anti-Rejection Medicines include:

- Tacrolimus (Prograf®, Hecoria®)
- Cyclosporine (Neoral®, Sandimmune®, Gengraf™)
- Mycophenolate (Myfortic®, CellCept®)
- Sirolimus (Rapamune®)
- Everolimus (Zortress®)
- Prednisone (Deltasone®)
- Alemtuzumab (Campath®)
- Thymoglobulin®
- Rituximab (Rituxan®)
- Basiliximab (Simulect®)
- Methylprednisolone (Solu-medrol®)
- Belatacept (Nulojix®)

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

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

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

Some important facts about your medicines:

- Most medicines are taken 1 to 2 times a day. A few medicines may need to be taken 3 or 4 times a day
- **Never stop taking your anti-rejection medicines.** If you do, you risk transplant rejection.
- **Never double the dose of any medicine.** If you forget to take a dose, follow these guidelines.

For medicines taken:

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

But remember, taking the **right dose** of your medicines at the **right time** is very important!

The following anti-rejection medicines are the most commonly used. If you have any questions please ask your transplant nurse coordinator.

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

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

How to Take

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

Possible Side Effects

Diarrhea

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

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

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

Nausea/Vomiting

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

Anemia

Your blood count will be checked closely for any decrease in your red blood cell (RBC) count. If you feel more tired or fatigued talk to a member of your Transplant Team at a clinic visit.

**Important Safety information for Women who take
Mycophenolate (Myfortic®, CellCept®)**

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

Important things to remember:

- If you get pregnant while taking mycophenolate or within 6 weeks after you stop, there is:
 - A higher risk of losing the pregnancy (miscarriage) in the first 3 months
 - A higher risk that the baby will have birth defects
- You will have pregnancy tests before you start and during mycophenolate treatment.
- Your doctor will talk with you about acceptable forms of birth control. It is also recommended that you inform your routine OB/GYN doctor about taking this medicine. Information about your birth control options is provided in the Mycophenolate REMS Overview & Your Birth Control Options booklet.
 - Unless you choose not to have sexual intercourse with a man at any time (abstinence), You will always use acceptable birth control
 - During your entire treatment with mycophenolate
 - For 6 weeks after you stop taking mycophenolate
- If you are thinking about having a baby during your mycophenolate treatment, you should talk with your doctor right away.
- You should tell your doctor right away if you get pregnant during your mycophenolate treatment or within 6 weeks after you stop.
- Your doctor will report any pregnancies to the Mycophenolate Pregnancy Registry.

Tacrolimus (Prograf®, Hecoria®)

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

How to Take:

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

Possible Side Effects:

Increased Blood Creatinine

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

High Blood Pressure

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

Hand Tremors

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

Thinning of Hair

You may notice a thinning of your hair.

Elevated Blood Sugar

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

Nausea/Vomiting

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

Seizures

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

Increased Potassium

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

Decreased Magnesium

If your blood magnesium level goes down, you will need to take a magnesium supplement.

Other Medicines

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

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

Your Transplant Team will explain these and other medicines in more detail as they are prescribed to you. If you have any questions, please ask.

[illegible]

APPENDIX A: Stress, Emotions and the Transplant Process

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

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

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

Depression

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

Clinical depression is not the same in everyone. But it often includes feeling sad and/or a loss of interest in most activities. One person may have a hard time concentrating, feel irritable, sleep poorly and have no appetite or energy. Another may feel tearful and hopeless, guilty and ashamed and feel no joy. No matter what the signs are, depression is distressing and it makes it difficult to live a normal life.

Having some or all of the symptoms that are listed in this chart, when felt for 2 weeks or longer, may be a sign of depression.

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

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

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

- Improving your mood
- Helping you cope with stress
- Adjusting to what is happening to you

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

Anxiety

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

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

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

Fear and anxiety can be caused by fear of the “unknown” or when:

- The worst-case scenario is assumed
- You feel you have little or no control

As a transplant patient, there are many aspects of your health and recovery that you cannot control. But there also are many things that you can and need to control. To ward off anxiety, try to remain focused on what you can control:

- Keep your follow-up appointments
- Follow medication guidelines
- Exercise and eat a healthy diet
- Maintain a positive outlook
- Be an active partner in your care

Another way to remain in control is having the information you need to understand:

- What is happening and why
- What is the best thing you can do to help

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

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

Stress

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

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

People also vary in how they view a situation. If you believe that you can cope with or overcome the challenges that face you, then you are likely to feel less stress.

Chronic stress can greatly strain body systems and damage them over time. When you have a weakened immune system, it is especially important to limit the amount of stress in your daily life so that the physical effects of stress will not harm your new organ.

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

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

Ideas to Help Reduce Stress

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

Coping

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

There is no “right way” to cope. The best way is for you to identify coping strategies that work for you and make you feel more comfortable and at peace with the events you face. It can be hard, especially when you already have had to cope with your illness, but think about what works for you. Some ideas are described in greater detail below. Your transplant team also can help you learn new ways to cope.

Gathering information: It often helps to gather as much information as you can about your medical condition, what to expect during the transplant process and what your responsibilities are throughout that process. Knowledge helps you establish more realistic expectations, which often can help lessen stress. Since stress, depression and anxiety can make it harder to concentrate and remember things, it often helps if you bring someone with you to your appointments. You also may bring a notebook to keep track of the information you receive. You should write down your questions before your appointments and then write what you learned during that appointment. Also, feel free to visit Northwestern Memorial’s Health Learning Center, a state-of-the-art health information library on the third floor of the Galter Pavilion. Health educators are available there to help you gather information about medical topics at no charge. For more information, contact the Health Learning Center at 312-926-LINK (5465) or by e-mail at HLC@nmh.org. The Alberto Culver Women’s Health Learning Center also is available in Prentice Women’s Hospital.

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

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

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

Humor: Laughter and a sense of humor are related to a better quality of life and better physical health. Laughter can improve sleep and mood and even reduce pain. It can help you relax your breathing and improve your heart rate and blood pressure. You can help improve your spirits by looking for the humor in your situation whenever possible or by making time to read funny things or watch television shows that make you laugh.

Communicating with Family and Friends about Your Transplant

You should not have to be on this journey by yourself. Share your concerns, questions, feelings and emotions with others. Tell them what you need and ask for help. For example, let family and friends know whether you want them to visit you in the hospital, to call more often or less often, to bring your favorite foods or magazines to the hospital, to let others know about your condition or just to be there for support. Loved ones usually feel more comfortable if you give them some direction.

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

How Should I Feel?

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

Advice for Family Members and Caregivers

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

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

Summary

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

Remember some of these ways to lessen your stress:

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

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

*For most individuals, receiving a new organ is a joyous time
filled with celebration, hope and a renewed appreciation for life.
We wish you all the best throughout your transplant journey.*

APPENDIX B: Resources

AMERICAN LIVER FOUNDATION

for information, education and support

800-223-0179

www.liverfoundation.org

AMERICAN ORGAN TRANSPLANT ASSOCIATION

for information, education and support

281-261-2682

aota@pdq.net

CENTERS FOR MEDICARE AND MEDICAID SERVICES

www.cms.hhs.gov

CHILDREN'S LIVER ASSOCIATION FOR SUPPORT SERVICES

www.classkids.org

LATINO ORGANIZATION FOR LIVER AWARENESS (LOLA)

information and education for Spanish speaking individuals

718-892-8697

MEDICARE

www.medicare.gov

NATIONAL COUNCIL ON PATIENT INFORMATION AND EDUCATION

for information and education

202-347-6711

ncpie@erols.com

NATIONAL FOUNDATION FOR TRANSPLANTS

for fundraising information and short-term financial assistance

800-489-3863

natfoundtx@aol.com

www.transplants.org

SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS

www.srtr.org

TRANSPLANT RECIPIENTS INTERNATIONAL ORGANIZATION (TRIO)

for information, education, networking and support

800-874-6386

www.trioweb.org

UNITED NETWORK FOR ORGAN SHARING

888-894-6361

www.unos.org

APPENDIX C: Blood Tests

A **CBC (Complete Blood Count)** with **platelets** tells if the body is “making” enough blood. It also gives important information about:

- Blood volume (**Hematocrit or Hct**)
- Blood count (**Red Blood Cells or RBCs**)
- The blood’s ability to carry needed oxygen to all parts of the body (**Hemoglobin or Hgb**)
- The blood’s ability to clot (**Platelets or Plts**)
- The body’s ability to fight or prevent infection (**White blood cells or WBCs**)

A **Chemistry Panel** measures the level of important chemicals in the body. It includes:

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

Cytomegalovirus (CMV) antibody: A blood test to check for exposure to the CMV virus. This is done *before* you get the transplant to help us know what your risk of getting CMV is after the transplant.

Cytomegalovirus (CMV) PCR Quantitative: A blood test to look for and measure the amount of CMV virus in your blood. *This* is the test to get *after* your transplant, not the CMV antibody test.

Quantiferon TB Gold detects any previous exposure to tuberculosis.

Liver Function Tests (LFTs) provide a good picture of your liver's condition:

- **Albumin** is a protein that is made by the liver. When the liver cannot make enough albumin, fluid leaks out of your blood vessels and into your tissues. This is one cause of edema.
- **Alpha-fetoprotein (AFP)** levels help monitor the growth of any liver tumors.
- **Bilirubin** is a by-product of hemoglobin breakdown. High bilirubin levels may cause jaundice and/or mean that you might have:
 - Liver injury
 - Blood flow problems to the liver (i.e., ischemia and blood clots)
 - Blockage of the bile ducts
- **GGT** (gamma glutamyl transpeptidase) is made in the bile duct. High levels indicate:
 - Duct blockage
 - Decreased blood flow
 - Liver rejection.
- **SGOT/AST** (serum glutamic oxaloacetic transaminase/aspartate aminotransferase) is an enzyme found in the liver. A high AST signals injury to the liver, kidney, heart, red blood cells, or muscles. It will also help us monitor for liver rejection after your transplant.
- **SGPT/ALT** (serum glutamic pyruvic transaminase/alanine aminotransferase) is another enzyme found in the liver. High levels may mean liver injury (e.g. disease or rejection)..

Prothrombin time (PT), Partial thromboplastin time (PTT) and International Normalization Rate (INR) give information about how fast your blood clots. Medication, liver disease and certain foods can increase or decrease the clotting time.

Other Diagnostic Blood Tests

One or more of these blood tests may be done to identify the *cause* of your liver failure:

- *Alpha-1 antitrypsin* detects the inherited deficiency of alpha-1 antitrypsin, a protein made by the liver.
- *Anti-mitochondrial antibody* is used to detect Primary Biliary Cirrhosis
- *Anti-nuclear antibody* helps diagnose autoimmune hepatitis
- *Anti-smooth muscle antibody* helps diagnose Primary Biliary Cirrhosis or chronic active hepatitis
- *Blood group or Blood type (ABO)* identifies your blood type
- *CA 19-9* helps detect bile duct or colon cancer
- *Carcinoembryonic antigen (CEA)* helps detect bile duct or colon cancer
- *Ceruloplasmin* detects liver failure due to high copper levels
- *Hemochromatosis panel* detects liver failure caused by high iron levels stored in the liver
- *Hereditary Thrombophilia Panel* is used to diagnose a defect in the body that causes risky clots to form
- *Hepatitis Serology* checks for exposure to the Hepatitis viruses (Hepatitis A, B, or C (or if needed, Hepatitis D and E)
- *Human Immunodeficiency Virus (HIV)* checks for exposure to the HIV virus, the virus that causes AIDS (acquired immune deficiency syndrome)
- *Homocysteine level* checks the levels of this amino acid. High levels increase the risk for heart disease, stroke and peripheral vascular disease
- *Iron Storage Panel/Ferritin* measures the amount of iron in your blood

APPENDIX D: Diagnostic Tests & Procedures

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

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

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

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

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

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

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

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

This will allow special steps to be taken both prior to and after the scan.

A **dobutamine stress echocardiogram (DSE)**. See under pharmacologic stress echo.

A **2-D echocardiogram** uses high frequency sound waves (ultrasounds) to look at how the various parts of the heart work.

An **upper endoscopy (EGD, gastroscopy or esophagogastro-duodenoscopy)** is an exam that can detect diseases of the esophagus, stomach and duodenum (top part of the small intestine). An EGD is used to find the cause of:

- Persistent nausea, vomiting
- Heartburn or stomach pain
- Ulcers or bleeding
- Swallowing problems

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

- May actually view the area
- Can take a small tissue sample (biopsy)

Endoscopic Retrograde Cholangiopancreatography (ERCP) is a test used to study the ducts (drainage paths) of the liver, pancreas, and gallbladder. It uses a thin flexible tube (endoscope) with a tiny video camera and light. The tube is inserted into the mouth and to the stomach. The doctor is able to see the small openings to the common bile duct and pancreatic duct. The exam lasts about one hour. ERCP is helpful in detecting diseases of the pancreas, bile ducts, liver and gallbladder. It can also allow the doctor to:

- Place a stent (tube) to open a blockage
- Repair narrowed ducts
- Obtain tissue biopsies
- Remove stones or sludge in the ducts
- Decide the need for surgery

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

- Diarrhea or constipation
- Bleeding
- Changes in bowel habits

The test takes about 15 minutes. During the exam, a small flexible tube (sigmoidoscope) is inserted into the rectum and to the descending colon. At the end of the tube is a tiny video camera with a light. This exam may be more helpful than x-rays alone since the doctor may:

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

A **liver doppler ultrasound** uses sound waves to project an image. This allows the doctor to view organs and areas within the body. A small, hand-held device called a transducer is placed on the skin over the area to be examined. The sound waves from the transducer are reflected off the internal organs back to the transducer. The sound waves create an image on a video screen. The images are seen and captured in real time, showing movement.

A liver doppler ultrasound looks at:

- The liver
- Its blood vessels (arteries and veins)
- Blood flow to and from the liver itself

Images of the gallbladder, pancreas and spleen also are shown as part of this exam. The test, done in the Ultrasound department, takes about 60 minutes.

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

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

Pulmonary Function Tests (PFTs). A **Full PFT** is a group of tests which check lung function such as:

- How easily the air moves in and out of the lungs
- The amount of air your lungs can hold
- How much oxygen (O₂) the lungs send to the heart.

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

Every MRI patient needs to be screened to ensure that certain safeguards are in place. If you have any metal inside of your body, please tell your doctor before the exam. This may include:

- Pacemaker
- Aneurysm clip
- Ear or eye implant
- Joint or bone rods or clips
- Metal plate
- Bullets or shrapnel

It is also helpful to talk with your doctor if you:

- Cannot lie flat (for about an hour)
- Have claustrophobia (are uncomfortable with closed-in spaces).

There are **specialized MRIs**:

MRA (Magnetic Resonance Angiography): to evaluate your arteries

MRV (Magnetic Resonance Venogram): to evaluate your veins

MRCP (Magnetic Resonance Cholangiography): to evaluate your bile ducts.

Abdominal paracentesis: First an ultra sound will be done of your abdomen to make the sight where they will insert a needle with a plastic catheter to drain the fluid (ascites). The catheter is inserted into the space within the lining of the abdomen and the needle is removed. The area where the needle is inserted will be numbed before starting the procedure. This can be done either in the clinic, hospital, or radiology department. An IV will be placed into your arm to administer fluid or albumin, but only if the doctor thinks it is needed. The need for paracentesis might be required on a regular or frequent basis. This will all depend on how frequently the fluid returns.

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

The test consists of 2 separate sets of pictures. The 1st set is taken when you are at rest. The 2nd is done after a medicine is used to briefly change the blood flow to your heart, much the same way blood flow changes during exercise. The test uses a small amount of 2 radioactive tracers to show the blood flow (perfusion) to the heart muscle. The amount of radiation used in this test is small and well within limits that are not harmful. Your total test time is 3 to 3½ hours.

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

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

A **thoracentesis** may be done to drain fluid from around your lungs. After numbing the area, the doctor inserts a needle into the chest. Using a thin tube the fluid is slowly removed. An ultrasound is done before to the procedure to locate the fluid.

A **transjugular intrahepatic portal-systemic shunt (TIPS)** is done to:

- Reduce the ascites
- Decrease fluid around the lungs (hydrothorax)
- Decrease the pressure in the liver's vascular system (portal pressure)
- Help prevent stomach and esophageal bleeding

Before the TIPS you will get a mild sedative to help you relax. The doctor injects numbing medicine into the side of your neck. A small tube (shunt) is inserted into the jugular vein in your neck and threaded down into the liver. Then the shunt is placed between two major blood vessels found in the liver.

APPENDIX E: Special Donor Circumstances

DCD - Liver

This is what will be read to you when a liver donation after cardiac death is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

DCD – Donation after Cardiac Death

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

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

On average, 70% of these livers will be fine over time. But livers from DCD donors have:

- A 10-15% higher chance of failing at one year than livers from brain-dead heart-beating donors
- An increased risk for bile duct problems and infections.

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

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

The final decision to accept the organ is yours.

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

Hepatitis B core antibody

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

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

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

Kidney/SPK/Pancreas

Excellent – Top of list with a PRA < 20%

Poor – PRA between 20%-80% or not included in top 5

Very Poor - PRA > 80% or low on list

Liver

Excellent – Calculated or Assigned* Meld > 25 or a status one

Poor – Calculated or Assigned* Meld 20-24

Very Poor – Calculated or Assigned* Meld < 20 or HCC out of Milan Criteria

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

•

Hepatitis C Antibody

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

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

You also have been exposed to the Hepatitis C virus.

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

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

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

The final decision to accept the organ is yours.

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

CDC Increased Risk Donor

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

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

LIST

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

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

Risk Factor	HIV Rate	HCV Rate	Compared to HD
Men who have sex with men	0.034%	0.038%	10 times
Injection drug user	0.053%	0.378%	Same
Hemophiliac	0.0002%	0.0005%	700 times
Prostitute	0.012%	0.115%	3 times
Sex partner with any of the above	0.011%	0.135%	3 times
Exposed to HIV through blood	0.005%	0.023%	15 times
Incarceration	0.006%	0.073%	5 times

For patients on HD: You should also know that there is also a risk (0.34%) of developing hepatitis C per year while on dialysis. You should also consider your risk of death if you stay on dialysis instead of accepting this offer. Your risk of death per year of dialysis is:

Age	Risk of Death
<65 years old	3.8%
66 – 69 years old	4.2%
70 – 74 years old	5.0%
75 – 84 years old	7.3%

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

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

Kidney/SPK/Pancreas

Excellent – Top of list with a PRA < 20%

Poor – PRA between 20-80% or not included in top 5

Very poor – PRA >80% or low on list

Liver

Excellent – Calculated or Assigned* Meld > 25 or a status one

Poor – Calculated or Assigned* Meld 20-24

Very Poor – Calculated or Assigned* Meld < 20 or HCC out of Milan Criteria

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

Donor with Other Risk Identified

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

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

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

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

The final decision to accept the organ is yours.

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

Split or Partial Liver: Partial liver for adult, partial liver to baby

This occurs when a liver is offered to an adult but there is also a baby who also needs the same liver. One option is to give the larger, right lobe of the donor liver to the adult and the smaller left lobe to the baby.

This is what will be read to you when a split or partial liver is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

Split or Partial Liver

You have been offered a liver. There is a baby who also needs a liver. If you agree to share part of this liver, we will remove the smaller lobe (about 20 and 25%) of the liver and give it to the baby. The rest of the liver would be given to you.

The potential risk to you is minimal. Our experience shows that:

- These livers work just as well as a whole liver
- There may be a very small chance of developing a bile leak which usually stops by itself.
- The liver will grow (regenerate) to a normal size within 4-6 weeks.

Your doctors are offering this to you because they believe:

- The risks to you are low
- You would be helping save a baby's life.

You will not need any added medications as a result of sharing this liver. The decision is yours and we will respect any decision you make. If you choose not to share, your decision will be kept confidential.

You are being offered this organ because your doctor believes that the benefit of this organ outweighs the risk.

Again, if you choose not to share, your decision will be kept confidential.

The final decision to accept and/or share the organ is yours.

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

Split or Partial Liver: Partial liver to baby, partial to adult

This occurs when a liver is offered to a baby but there is also an adult who also needs the same liver. One option is to give the larger, right lobe of the donor liver to the adult and the smaller left lobe to the baby.

This is what will be read to you when a split or partial liver is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

Split or Partial Liver

You are being asked whether you are willing to accept a partial liver. This liver is being offered to a sick baby. Since the baby does not need the whole liver and because of your medical condition, we are offering you the other part of this liver. This represents about 75% of the size of a normal liver.

This type of partial liver has a slightly increased risk over a whole liver. This includes:

- The potential for clotting of the hepatic artery
- Bleeding
- Bile leaks
- Infection (sepsis)

If there is a significant problem with the liver (although the chances of this are extremely low), you will be placed on the liver transplant waiting list with the highest priority. But you could be too sick to get another liver or we might not find one in time.

In our experience, this type of partial liver tends to work as well as a whole liver. You will not need to take any added medications as a result of accepting this liver. The liver will regenerate or grow to a full size within 4-6 weeks. There is no difference in rejection rates between this type of partial liver and from whole livers.

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

Your doctors have considered you for a split liver because they believe that the risk of waiting for a whole liver is much higher than the risk of accepting this liver. Therefore, we are advising you to accept this liver, although the decision is yours.

The reason that you are being offered this liver is that split livers are not always offered according to the priority list. Your doctor has selected you for this because of your particular circumstances.

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

Split or Partial Liver ...partial liver to child, right lobe to adult

This occurs when a liver is offered to a child but there is also an adult who also needs the same liver. One option is to give the larger, right lobe of the donor liver to the adult and the smaller left lobe to the child.

This is what will be read to you when a split or partial liver is offered to you. After hearing this, you will be asked to confirm whether or not you are accepting this offer. The coordinator will document your response as required.

Split or Partial Liver

You are being asked whether you are willing to accept a partial liver. This liver is being offered to a sick child. Since the child does not need the whole liver and because of your medical condition, we are offering you the other half of this liver.

This type of partial liver has increased risks over a whole liver transplant. This includes:

- Clotting in the hepatic artery
- Bleeding
- Bile leaks
- Infection (sepsis)

Some of these livers do not work at all (primary non-function). If this liver does not work you will be placed on the liver transplant waiting list with the highest priority. But you could be too sick to get another liver or we might not find one in time.

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

The partial liver usually regenerates or grows to full size within 4-6 weeks. The outcomes of these transplants are good, but not as good as a whole liver. These livers:

- Do not always work well right away?
- Have more complications

Once the liver works and grows, it is as good as a whole liver. There is no difference in rejection rates between partial livers and whole livers.

Your doctors have considered you for a split liver because they believe that the risk of waiting for a whole liver is much higher than the risk of accepting this liver. Based on our experience, we believe that the benefits of accepting this liver far outweigh the risk of turning it down. Therefore, we are advising you to accept this liver, although the decision is yours.

The reason that you are being offered this liver is that split livers are not always offered according to the priority list. Your doctor has selected you for this because of your particular circumstances. If you decide not to accept this organ you **will not** lose your place on the list. However, your doctor believes that your chances of getting an offer of a whole liver are extremely low.

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

Northwestern Memorial is an equal opportunity employer that welcomes, respects and serves with dignity all people and does not discriminate, including in hiring, or employment, or admission, or access to, or treatment in its programs or activities on the basis of race, color, gender, national origin, religion, disability, handicap, age, Vietnam or other veteran status, sexual orientation or any other status protected by relevant law. To arrange for TDD/TTY, auxiliary aids and foreign language interpretation services, or for issues related to the Rehabilitation Act of 1973, call the Patient Representative department at 312-926-3112, TDD number 312-926-6363.

Questions & Answers
for Transplant
Candidates *about*
Multiple Listing *and*
Waiting Time Transfer



Who are UNOS and the OPTN?

United Network for Organ Sharing (UNOS) is a non-profit charitable organization that manages the nation's transplant system — known as the Organ Procurement and Transplantation Network (OPTN) — under contract with the federal government. As the OPTN, UNOS helps create and define organ sharing policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants.

All transplant programs and organ procurement organizations throughout the country are OPTN/UNOS members and are obligated to follow the policies the OPTN creates for allocating organs.

How am I listed for a transplant?

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

How am I considered for organs from deceased donors?

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

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

- **local.** This is the area served by the local organ procurement organization (OPO) where the donation occurs. There are 58 OPOs nationwide. These areas are often statewide but can be smaller (such as a large city or part of a state) or larger (a multi-state area). Your transplant program can tell you what your local area is.
- **region or zone.** If there are no suitable local matches, organs are offered to patients at transplant hospitals in a wider area. Kidneys, livers, pancreases and intestinal organs are first offered within one of 11 regions of the United States. Heart and lung offers are considered for candidates within 500 miles of the donor site, then 1,000 miles, then 1,500 miles.
- **nationwide.** If there are no matches in the local area or region, organs will be offered to anyone in the United States who is a potential match.

What is multiple listing?

Multiple listing involves registering at two or more transplant hospitals. Since candidates at hospitals local to the donor hospital are usually considered ahead of those who are more distant, multiple listing may increase your chances of receiving a local organ offer.

Could multiple listing shorten my waiting time for a transplant?

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

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

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

Are there any restrictions?

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

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

What is involved in multiple listing?

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

Check with your insurance provider to see if they will reimburse the cost of additional evaluations. You should also consider other costs associated with listing that insurance may not cover. For example, you may need to pay for travel and lodging if the hospital is further from your home. You should also find

out whether your post-transplant medical care will be provided at the transplant hospital or can be transferred to a facility closer to your home. In addition, you need to maintain current lab results and contact information for each transplant program where you list. Each program will need current information should they receive an organ offer for you. Through the OPTN database, your program can know if you are multiple-listed but may not know the other hospital(s) where you are listed.

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

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

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

If you are listed for a kidney transplant, your waiting time will be calculated from when you start dialysis to treat kidney failure. Your waiting time will be the same at each transplant program where you list, as long as each program has the same information about when you started dialysis.

If you are listed for any other organ type, your waiting time at each hospital will start from the date that program listed you. The longest amount of time you have waited at any hospital is called your *primary waiting time*. OPTN policy allows you to transfer your primary waiting time to another hospital, or to switch time between programs. (For example, if you have waited 9 months at Hospital A and 6 months at Hospital B, you could switch to have 6 months at Hospital A and 9 months at Hospital B).

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

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

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

If you want to end your listing at one hospital and transfer to another, your primary waiting time can be transferred as long as you coordinate with both programs. The new transplant program will probably ask you to request in writing to transfer the waiting time. Keep in mind that if you end your listing at one program *before* another program formally accepts you, *you may risk losing all previous waiting time.*

Sometimes a transplant program may inactivate for a period of time (for example, to replace a key member of the transplant team who leaves) or close its operations. If this happens, the OPTN requires that the program contact you and provide for your continuing care. If the inactivation is short-term you may choose to remain listed until the program becomes active again, but you will not receive organ offers during that time. If the program closes, the staff will work with you to arrange care at another hospital without loss of your primary waiting time.

Where can I get additional information?

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

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

UNOS also maintains a toll-free phone information line for transplant candidates, recipients and family members. The number for Patient Services is 1-888-894-6361.

Note to transplant candidates/family members:

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

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

Signature of Transplant Candidate/Family Member

Printed Name of Transplant Candidate

Date Received

Signature of Transplant Center Staff Member Providing Booklet

*Our mission is to advance organ availability and transplantation
by uniting and supporting its communities for the benefit of patients
through education, technology and policy development.*



www.unos.org/social



700 North 4th Street, Richmond, VA 23219

www.unos.org



*Questions and Answers
for Transplant Candidates about*

Liver Allocation

Questions and Answers for Transplant Candidates about the Liver Allocation System

United Network for Organ Sharing (UNOS) is a non-profit charitable organization that manages the nation's transplant system—known as the Organ Procurement and Transplantation Network (OPTN)—under contract with the federal government. As the OPTN, UNOS helps create and define organ sharing policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants.

All transplant programs and organ procurement organizations throughout the country are OPTN/UNOS members and are obligated to follow the policies the OPTN creates for allocating organs.

As part of this process, UNOS developed a system for prioritizing candidates waiting for liver transplants based on statistical formulas that are designed to predict who needs a liver transplant most urgently. The MELD (Model for End- Stage Liver Disease) is used for candidates age 12 and older and the PELD (Pediatric End-Stage Liver Disease Model) is used for patients age 11 and younger.

This document explains the system and how it affects those needing a transplant.

What is MELD? How is it used?

The Model for End-Stage Liver Disease (MELD) is a numerical scale, ranging from 6 (less ill) to 40 (gravely ill), used for liver transplant candidates age 12 and older. It gives each person a 'score' (number) based on how urgently he or she needs a liver transplant within the next three months. The number is calculated by a formula using four routine lab test results:

- bilirubin, which measures how effectively the liver excretes bile
- INR (prothrombin time), which measures the liver's ability to make blood clotting factors
- creatinine, which measures kidney function (Impaired kidney function is often associated with severe liver disease.)
- serum sodium, which measures the severity of conditions such as portal hypertension.

The only priority exceptions to MELD are the categories known as Status 1A and 1B. Status 1A patients have acute (sudden and severe onset) liver failure and a life expectancy of hours to a few days without a transplant. Status 1B is reserved for very sick, chronically ill pediatric patients (age less than 18). Less than one percent of liver transplant candidates are in these categories at any one time. All other liver candidates age 12 and older are prioritized by the MELD system.

A patient's score may go up or down over time depending on the status of his or her liver disease. Most candidates will have their MELD score assessed a number of times while they are on the waiting list. This will help ensure that donated livers go to the patients in greatest need at that moment.

MELD has been shown to rank patients on the waiting list reliably in terms of their short-term risk of death. The MELD formulas are simple, objective and verifiable, and yield consistent results whenever the score is calculated.

What is PELD? How does it differ from MELD?

Candidates age 11 and younger are placed in categories according to the Pediatric End-Stage Liver Disease (PELD) scoring system. Again, a small group of urgent patients may be listed as a Status 1A or 1B. All other candidates in this age range receive priority through PELD.

PELD is similar to MELD but uses some different factors to recognize the specific growth and development needs of children. PELD scores may also range higher or lower than the range of MELD scores. The measures used are as follows:

- bilirubin, which measures how effectively the liver excretes bile
- INR (prothrombin time), which measures the liver's ability to make blood clotting factors
- albumin, which measures the liver's ability to maintain nutrition
- growth failure
- whether the child is less than one year old

As with MELD, a patient's score may go up or down over time depending on the degree of his or her disease severity. Most candidates will have their PELD score assessed a number of times while they are on the waiting list. This will help ensure that donated livers go to the patients in greatest need at that moment.

How are livers allocated?

First, transplant candidates that are not compatible with the donor based on a number of characteristics (blood type, height, weight, etc.) are screened from the match run that determines the order a liver is offered. The remaining candidates on this match run are prioritized based on the following factors:

- the donor's age
- their medical urgency
- their geographical proximity to the donor (local—defined by the Organ Procurement Organization's service area; regional—UNOS has 11 allocation regions in the U.S.; national—all remaining candidates in the nation)

Livers from adult donors are allocated first to the most urgent candidates located in the same region as the donor; Status 1A candidates, followed by Status 1B candidates. The allocation sequence provides broader access to those most in need of a liver (those with scores higher than 35) and those who would receive the most benefit (those with scores higher than 15). Therefore, after regional Status 1A and 1B candidates, liver offers are then made to

- candidates with MELD/PELD scores 35 and higher within the donor's region, with offers first made locally, then regionally (i.e., local 40) regional 40, local 39, regional 39, etc.)
- local candidates with scores greater than 15
- regional candidates with scores greater than 15
- national candidates in Status 1A or 1B
- national candidates with scores greater than 15
- candidates with scores less than 15 locally, regionally, then nationally

If a combined liver-intestine is being offered, candidates waiting for a liver-intestine anywhere in the country may be offered the combination (based on their MELD/PELD score) after local candidates with MELD/PELD scores of 29 or higher.

Partly because pediatric transplant candidates need smaller organs, they will receive priority in the liver offer sequence if the donor is younger than 18.

Liver offer process for donors 0-10 years of age

1. Offers are first extended to all compatible pediatric Status 1A candidates located in the same region as the donor.
2. Next, the liver is offered to the remaining Status 1A candidates across the nation that are 0-11 years old.

3. If the liver has not been accepted yet, it is offered to local adult Status 1A potential transplant recipients then to Status 1A adults in the same region.
4. Next, all pediatric Status 1B candidates in the region receive the liver offer, followed by all candidates 0-11 years old in the region in order of decreasing PELD score.
5. If no one has accepted the liver at this point, it is offered to adolescent (12-17 years old) candidates that are local to the donor and have a MELD score greater than or equal to 15, then to local adults that have a MELD score greater than or equal to 15.
6. That same adolescent/adult MELD score greater than or equal to 15 sequence of offers would then be made to those potential transplant recipients in the region.
7. Following these offers, candidates with a MELD score less than 15 are offered the liver using the same adolescent/adult progression locally, then regionally.
8. If not accepted for any of these patients, the liver is then offered to potential recipients nationwide, with similar pediatric priority and those most urgent patients being offered the liver first.

Is waiting time counted in the system?

Various studies report that waiting time is a poor indicator of how urgently a patient needs a liver transplant. This is because some patients are listed for a transplant very early in their disease, while others are listed only when they become much sicker.

Under the MELD/PELD system with a wide range of scores, waiting time is not often used to break ties. Waiting time will only determine who comes first when there are two or more patients in the same allocation classification with the same MELD or PELD score.

Do MELD and PELD account for all conditions?

MELD/PELD scores reflect the medical need of most liver transplant candidates. However, there may be special exceptions for patients with medical conditions not covered by MELD and PELD. If your transplant team believes your case qualifies for an exception, they may submit information to their regional review board (RRB) and request a higher score. The RRB will consider the medical facts and determine whether or not to grant a higher score.

Is this system likely to change?

Liver allocation policy based on MELD and PELD has changed as transplant professionals have applied and learned from the system, and future changes will likely be required to better meet patients' needs. In fact, this system is designed to be flexible and allow improvements. In transplantation, as in all scientific fields, new studies are taking place all the time to learn how to save more lives and help people live longer and better.

For more information

Start with your doctor or the medical team at your transplant center. They know the most about your specific medical condition and treatment. Don't be afraid to ask questions. It will help you to have a detailed understanding of all your treatment options.

UNOS' Patient Services phone line (888-894-6361) can provide information about the OPTN and UNOS, allocation policy and other resources available to you. Additional information is available online on the following websites:

<http://www.transplantliving.org>

<http://optn.transplant.hrsa.gov>

<http://www.unos.org>

<http://www.srtr.org>

*Our mission is to advance organ availability and transplantation
by uniting and supporting its communities for the benefit of patients
through education, technology and policy development.*



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UNOSSM

UNITED NETWORK FOR ORGAN SHARING

700 North 4th Street, Richmond, VA 23219

www.unos.org

Human Immunodeficiency Virus (HIV) Testing

What is HIV?

HIV is a virus that:

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

What is AIDS?

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

How does someone get HIV?

HIV is found in the blood and body fluid (semen and vaginal secretions) of infected persons. The virus is spread from the infected person to others:

- During sex – vaginal, anal or oral.
- While sharing needles/devices used for injecting drugs or tattooing.
- By passing the virus from an HIV-infected woman to her baby during pregnancy and birth, or by breastfeeding.

How is HIV diagnosed?

A person with HIV may look and feel healthy. Many are often unaware they have HIV and can infect others. Only an HIV test can tell if you have been exposed to the virus. If you have, your immune system makes proteins called antibodies. It takes most people up to 12 weeks after exposure before the antibodies can be detected (“window period”). But in some cases, it may take as long as 6 months.

*Early testing
and treatment
can prevent
the spread of
HIV/AIDS.*

If your test is positive for HIV antibodies, it means you are infected and can infect others. If the test is negative, it usually means you are not infected. You should, however, be tested again if, in the 6 months prior to the test, you engaged in behavior that could transmit the virus.

An HIV antibody test can be done in 1 of 2 ways:

- Blood test.
- Mouth swab.

Early testing and treatment can:

- Prolong life and keep people out of the hospital.
- Prevent the spread of HIV/AIDS.

Where is testing done?

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

How can HIV be prevented?

Never share needles or injection equipment. Practice “safe sex.”

- Use latex condoms correctly every time you have vaginal, anal or oral sex. This can greatly lower your risk of infection. The only sure way to prevent HIV is not to have anal, vaginal or oral sex.
- Do not impair your judgment with drugs or alcohol.

How can I obtain more information about HIV?

Call the free and anonymous AIDS/HIV and STD Hotline at 1-800-243-2437 or TTY (hearing impaired use only) 1-800-782-0423 to learn more about:

- Your risk.
- HIV or other sexually transmitted diseases (STDs).

Illinois Department of Public Health (IDPH) www.idph.state.il.us

Centers for Disease Control and Prevention (CDC) www.cdc.gov/std/

CDC-INFO Hotline (24 hours, 7 days a week)

- 1-800-232-4636 (English and Spanish).
- 1-888-232-6348 (TTY).

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

Northwestern Memorial is an equal opportunity employer that welcomes, respects and serves with dignity all people and does not discriminate, including in hiring, or employment, or admission, or access to, or treatment in its programs or activities on the basis of race, color, gender, national origin, religion, disability, handicap, age, Vietnam or other veteran status, sexual orientation or any other status protected by relevant law. To arrange for TDD/TTY, auxiliary aids and foreign language interpretation services, 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.

Developed by: HIV Center

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For more information about Northwestern Memorial Hospital, please visit www.nmh.org.

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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 Feinberg School of Medicine. The hospital, which is located near the medical school on the Northwestern University campus, serves as a regional and national referral center as well as a local hospital for the community.

As the No. 1 hospital in Illinois as ranked by U.S. News & World Report, 2019-2020, Northwestern Memorial Hospital 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 Northwestern Medicine Organ Transplant Center is one of the top programs in the country for patient care, innovation and research. More than 450 organs are transplanted each year at Northwestern Memorial Hospital, making the program a national leader both in terms of the number of transplants and its excellent outcomes.

Patients are supported by comprehensive and compassionate care from a team of healthcare professionals through each step of the transplant process.



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nm.org/transplant