



**Your Liver Transplant:  
What You Need to Know**

**Beaumont**

# Beaumont Transplant Office and Clinic Directory

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# The Beaumont Liver Transplant Program

## Introduction

Welcome to the Beaumont Liver Transplant Program. We believe a transplant has the potential to increase the length of your life and improve its quality. Liver transplantation is a standard treatment for patients with end-stage liver disease (ESLD) and primary liver cancer. A donor liver can be from a living donor or a deceased donor. Once the liver is implanted, the recipient will need to take lifelong immunosuppressant (also known as anti-rejection) medications to prevent the body from rejecting the transplanted organ.

## Objectives

This booklet will help you understand the following information:

- end-stage liver disease, or ESLD
- the major forms of treatment now available
- the diagnostic studies needed during the evaluation phase
- the minimum time it takes to complete the evaluation
- the assessment of needs by transplant social worker, financial coordinator, dietitian and physician
- admission to the hospital
- expectations before and after surgery
- life after a liver transplant

This liver transplant booklet provides general information about the liver transplant evaluation process and briefly reviews what to expect post-transplantation. It adds to the information you receive when you complete your liver transplant evaluation.

A signature statement is provided at the back of this booklet. We will ask that you sign it at the time of your evaluation. You will also be offered the opportunity to have your questions and concerns answered.

Please keep in mind that this booklet is for general information only. Your individual treatment and experience may vary.

The Beaumont Liver Transplant Program provides comprehensive medical care to patients with chronic liver disease and guides them in choosing the best possible individualized treatment options for end stage liver disease.

Beaumont Transplant Program's data on treatment outcomes is available for national comparison at [www.srtr.org](http://www.srtr.org). This data includes comparisons of patient and transplanted organ survival as well as other data.

Our program is Medicare-certified in both adult kidney and adult liver transplants. When a center is certified by Medicare and specific conditions are met, the transplant recipient's immunosuppressant medications can be covered under Medicare Part B at the normal reimbursement rate of 80 percent. If a transplant center is a non-approved facility or if the center loses their Medicare certification, the center is unable to bill Medicare for any services related to the transplant.

### **Multidisciplinary team**

The specialized multidisciplinary transplant team includes highly dedicated transplant surgeons and hepatologists, nephrologists and immunologists, as well as transplant nurse coordinators, financial coordinators, social workers, dietitians and pharmacists. We work very closely with our patients and their families, referring physicians and other hospital disciplines and staff members to provide all the support, guidance and leading edge medical care needed in preparation for liver failure and ensuing the transplant process.

The Beaumont transplant team provides coverage for outpatients 24 hours a day, 365 days a year. There is a dedicated transplant surgeon and physician available on-call at all times.

### **More than 30 years of excellence**

Beaumont's first kidney transplant was performed in 1972, and liver transplants began in 2010. The liver transplant surgeons and hepatologists have a combined experience of 40 years

in liver transplantation. This includes performing transplants in more than 600 patients and caring for thousands of patients with liver disease.

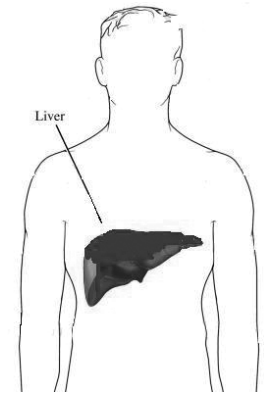
### **Patient education and support groups**

Our liver support group provides pre- and post-liver transplant patients with transplant education and an opportunity to interact with each other. This support group is led by a transplant social worker.

## **General information**

### **Where is the liver?**

Your liver is below your ribs in the upper right side of your abdomen. A normal adult liver weighs about two to four pounds (see figure).



### **What does the liver do?**

The liver detoxifies the blood and filters out harmful compounds. When the liver starts to fail, toxins can build up in the bloodstream. This can lead to the eyes and skin becoming yellow (jaundice), or the person can become forgetful or sleepy (encephalopathy).

The liver also regulates how your body uses the food you eat. After your intestine absorbs food, it goes to the liver, which makes proteins and other nutrients to help your body. Many people with ESLD complain of fatigue, muscle loss or swollen legs because the liver is unable to process nutrients effectively.

The liver also helps regulate the body's hormones or chemicals that regulate other organs. Patients with ESLD can also develop kidney disease secondary to their liver failure. Liver failure can also lead to pressure build up in the veins of the stomach and intestines, leading to bleeding and anemia.

# Liver failure

## Alternative treatments

If you have liver failure, there are two options for treatment. These options include medications to help treat the symptoms of liver disease (water retention, encephalopathy, bleeding), or liver transplant.

Medical therapy has several main forms:

- Diuretics, also known as water pills, may be given to help the body get rid of extra fluids.
- Lactulose (a sugar that your body cannot absorb) can help cleanse the intestine of toxins to reduce encephalopathy.
- A gastroenterologist can perform endoscopy (a scope to look down the throat and into the stomach) to prevent bleeding.
- Medical therapy can help restore some of the balance lost from liver failure. It does not return the patient to a normal level of liver function.

Liver transplantation is an option for patients for whom medical treatment has failed. Liver transplant has the potential to give you a chance at a life free of liver failure, the symptoms of liver disease and the need for medical treatments.

## Transplantation

Transplants have become a widely accepted treatment option for people with end-stage liver disease. In the United States, about 6,000 liver transplants are performed each year. The list of organs and tissues that can be transplanted continues to grow with improved technology.

## What are the different types of liver transplants?

Transplanted livers can be from a living donor, where a part of the liver is donated, or it can be from a deceased donor. Deceased donor transplants involve the transplant of part or all of the liver, and is preferred because it does not require a healthy person to donate.

## Live-donor liver transplants

A live donor is someone who is a healthy volunteer who has a compatible blood type and has been through a donor evaluation. Patients who have the option of a live-donor liver transplant have certain advantages. Surgery dates can be arranged for a time that is convenient for both the recipient and the donor. Typically, the liver starts working immediately and the liver will grow to full size in several weeks.

However, there are certain limitations to live donor liver transplants as well. First, the risks of complications are increased for the recipient. Second, a partial live donor organ will not suffice for sicker ESLD patients.

## Deceased-donor liver transplants

Deceased donors are individuals who have been declared brain dead. The donor has usually consented in advance to be an organ donor. The individual's family has consented to organ and tissue donation. When you are on the waiting list for a liver, you are waiting for a deceased liver donor. The vast majority, 90 percent, of transplanted livers in the United States are from deceased donors. Unlike the live donor, the surgery cannot be scheduled ahead of time because of the wait for the availability of an organ from a deceased donor.

## Criteria for liver transplant waitlist candidacy

- Each candidate presenting for liver transplantation will undergo a detailed evaluation by a multidisciplinary team, including a transplant hepatologist, surgeon, nurse coordinator, social worker, dietitian and financial coordinator. This process is conducted to obtain a comprehensive medical and psychosocial assessment of the patient. Additional testing to identify medical conditions that would increase the risk of surgery and would preclude the use of chronic immunosuppression may be required. In the event that such risks are identified, patients will be counseled regarding therapy to treat these conditions, or may be advised that they are not candidates for liver transplantation.
- Patients must have significant liver disease or liver failure necessitating medical treatments. To qualify for a liver transplant, previous medical and surgical therapy must have been optimized and transplantation would offer realistic expectations of functional improvement or extension of life.
- Liver transplant candidates should generally be between the ages of 18 and 75 years old. Patients over 75 years old are considered and can be referred for evaluation if the individual is highly motivated, and does not exhibit advanced atherosclerotic disease as manifested by coronary artery disease and peripheral vascular disease. Patients under the age of 16 should be referred to a pediatric transplant program.
- Patients must be free of cancer outside of the liver. A prior history of cancer with current complete remission may be referred for evaluation, and a cancer-free period of follow-up prior to transplant will be recommended by the transplant committee, individualized by cancer type.
- Active alcohol and/or substance abuse, AIDS or Class IV New York Heart Association congestive heart failure related to cardiomyopathy or ischemic heart disease are exclusion criteria for liver transplantation at this center.

- Successful candidates for liver transplantation must demonstrate a level of responsibility and presence of psychosocial support systems sufficient to achieve compliance with immunosuppressive medication regimens and frequent office follow-up visits necessary for transplant success. The transplant team may deny a patient who has a history of a behavior pattern or psychiatric illness which is likely to prevent the patient adhering to the post-transplant regimen.
- When reviewing the option of transplant surgery, the recipient must give consideration to the financial responsibility of their decision. A suitable candidate must be able to meet out-of-pocket costs in order to avoid complications resulting from an inability to cover expenses for medications and services. The transplant committee may advise against transplant surgery if a potential recipient is unable to demonstrate the ability to meet anticipated expenses.
- Determination for transplant candidate eligibility has been developed within the framework of the hospital's mission for the care of persons without regard to race, national origin, religion, gender and sexual orientation.

### How do I get in touch with the Beaumont transplant office to discuss a liver transplant?

If you are interested in pursuing a liver transplant, ask your gastroenterologist or primary physician to refer you to the Beaumont Liver Transplant Program.

When you call to set up your transplant evaluation appointment, you will be asked some health history questions, demographic information, insurance questions and possibly permission to gather results of medical tests performed elsewhere.

## Who will I see?

During your transplant evaluation, you will meet the following people:

**Transplant nurse coordinator:** The transplant nurse coordinator's role is to provide continuity of care while you are being evaluated for your transplant. The transplant nurse coordinator will work closely with you to be sure that tests are being scheduled and completed, results are being sent to the transplant office, communication lines are staying open, and questions are being answered. It is very important that you keep in touch with your coordinator. Any test results that you might have from other hospitals should be sent directly to your coordinator.

Your transplant nurse coordinator is a liaison between the transplant surgeon and hepatologist and you to be sure that accurate information is being shared and recorded in your medical record. Your work-up is successfully completed when all of the necessary medical information has been reviewed and approved by the transplant team. If there are no contraindications to transplant, the transplant nurse coordinator will place your name on the waitlist.

**Transplant social worker:** The social worker's role is to make sure you have adequate emotional support and resources to help in your adjustment to a liver transplant. The goal is to help you find appropriate methods to manage stress you may have during the transplant work-up, your wait for a transplant, and after you receive your transplant. At the time of your evaluation, the social worker will meet with you, and your support person, to discuss how you are adjusting to your liver failure and how you plan on coping with the transplant surgery and post-transplant experience. The social worker will ask you about substance (drugs or alcohol) abuse. Your liver detoxifies these substances so use of them causes your liver to work harder and may result in liver failure. Patients with a history of alcohol and/or substance abuse must have at least six months of abstinence from alcohol and/or

recreational drugs prior to being listed for a liver transplant. The social worker will provide resources to assist with this.

As this is a major surgery, each candidate for liver transplantation must identify at least two support persons who will be able to assist them through the pre and post-operative periods. The social worker will meet with you and your support persons to discuss your support plan.

**Transplant financial coordinator:** The transplant financial coordinator will review your financial situation and counsel you regarding the available resources that may help you pay for your transplant, follow-up care, and your transplant medications.

**Transplant surgeon:** The transplant surgeon will also ask you about your medical history and discuss the liver transplant operation. The liver transplant surgery, expected outcomes, and potential complications will be discussed in detail.

**Transplant hepatologist:** The transplant hepatologist will complete a medical evaluation including a physical exam. For your safety, it is vital to know everything about your health history, recent medical problems, hospitalizations and test results.

**Transplant dietitian:** The dietitian will provide a nutritional assessment and education during your evaluation.

**Transplant pharmacist:** The transplant pharmacist will participate in your transplant care by reviewing and evaluating your medications during your hospital stay for your liver transplant. The transplant pharmacist will also participate in the medication education for you and your family members and to prepare you for going home.

**Transplant assistant:** The day of your evaluation appointment, the transplant assistant will make copies of your insurance cards, accumulates medical records you have brought with you or that have been sent, and coordinates your appointments with the individual members of the transplant team. The transplant assistant is available to help you schedule the tests that will be part of your transplant workup.

## The liver transplant workup

Your liver transplant work up will be specific just for you. It will take into account your medical and surgical history and age. You are responsible for completing your pre-transplant work up. Your transplant nurse coordinator and the transplant assistant will be available to help you arrange the tests. Your required tests need to be completed and approved by the transplant team before your name is added to the waitlist. Your transplant work-up may include the following:

**Chest X-ray:** A chest X-ray allows us to look at your lungs. Please bring a report of your chest X-ray if you have had one within one year of the evaluation.

**EKG:** This is an electrocardiogram. The EKG tells us about your heart rhythms. Please bring a report of your EKG if you have had one done within one year of the evaluation.

**Abdominal imaging:** Patients with liver cirrhosis are at increased risk of liver cancer. Screening for cancer with either ultrasound, CT, or MRI is part of the pre-transplant work-up. Depending on the findings, repeat imaging guidelines will be recommended at three to six month intervals while on the transplant waiting list.

**Dental consult:** Visit your dentist to have your teeth and gums evaluated for active infections. If you have dentures, you should also have a dental consult. Your dentist will need to write a dental clearance letter based on the evaluation.

**TB skin test:** A tuberculin skin test is required every two years while you are on the waiting list. This test can be done in our transplant office or at your primary care physician's office.

**Pneumonia vaccine:** A pneumonia vaccine is required. This vaccination requires one booster after five years. It can be done in our transplant office or at your primary care physician's office.

**Blood work:** Blood work identifies immunity and exposure to viruses that might be significant to your liver transplant. Blood work will be done during your first evaluation visit to the transplant

office and just before your name is added to the waitlist.

**Colonoscopy:** All patients over age 50 need to have a colonoscopy. The need for future tests will follow the American Cancer Society guidelines.

**Cardiac and pulmonary evaluations:** In order to achieve successful outcomes in liver transplant surgery, we need to ensure that the recipient has sufficient cardiac and pulmonary reserve.

A cardiology evaluation, including a stress test and 2D echocardiogram is routine for all patients. A pulmonary consultation may also be required of patients with history of heavy tobacco use or chronic lung diseases such as asthma.

### Females

**Pap and pelvic exam:** Females must have a pap and pelvic exam. Women who have had a hysterectomy must also have a pelvic exam.

**Mammogram:** Females over the age of 40 must have a mammogram. Follow up mammograms should be done according to the American Cancer Society and/or your physician's guidelines.

### Males

**PSA (Prostate Specific Antigen):** African-American men or patients with a family history of prostate cancer should have a PSA starting at age 40, otherwise starting at age 50.

### Additional Testing

Based on the results of your initial testing or findings on the physical exam, additional testing may be required to complete your evaluation.



## Being on the “list”

The “list” is the generic term we use for the database which is maintained by United Network for Organ Sharing, or UNOS, for those patients who qualify for organ transplantation. UNOS is the federal agency responsible for keeping the national computer list. Once your name has been added to UNet, you will then be eligible for matches. The list is broken down into different regions and further broken down into the local area.

How long you are on the list depends on the number of donor organs available for transplants and how ill you are. The system determines how sick you are based on your liver blood tests. These tests give you a score, called Model for End-Stage Liver Disease, or MELD score. This system prioritizes the allocation of livers to adult patients waiting for a liver transplant. MELD is a numerical scale used for adult liver transplant candidates. The range is from 6 (less ill) to 40 (gravely ill). The individual score determines how urgently a patient needs a liver transplant within the next three months. The number is calculated using the most recent results of four laboratory tests:

- Bilirubin measures how effectively the liver excretes bile.
- INR measures the liver’s ability to make blood clotting factors.
- Creatinine measures kidney function. Impaired kidney function often results from severe liver disease.
- Sodium

### How is the decision made about who gets an organ or tissue transplant?

The people who have the highest MELD score are offered the next available compatible liver for transplant. As you get sicker, we must check your blood tests more often to ensure you get the score you deserve. Depending on your blood type and MELD score, the wait for a liver can take six months to over a year. Your place on the list will vary as your MELD score changes.

When a donor liver becomes available anywhere in the country, the donor liver information, including the blood type and body size, is put in the UNOS national computer. The computer then matches that information to the patients on the waiting list.

When that individual is identified, he or she is called by the transplant office to come to the hospital to receive the liver transplant. In your case, that will be Beaumont Hospital, Royal Oak.

### Do I have to be seen routinely by the transplant office to remain on the “list”?

While you are on the list, you will be required to see us every three months for a clinic visit. The frequency of the visits will be based on your clinical condition and MELD score. Some of the initial evaluation tests may need to be updated.

Please bring these items to your appointment:

- a current list of your medications
- current health insurance cards, including Medicare and Medicaid
- changes in address/telephone numbers
- your vacation schedule, including location, dates and telephone numbers

### What is “hold status”?

If a medical problem makes it unsafe to receive a transplant, your name is placed “on hold.” You may also be placed on hold for non-adherence to the medical plan (missing appointments; not taking medications, etc.) or if you do not have adequate support. Hold status does not mean you are taken off the list.

### What happens when I get called for a deceased donor liver transplant?

The transplant physician or transplant nurse coordinator will use the list of phone numbers you provided to notify you when a liver is available. This is why we need updates on changes in your phone number or address and why we also need information about where you will be during vacations.

The call that a liver is available could happen at any time of the day or night. When you receive this call, you will be instructed to check in at registration. Then you will be directed to the Transplant Unit.

Please make sure you bring your current medications, health insurance cards and any relevant information about any recent hospital visits. Do not eat or drink anything after you get the call from the transplant physician or the transplant nurse coordinator, unless instructed otherwise.

When you arrive on the transplant unit, the staff will begin preparing you for your transplant. Your family may stay with you until you go to surgery except for times the doctor or nurse may ask your family to step out for a moment. During the operation, your family can wait in the Surgical Waiting Room.

### **Organ donor risk factors**

When waiting for transplant, your transplant center may accept or reject an organ on your behalf. Organ donor risk factors that could affect the success of the transplant include donor age, medical and social history and condition of the organs. Although all donors are screened for cancer and infectious diseases, there is a small possibility that these diseases may not be recognized in the donor and then transferred to the recipient.

## **Surgical procedure**

When you are called into the hospital for a deceased donor liver transplant, your records will be reviewed by health care professionals involved in your care, including the transplant surgeon, hepatologist and anesthesia team. Then you will be taken to the preoperative area and have IVs placed before proceeding to surgery.

Once in the operating room, you will be administered general anesthesia, including a breathing tube, while you are sleeping. The liver transplant operation takes approximately six to twelve hours but can vary depending on individual complexities.

The incision is located in the upper abdomen. Your diseased liver is removed and then the donor liver is placed. This includes connection of two veins, an artery and finally the bile duct.

You will be taken to the intensive care unit to awaken and begin recovery. When you awaken, you will have monitoring devices around you. In addition, you will have a drain in your side, a catheter in your bladder and a small tube in your nose to help prevent nausea and give medicines. You will be closely monitored in the intensive care unit for about 24 to 48 hours after surgery. When ready, you will be moved to a private hospital room on the transplant unit. Your catheter, drain and IV lines will be removed when they are no longer necessary. We anticipate that you will stay in the hospital approximately five to 10 days.

### **Is there a risk with liver transplant surgery?**

There is some risk right after a transplant. Despite our best efforts to reduce this risk (for example, by carefully checking for other illnesses during the evaluation), complications still can occur. If you have chronic medical conditions (including obesity), these can increase the risk for complications. The doctors and surgeons will explain your risks for surgery during the transplant evaluation. When you make your decision about having a liver transplant, you must think about the possible benefits as well as the risks of surgery.

Possible complications could include infection, heart attack, blood clots, stroke, bile leak, multisystem organ failure or even a combination of events that can be fatal.

### **When will my new liver start functioning?**

Your new liver will most likely start functioning right away.

It is rare that a new liver does not function; however in this unlikely event, this situation is readily apparent. If this occurs, you are listed as a “status 1,” the highest priority, and retransplanted as soon as a suitable donor liver is available.

Occasionally, the liver function may take a few days to normalize. This does not affect the long term outcome but can increase the hospital stay and risk of other complications such as infection.

### **How will I learn to take care of my new liver?**

The post-transplant nurse coordinators and nurses on the transplant unit will teach you about your medicines, diet, activity, signs and symptoms of rejection and infection and provide you other information you need to know before you go home. You will also be given the discharge booklet ‘After Your Liver Transplant - What You Need to Know’.

You are responsible for working with the transplant unit nurses, post-transplant nurse coordinators and the transplant doctors to learn about your medical care. Actively taking part in your recovery and caring for your new liver transplant is essential.

## **Potential medical, surgical and psychosocial risks of liver transplantation**

### **Peri-operative surgical risk factors to recipient**

Prior to transplant, you will be evaluated for medical conditions that could increase your surgical risk. Even if you passed the preliminary screening, complications may still occur.

**General complications** of surgery include, but are not limited to, the risks of general anesthesia and invasive monitoring, cardiopulmonary complications, bleeding, infection, bile leak and multisystem organ failure. Any of these complications have the potential to become complex and life threatening. Inability to reverse the complication can lead to death.

**Cardiopulmonary complications** include heart attack, congestive heart failure, stroke, blood clot and pulmonary embolism. Pre-operative testing, peri-operative monitoring and preventative therapies are instituted to decrease your chances of complications.

**Bleeding** can occur in the operating room or after the operation. Surgical patients are frequently monitored for signs or symptoms of bleeding. If bleeding is severe, it may require treatment by blood transfusion or re-operation. Bleeding around the area of your new liver may put extra pressure on your liver, compromising its function. Patients with bleeding or clotting abnormalities or patients who take anti-coagulation therapy such as Coumadin or anti-platelet agents such as aspirin or Plavix are at higher risk for bleeding. Patients who refuse to accept blood products for religious or personal reasons should discuss their wishes with the transplant team during their initial evaluation.

**Infection** can occur during or after your hospitalization. Antibiotic medications are given to you before and after surgery to reduce your chance of infection. Infection in your surgical wound needs to be treated with antibiotics. If the infection is severe, you may need to be taken back to the operating room to clean or re-close the area.

## Potential risks

**Arterial or venous thrombosis:** Blood is brought through your new liver through its hepatic artery and portal vein. If blood in these vessels clots, it usually can be reversed with medicines or surgery. If this is unsuccessful and results in loss of the liver, you will need a retransplant of a new liver. Chances of this happening are increased in patients with blood that clots quickly (hypercoaguable) or in a patient with blood vessel disease. You will undergo ultrasound examination during your hospital stay to confirm good blood flow to and from your liver.

**Bile duct:** The bile duct is the structure that carries bile from your new liver to your intestine. It will be connected to your intestine during your transplant operation. This connection has the potential to leak or scar and cause narrowing. Most of these complications can be corrected non-operatively but occasionally require re-operation.

In the event of a leak, a small plastic stent will be placed by the gastroenterologist into the bile duct to help the leak heal. This internal stent is removed two to six weeks after surgery by a procedure in the Gastroenterology Clinic.

Obese patients are at increased risk for **wound complications**, including infection and hernia. We encourage patients to maintain a healthy lifestyle while waiting for transplantation. Any infection occurring in the transplant wound leads to increased risk of hernia developing in the wound.

**Pain** in the surgical wound is an expected consequence of surgery. Everyone has his or her own threshold for pain and pain medications. Our team of physicians and nurses will work with you to maintain a tolerable level of comfort after your surgery. It is important to maintain enough pain control so you are able to take short walks and participate in breathing exercises.

**Post surgical infections** can occur in many forms including thrush, urinary tract infection, pneumonia or blood infection. These may be more serious for a transplant recipient because

of a compromised immune system. Early on you will be asked to participate in short walks, do breathing exercises and will be on antibiotics after the operation to help prevent these infections.

## Hospital stay

When you come to the hospital for your transplant, you will be asked to refrain from eating or drinking in order to administer anesthesia. After surgery, your diet will be restarted with liquids and replaced with normal foods as your stomach tolerates it. Some patients do not tolerate food early after surgery, but food tolerance will improve over time.

The transplant process is a physically and emotionally stressful time for the recipient. You are removed from your normal surroundings and subjected to anesthetic, sedation, pain and immunosuppressant medications, all of which can cause confusion. In some patients, this can lead to delirium or depression. Psychiatrists and social workers are part of the transplant team and can help the recipient cope with the emotional stress of transplant.

# Transplant medications

## Immunosuppression (anti-rejection medications)

Your body's normal response to a foreign body, like a transplanted organ, is rejection. As long as the transplanted liver is in your body, there is a possibility of rejection. Immunosuppressants, or anti-rejection medications, decrease the risk of rejection.

The combinations and doses of the medicines may change over time. Right after your transplant, you may be taking high doses of medicines. When the liver is more stable, the medicines are reduced gradually to maintenance levels.

These medicines are critical to avoid rejection. Even minor changes in the way you take them can be harmful for you and your liver. You will be given directions about what, when and how much of each medicine you take.

Liver transplant patients are required to take lifelong immunosuppression medications, which have short- and long-term side effects. They require that you keep a regular dosing schedule and have frequent blood draws to check if the drug is at an appropriate level. The drugs may have side effects such as stomach upset, nausea, diarrhea, weight gain, osteoporosis, diabetes, high blood pressure and decreased blood counts. Immunosuppression places patients at higher risk for more serious or rare infections. Patients on long-term immunosuppression are also at higher risk for certain cancers, such as skin cancer and lymphoma, and are encouraged to participate in age-appropriate cancer screening.

## What kind of medicine will I be taking?

While you are in the hospital, you will take a combination of anti-rejection medicines. Immediately after the transplant, you will be given corticosteroids through your IV. This is to prevent acute rejection. These will be changed to pills when your liver is working well and your Prograf (tacrolimus) level is at goal.

Prograf will be started once your liver is working well. This medication is taken twice a day, with the doses twelve hours apart. The dose depends on the level of the medicine in your blood.

These blood levels are very important, so do not take your dose of Prograf before you come to the clinic for lab work. Bring your dose with you to take after your blood has been drawn.

Deltasone (prednisone) will be the pill form of corticosteroids given to you starting the fourth day after the transplant. It will be given once a day in the morning. If everything is going well, by the end of two months you will be taking 5 mg of prednisone once a day. If everything continues to go well, by the end of three months the majority of patients will be off of prednisone completely. It is very important that you take this medicine **exactly** as directed. You need to pay attention to your medicines and any changes that are made. This is vital to the success of your transplant.

## Continue to follow these rules after your liver transplant:

- Keep a record of all the medicines you take, including the dose and frequency.
- Take all your medicines exactly as directed.
- Report any side effects to your transplant nurse, doctor or pharmacist.
- Do not take any over-the-counter medicines without talking with your doctor first.
- Some medicines can interact with your immunosuppressants and could harm your liver. If a doctor other than your hepatologist prescribes a medicine, check with your transplant doctor, transplant nurses or transplant pharmacist to make sure that it is okay to take.
- Call your pharmacist for refills at least one week before you are due to run out of your medicine. Also make sure you will have enough medicine if you will be away from home.

## Immunosuppressant medicines

The following is a list of immunosuppressant medicines that you may be taking. Based on your case, you may be on a combination of different immunosuppressant medicines.

## Transplant medicines

Generic name	Brand name
tacrolimus	Prograf
mycophenolate mofetil	CellCept
prednisone	Deltasone

**Do not change the dose or stop taking this medicine unless you have talked to your transplant physician or post-transplant nurse coordinator.** All immunosuppressants lower your resistance to infection. They also have the potential to make you more prone to cancer. You will be closely monitored after transplant. The goal is to give you just enough medicine to prevent rejection so these side effects can be avoided.

**Prograf (tacrolimus):** Prograf is usually given as a pill form twice a day. This medicine inhibits certain types of white blood cells, called lymphocytes, that are involved in rejection. Side effects may include increased blood sugar, hand tremors, increased potassium levels, decreased magnesium levels and increased blood pressure. In high doses, it can also be harmful to your kidneys. Blood levels of this medicine will be monitored to try to avoid this effect.

**Deltasone (prednisone):** Prednisone can be given intravenously or in pill form. It reduces inflammation and antibody production.

By reducing antibodies, prednisone helps prevent rejection or control rejection if it has already started.

Side effects may include upset stomach, stomach ulcers, acne, mood swings, increased appetite, weight gain, fluid retention, increased blood pressure, cataracts, muscle wasting, brittle bones and high blood sugar. Many of these side effects will disappear as your prednisone dose is lowered.

**CellCept (mycophenolate mofetil):** CellCept is usually given as a pill form twice a day. This medicine limits certain types of white blood cells (lymphocytes). Lymphocytes take part in the rejection process. CellCept is used to prevent and treat acute and chronic rejection.

Side effects may include stomach upset, diarrhea, decreased blood counts and lowered resistance to infection.

## Other medicines

Right after your transplant, you will take four more medicines. Bactrim SS, Valcyte and Nystatin are used to help protect your body from infection. Protonix is used to prevent stomach upset and ulcers.

### **Bactrim, SMX/TMP (sulfamethoxazole and trimethoprim):**

Bactrim is an antibiotic. It helps prevent upper respiratory infections and urinary tract infections. **Let your doctor know if you are allergic to sulfa medicines.** Take this medicine with a full glass of water. Side effects may include stomach upset and sensitivity to sunlight. Wear protective clothing and sunscreen with an SPF of 30 or greater when outdoors.

### **Mycostatin (nystatin):**

Nystatin is an anti-fungal medication. It helps to prevent fungal infections in the mouth. This mouth infection, called thrush, is identified by a white coating on the tongue and inner cheeks. Nystatin comes as a liquid and you should swish the prescribed amount in your mouth for 30 seconds and then swallow four times a day, usually after meals and at bedtime. Do not eat or drink for 30 minutes after doing this. Side effects are rare but may include mild nausea and abdominal pain.

### **Valcyte (valganciclovir):**

Valcyte is an anti-viral medication. It helps to prevent infection caused by viruses including cytomegalovirus, also known as CMV. Side effects may include nausea, vomiting, diarrhea or decreased blood counts.

**Protonix (pantoprazole):** This medicine helps prevent stomach and duodenal ulcers. It reduces the amount of acid in your stomach. Side effects are not common but could include headache, constipation, diarrhea and abdominal pain.

## Additional information

### Insurability

Future health problems related to transplantation may not be covered by your insurance or may affect your ability to obtain health insurance, disability or life insurance. Please check with your current insurance carriers including health, short/long term disability and life to help clarify these issues.

### Right to refuse transplant

Even if you decided to pursue transplant, you retain the right to refuse transplant any time prior to surgery.

### National and transplant specific outcomes

Beaumont and national volume and outcome data is compiled and available at [srtr.org](http://srtr.org). This data includes comparisons of patient and liver survival as well as other data.

## Definitions of terms

**Acute rejection:** Acute rejection can happen at any time after a transplant. During an acute rejection episode, the serum (blood) liver function tests rise. This can usually be treated by taking a higher dose or different type of immunosuppressive medicine until the blood tests return to a baseline.

**Anti-rejection medicine:** These drugs are taken every day through the life of the transplanted liver. They are also known as immunosuppressive medicine. They help prevent the immune system from rejecting the new liver.

**Ascites:** A buildup of fluid in the abdomen, usually associated with liver disease.

**Bile:** Thick alkaline fluid that is secreted by the liver and stored in the gallbladder.

**Bile duct:** Any of the ducts (tube) that convey bile from the liver.

**Biliary atresia:** A condition that results when the bile ducts inside or outside the liver don't have normal openings. Bile becomes trapped in the liver, causing jaundice and cirrhosis. This condition is present from birth and, without surgery, may cause death.

**Bilirubin:** A breakdown product of hemoglobin from blood cells, the results of which are used in the MELD calculations as a measure of the severity of liver disease.

**Blood typing:** A blood test that indicates blood group. You can be O, A, B or AB. The recipient's blood type needs to be compatible with the donor's blood type to receive the transplant.

**CDC High Risk Donor:** Donor factors that are defined by the CDC (Centers for Disease Control and Prevention) as potentially raising the risk of HIV infection in the donor, with the potential for transmission of HIV via the donor organ.

**Chronic rejection:** Chronic rejection is a process that may happen after a transplant, it can develop over months or even years, during this process, the bilirubin slowly rises. There is no known treatment for chronic rejection, but changing medicines may slow the damage to the liver.

**Cirrhosis:** A chronic liver condition caused by scar tissue and damage to cells which replaces normal, healthy liver tissue. Cirrhosis makes it hard for the liver to remove poisons (toxins) like alcohol and drugs from the blood. These toxins build up in the blood and may affect the brain.

**Creatinine:** A product of muscle metabolism. Creatinine level serves as a very good indicator of kidney function.

**Deceased donor:** An individual whose tissues or organs are donated after his or her death (sometimes called a “cadaveric donor”). Such donations come from two sources: patients who have suffered brain death and patients whose hearts have irreversibly stopped beating. The latter group is referred to as “donation cardiac death” (DCD), or sometimes as “nonheartbeating” donors.

**Donor hepatectomy:** Removal of a portion of liver for donation from a living person.

**Expanded criteria donor (ECD):** A donor that is not considered to be “ideal” or “standard.” Characteristics may include advanced donor age, prior infection with hepatitis B or hepatitis C, hypertension or diabetes mellitus, abnormal donor organ function and nonheartbeating status of a deceased donor. The term “expanded” is used because an expansion of the donor pool is considered to increase transplantation.

**Encephalopathy:** Serious brain function abnormalities experienced by some patients with advanced liver disease and other diseases. Symptoms most commonly include confusion, disorientation, insomnia and may progress to coma.

**End-stage liver disease (ESLD):** Irreversible liver failure that requires transplantation as hepatic replacement therapy.

**Fatty liver:** A build up of excess fat in liver cells.

**Fulminant:** A medical event that occurs very quickly with an acute onset, as in fulminant liver failure. This usually occurs over days, not weeks.

**Fulminant hepatic failure (FHF):** Acute liver failure with no preexisting liver disease.

**Gallbladder:** A pear-shaped sac lying beneath the right lobe of the liver, in which bile is stored.

**Glucose:** A type of sugar found in the blood.

**Graft:** Your “new” liver.

**Hepatic:** Having to do with, or referring to, the liver.

**Hepatitis:** A viral infection or non-specific inflammation of the liver that can lead to liver failure.

**Hepatitis A:** An inflammation of the liver caused by the hepatitis A virus, or HAV. Hepatitis A is transmitted when fecal matter from someone who has the disease is ingested, either directly or via food or water contaminated with the fecal matter.

**Hepatitis B:** An inflammation of the liver caused by the hepatitis B virus, or HBV. Hepatitis B is transmitted through blood and infected bodily fluids. It is spread through unprotected sex; through sharing razors or toothbrushes with an infected person; through living in a household with an infected person; from an infected mother to her newborn child at birth; via unsterilized needles, including tattoo or piercing needles; through sharing IV drug needles; and through human bites.

**Hepatitis C:** An inflammation of the liver caused by the hepatitis C virus, or HCV. HCV is transmitted primarily through direct exposure to infected blood through an opening in the skin or mucous membrane. The virus infects the liver, causing inflammation that results in damage to liver tissue. Hepatitis C is the leading cause of liver failure that leads to transplantation.

**Hepatologist:** A specialist who is an expert in the diagnosis and treatment of liver diseases.



**Hypertension:** Another word for high blood pressure.

**Immunosuppressive medicines:** Medications taken every day after the transplant. They help prevent the recipient's immune system from fighting against and rejecting the new liver. Also known as anti-rejection medicine.

**Intravenous (IV):** A small catheter placed into a vein; refers to the fluids and medicines that are injected into a vein through a needle or catheter.

**Jaundice:** A symptom of many disorders. Jaundice causes the skin and the whites of the eyes to turn yellow.

**Kidneys:** Two bean-shaped organs located beside the spine, just above the waist. They remove waste and balance fluids in the body by producing urine.

**Liver:** The largest organ in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, stores substances like vitamins and helps process proteins, carbohydrates and fats. It also removes wastes from the blood. A living donor can give part of his or her liver, after which the liver will regenerate itself in both the donor and recipient.

**Liver enzymes:** Liver enzymes are substances produced by the liver. When the liver is injured, these enzyme levels can be higher than normal.

**Model for end-stage liver disease (MELD):** The scoring system used to measure the illness severity in liver transplant candidates was implemented in February 2002. This system prioritizes the allocation of livers to adult patients waiting for a liver transplant. MELD is a numerical scale used for adult liver transplant candidates. The range is from 6 (less ill) to 40 (gravely ill). The individual score determines how urgently a patient needs a liver transplant within the next three months. The number is calculated using the most recent results of three laboratory tests:

- **Bilirubin** measures how effectively the liver excretes bile.
- **INR** measures the liver's ability to make blood clotting factors.
- **Creatinine** measures kidney function. Impaired kidney function is often associated with severe liver disease.

**Rejection:** The process by which the body responds to a "foreign object," such as a new liver. Rejection can be acute or chronic (see definitions: acute rejection and chronic rejection).

**Renal:** Having to do with the kidneys or referring to them.

**Standard criteria donor (SCD):** Refers to all deceased donors that do not meet the criteria for inclusion under expanded criteria donors.

**Split liver:** A split liver transplant occurs when the donor liver is divided into segments and then transplanted. These segments may be transplanted into more than one recipient, or a segment could be transplanted into a child for whom an entire adult liver would be too large.

**Transplant:** Transferring organs or tissues from a donor to a recipient.

## Resources

### **Beaumont Transplant Support Group**

The Transplant Connection meets regularly. Please refer to the schedule provided to you. The group is for pre- and post-transplant patients, their families, friends and caregivers. For more information, call the Beaumont Transplant Clinic at **248-551-1033** (option 3).

### **American Liver Foundation**

39 Broadway, Suite 2700  
New York, NY 10006  
212-668-1000 or 800-465-4837  
[www.liverfoundation.org](http://www.liverfoundation.org)

### **American Liver Foundation (Financial Assistance resources)**

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

### **The National Foundation for Transplants**

5350 Poplar Ave., Suite 430  
Memphis, Tennessee 38119  
901-684-1697 or 800-489-3863  
[www.transplants.org](http://www.transplants.org)

The Organ Transplant Fund's fundamental mission is reaching out to help those who seek a new life through transplants. They provide health care support services, financial assistance and advocacy programs to transplant candidates, recipients and their families nationwide.

Conducts programs in research, education, and community and patient services. Operates telephone referral service. Educational materials are free of charge to the patient. No membership fee for patients and their families.

### **United Network for Organ Sharing (UNOS)**

700 North 4th Street  
Richmond, VA 23219  
804-782-4800  
[www.unos.org](http://www.unos.org)

Provides support services for those who plan to undergo a transplant or who have already had a transplant. Supports a computerized registry of all potential organ recipients, according to tissue type and medical need.

## Resources Serving Michigan

### **Gift of Life Michigan**

3861 Research Park Drive  
Ann Arbor, MI 48108  
866-500-5801  
[www.giftoflifemichigan.org](http://www.giftoflifemichigan.org)

### **Michigan Rehabilitation Services**

Administrative Offices  
333 S. Grand Avenue  
Lansing, MI 48909  
517-373-3390 or 800-605-6722  
517-373-0565 (fax)  
[www.michigan.gov/mrs](http://www.michigan.gov/mrs)

## Beaumont Multi-Organ Transplantation Department

### Transplant Administrative Staff

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Dilip Samarapungavan, M.D.

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M. Rasm AISibae, M.D.

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Steven Cohn, M.D.

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## Beaumont Multi-Organ Transplantation

### Liver Transplant Recipient Candidate Signature Sheet

Our transplant center feels the "Your Liver Transplant: What You Need to Know" is important written information to assist your decision making and to learn about the liver transplant process, in addition to short and long term considerations. Please also note that it is a federal crime for any person to knowingly acquire, obtain, or otherwise transfer any human organ for valuable consideration (i.e., anything of value such as cash, property, vacations). Your signature below confirms that you have received and read the recipient education booklet along with the materials listed below, and have had the opportunity to have any questions or concerns answered regarding being a Liver Transplant Recipient Candidate. Our center will keep this form on file in your medical record.

#### Materials:

- Your Liver Transplant: What You Need To Know
- Transplant Team Profile Sheets
- American Liver Foundation Information Sheets
- Pneumococcal Polysaccharide Vaccine. What You Need to Know
- What You Should Know About HIV
- UNOS What Every Patient Needs to Know
- UNOS Facts and Figures
- Patient Rights and Responsibilities
- Memorandum for Dental Evaluation
- Transplant Connection Support Group Flyer
- Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer
- Questions and Answers for Transplant Candidates about Liver Allocation
- Financial Handbook for Liver Transplant Patients
- SRTR Data comparing Beaumont Transplant Center to the Nation
- Notice of Privacy Practices
- Received education presented by a Nurse Coordinator

I consent to proceeding with testing as a potential Liver Transplant Recipient Candidate. I have received the booklet "Your Liver Transplant: What You Need to Know" along with the materials listed above and I will call **248-551-1033** if I have any questions regarding being a Liver Transplant Recipient Candidate.

_____ Signature of Liver Transplant Recipient Candidate	_____ Date	_____ Time
_____ Printed Name of Liver Transplant Recipient Candidate	_____ Date	_____ Time
_____ Signature of Transplant Center Staff Member Providing Booklet	_____ Date Received	_____ Time



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