





# CONTENTS

## Section 1

Welcome.....1

## Section 2

Your liver.....2

Liver failure .....2

## Section 3



# SECTION 1

## WELCOME

Welcome to Beaumont's Liver Transplant Program. We are looking forward



Eventually the scarring will lead to a condition called cirrhosis. Cirrhosis is an irreversible condition. Cirrhosis can usually be diagnosed by imaging such as abdominal ultrasound, computerized tomography (CT) scan or magnetic resonance imaging (MRI). Some patients may require a liver biopsy.

Some of the symptoms you may experience due to your liver failure include:

- fatigue
- intense itching
- yellowing of skin or eyes (jaundice)
- swelling in your abdomen (ascites) and/or legs
- confusion or forgetfulness (hepatic encephalopathy)
- prolonged or excessive bleeding (especially gastrointestinal bleeding)
- muscle wasting (loss of muscle mass)

Sometimes a patient's cirrhosis can be managed with medical therapies, which are mainly aimed at symptom management. Liver transplant is the only life-saving option for patients who have not responded to medical therapies.

Liver transplant may also be offered as a treatment for patients with certain types of cancer, primarily liver cancer without metastasis (spread of the cancer).

## SECTION 3

### TYPES OF LIVER TRANSPLANTS

Livers for transplant can be obtained from a living donor (living-related or living non-related) or a deceased donor.

#### Living Donor

With living donor liver transplants, a healthy adult donates a portion of their liver to be placed in the recipient. Both livers then regrow to normal size within a few weeks. Donors must go through a careful screening process to minimize the risks associated with the procedure.

Not every patient is a candidate for a living donor liver transplant. We encourage you to speak with the transplant physician about your options.

#### Deceased Donor

Deceased donors are individuals who have arranged in advance to be an organ donor or their family has granted permission to donate their organs either after cardiac or brain death.

Patients on the transplant waiting list are waiting for a deceased donor.

Transplant recipients who receive an organ from a deceased donor typically receive a whole liver as opposed to a partial liver.

It is important to know that a liver transplant is considered a treatment, not a cure.

It will require a lifetime commitment from you, which includes:

- lifelong use of medications
- frequent visits with the transplant team (including blood work and physician visits)
- follow-up testing



## SECTION 4

### MEDICAL THERAPIES

Options for treating liver disease vary depending on the symptoms you are experiencing. Not every patient's treatment is the same.

#### Hepatic Encephalopathy

Patients or family members may notice personality changes, confusion, forgetfulness, sleep disturbances or lethargy. If not treated, hepatic encephalopathy can lead to a coma.

These mental status changes result from toxins building up in the blood due to the liver's inability to filter them out effectively.

Treatments for hepatic encephalopathy include:

- **Lactulose**: A sugary syrup that removes excess ammonia from the intestine by a laxative effect. Everyone's response is different but the goal is to adjust the dose to achieve three to four bowel movements per day.
- **Rifaximin**: This is an antibiotic that helps to eliminate ammonia producing bacteria in your gut.
- **Zinc**: A supplement that helps decrease ammonia levels in your blood.

#### Ascites

Ascites is fluid that builds up in your abdomen causing uncomfortable swelling and tightness (distension). A large amount of fluid in the abdomen may also cause shortness of breath.

Treatment for ascites may include:

- **Diuretics**: Sometimes called "water pills". These medications help eliminate excess fluid through urine. Examples include furosemide (Lasix), spironolactone (Aldactone), amiloride (Midamor) and bumetanide (Bumex).
- **Paracentesis**: Under ultrasound guidance, a needle is inserted into the abdomen to drain extra fluid from the abdomen.
- **Diet**: Maintaining a strict low sodium diet is important. A diet high in sodium can cause excess fluid to remain in your body.

- **Transjugular Intrahepatic Portosystemic Shunt (TIPS)** ( **IP** ): In some cases, ascites may be severe and diuretic therapy has failed or is unable to be used. These patients may be evaluated to have a TIPS placed.
  - This procedure is performed in interventional radiology. A shunt is placed from the hepatic vein to your portal vein to decrease the pressure. This shunts blood around the liver, instead of through it. As a result, it may place patients at higher risk for developing symptoms of hepatic encephalopathy. Typically, these symptoms can be managed with medications, but if severe, a TIPS can be reversed.

## **E** **Esophageal Varices**

Esophageal varices are enlarged veins that form in your esophagus because of high pressure in your portal vein. These veins are at increased risk for rupture and bleeding.

Treatment for esophageal varices may include:

- **Esophagogastroduodenoscopy (EGD)**: A camera is used to visualize your stomach and esophagus to check for the size, number and location of varices. If needed, bands may be placed to help prevent bleeding.
- **Beta Blockers**: A medication used to keep your blood pressure down to keep pressure off the varices to prevent bleeding.
- **IP**: In severe cases, a TIPS may be considered to help alleviate the pressure

## A *Radiofrequency Ablation*

This treatment is mostly used for smaller tumors. A thin, needle-like probe is inserted into the tumor where it is destroyed by using heat (microwave ablation), cold (cryoablation) or high frequency currents (radiofrequency ablation).

## ACE (*Arterial Chemoembolization*)

Used for larger tumors. The goal is to embolize, or "block", the blood flow to the tumor. Many times, the tumor site is treated with chemotherapy (medication to destroy cancer cells) before embolization to treat the area more effectively. The type of chemotherapy used in this procedure is localized to the tumor, so patients do not typically experience effects usually associated with chemotherapy (hair loss, nausea, vomiting).

## ARE (*Arterial Radiation Embolization*)

Another option for larger tumors. This utilizes embolization and radiation therapy. Small radioactive beads are placed in the hepatic artery. Over several days, the beads give off small amounts of radiation that are directed to the blood vessels that are connected to the liver tumor.

## BR (*Breast Radiation Therapy*)

These radiation therapies use guided imaging (CT or MRI) to target the exact area of the tumor and deliver high doses of radiation to the area. This causes the tumor to shrink, with minimal damage done to the healthy tissue surrounding the tumor.

# SECTION 5

Your evaluation appointment can last up to six hours. You must bring a support person with you. If you are a candidate for transplant, you will be required to identify two support people (an additional support person). Your support team is expected to actively participate throughout the transplant process and will be asked to sign

- **Transplant Social Worker** : The transplant 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 social worker can help you find healthy ways to manage stress during your pre-transplant work-up, your wait for a liver transplant and after you receive your liver transplant.
  - At the time of your evaluation, the social worker will meet with you, and possibly 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.
- **Transplant Financial Representative** : The transplant financial representative will discuss your financial situation and counsel you about resources that may help you pay for your transplant, follow-up care and your transplant medicines.
- **Transplant Dietitian** : The transplant dietitian will complete a nutritional assessment and education about how to maintain a healthy diet.
- **Transplant Pharmacist** : The transplant pharmacist will review your medications and will provide education as needed.
- **Transplant Program Coordinator** : On the day of your evaluation appointment, the transplant program coordinator schedules your meetings with the individual members of the transplant team.
  - If you are considered to be a potential candidate for a kidney transplant, the transplant program coordinator will work with the nurse coordinators to help keep you informed of important information related to your evaluation. The program coordinator is also available to help you schedule the tests that will be part of your kidney transplant work-up.

# SECTION 6

- **C** : Testing may include a two dimensional (2D) echocardiogram, stress test or coronary computed tomography angiogram (CTA) and/or a consultation with a cardiologist.
  - This will identify underlying heart disease or a heart condition that would make it unsafe for you to undergo surgery. In certain cases, a cardiac catheterization may be required.
- **C - y / C y (C )**: To make sure that there is no lung disease.
  - A chest CT is performed for patients with liver cancer to ensure there is no metastatic disease (spread of the cancer to other areas), which could be a barrier to transplant.
- **L** : This is done through ultrasound, CT scan or magnetic resonance imaging (MRI) to screen patients for liver cancer and to look for formation of blood clots in your liver arteries or veins. Depending on the results and your medical condition, this may be required to be repeated in intervals of every three to six months.
- **C y**: Required for patients who meet the current American Cancer Society guidelines for screening for colon cancer or who have conditions that make them more prone to colon cancer.
- **EGD (E y)**: This upper endoscopy screens for esophageal varices (enlarged blood vessels in your esophagus) or stomach ulcers that may place you at risk for bleeding.
- **D** : A dentist must examine you to verify that you are free of active oral infection or gum disease.
- **( B )** : This will be done by TB Quantiferon blood test. If you have risk factors for TB or have had previous exposure, additional testing may be required.
- **I I** : We require immunizations for pneumonia and hepatitis A and B prior to transplant. We strongly encourage an influenza vaccine and vaccination for COVID-19. Speak with your primary care physician to ensure all your immunizations are up to date.



- Pap smear: Women must have an up to date pap smear and pelvic exam. This is repeated annually while on the wait list.
- Mammogram: Breast cancer screening is required based on the American Cancer Society's guidelines.

## M

- Prostate specific antigen (PSA) screening: This is a blood test that screens for prostate cancer.

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Depending on the results of your initial testing, additional studies may be required to complete your evaluation. These may include more detailed cardiopulmonary evaluations, pulmonary function tests or consultations with specialty providers.



## Alcohol and Drugs of Abuse

Alcohol and drugs of abuse are toxic to the liver. Alcohol includes “hard alcohol” such as vodka or whiskey, but also includes beer and wine.

Patients with substance use issues may be required to attend group meetings regularly, as well as engage in counseling to help develop a relapse prevention plan. Each patient’s requirements will vary.

All patients are randomly screened for alcohol and/or drugs of abuse throughout the transplant process to verify compliance. To avoid false positive alcohol results, avoid all substances that contain alcohol and alcohol products. This includes, but is not limited to, mouthwashes (which actually contains a small amount of alcohol), certain over-the-counter medications, and certain foods. “Non-alcoholic” beer and foods that contain wine are not to be consumed. It is the expectation of the transplant team that patients will have life-long abstinence from these substances.

In some cases, liver transplant may be considered for patients with less than six months of alcohol abstinence. These patients must meet strict criteria and have a low risk for returning to alcohol use after transplant. These patients are required to commit to engaging in routine therapy to support their continued abstinence.

## SECTION 8

### TRANSPLANT WAITING LIST

The transplant team will review your medical and psychosocial testing to decide if you are eligible to be placed on the liver transplant waiting list. Some contraindications to transplant may include (but are not limited to):

- severe underlying heart or lung disease
- active malignancy or aggressive liver cancer determined to be out of criteria for transplant
- elevated body mass index (BMI)
- inadequate support team (family or friends who can help you after your transplant)
- medical non-compliance
- active substance abuse
- poor functional or nutritional status
- lack of insurance
- behavior patterns or psychiatric illness that are barriers to compliance with care of the transplant

If the team determines that you are a candidate for liver transplant, your name will be added to the deceased donor transplant waiting list. A waiting list for transplant is necessary because there are more people waiting for a liver transplant than available organ donors.

The waiting list is managed by the Organ Procurement and Transplantation Network (OPTN) which is managed by the Federal Government. The OPTN currently has contracted with the United Network for Organ Sharing (UNOS) to manage the duties of the OPTN.



# MELD EXCEPTIONS

It is not known what the actual risk of transmission is but it is thought to be less than

## SECTION 10

### NOTIFICATION OF POTENTIAL TRANSPLANT

The call that a liver is available could happen at any time of day or night. This call will come from a service that Beaumont Transplant contracts to assist with organ offers. It is important to know that you will not recognize the number of the person who is calling with the organ notification. You should answer all calls, even those from out of state numbers.

Due to time constraints associated with transplant, it is crucial that you check your messages frequently and return any missed calls promptly. Failure to do this may result in the need to bypass your offer to the next available patient.

You will be given instructions on what time to report to the hospital, where to register and when you must avoid eating or drinking. You must be accompanied by a member of your support team when you arrive.

You will be admitted to the transplant unit where you will be prepared for surgery. You will meet with the surgical team who will answer any final questions you have about the surgery.

Once admitted for a liver transplant, there are circumstances which may require cancelling the surgery. The transplant cannot be performed if you have an active, serious infection or other serious medical issues.

Changes in the medical condition of the potential liver donor or issues with the quality of the liver may also cause your surgery to be cancelled.

While having your surgery cancelled may be frustrating, please remember that the transplant team wants your transplant to be successful and would not complete the transplant surgery if it could endanger your health.





# SECTION 12

## POTENTIAL RISKS OF LIVER TRANSPLANT

As with any surgical procedure, there are potential risks involved. The transplant team will monitor you closely to identify and treat complications quickly.

**C** **Cardiopulmonary Complications** :

**C** **Cardiopulmonary Complications** : Including, but not limited to, heart attack, stroke, blood clot, pulmonary embolism (blood clot in the lung).

**B** **Bleeding** : This usually occurs in the first 12-24 hours after surgery. May require returning to the operating room and/or a blood transfusion.

**B** **Bile Duct Complications** : The bile ducts are small, delicate tubes that drain bile from the liver. Some patients may experience a leak or stricture in the bile ducts.

**J** **Immunosuppression** : As described in the next section about antirejection medications, you will be educated about signs of rejection after surgery.

## SECTION 13

### IMMUNOSUPPRESSION MEDICATIONS

Your body's natural response to a foreign object is rejection. Immunosuppressants, or antirejection medications, are critical to avoid rejection after transplant. Right after surgery you will be on high doses of immunosuppression but these doses will gradually decrease as you get further out from surgery.

Prograf (tacrolimus) and prednisone are used to prevent rejection. Prograf helps inhibit certain types of white blood cells, called lymphocytes, that are involved in rejection. Prednisone is a steroid that helps reduce inflammation and antibody production.

Patients may also be on an additional antirejection medication called CellCept (mycophenolate mofetil), based on their condition.

## SECTION 14

### PREPARATION FOR DISCHARGE

While you are in the hospital, the nursing staff, transplant physicians and surgeons will provide education to you about caring for yourself at home.

In preparation for discharge, you and your support team will meet with several different team members who will provide you with additional education about how to care for yourself and your new liver. These team members include a transplant nurse, transplant dietitian and transplant pharmacist. You will also receive written educational materials to assist you with keeping yourself and your transplanted liver healthy.

The transplant social worker will assess your situation for any discharge needs.

A Continuing Care nurse will determine if special equipment or help is needed at home.

Some patients will require additional physical therapy to regain strength and stability in order to be safe at home. This may be completed at home or in an inpatient or outpatient rehabilitation unit, based on individual needs.

#### F

After discharge to home, you will have frequent follow-up visits in the transplant clinic. You will be unable to drive for several weeks after your transplant, so plan for someone reliable to bring you to your clinic visits.

If you live far from the Beaumont Transplant Center, you may want to consider staying in the area for several weeks after your transplant.

You will be expected to follow-up with the transplant team for the life of your transplant. Close monitoring is crucial to the long-term success of your health.

#### C

Transplant can be emotionally difficult. Having the proper support is extremely important. Beaumont offers a transplant support group that meets regularly to provide patients, families and caregivers a forum to share ideas, thoughts, stories and gather additional information. The support group is open to patients who are under evaluation, actively listed and post-transplant. We highly encourage patients to participate. More information can be obtained from the transplant social worker.

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### AF ER HO R N MBER: 248-551-1033

Call to speak with a physician after hours or on the weekend. We will take your name and contact information, and a transplant physician will return your call.

# SECTION 15

## DEFINITIONS OF TERMS

A  $r$  :

**D** : A person who has donated organs after dying from a brain injury or cardiac death.

**D** : The bottom blood pressure number. Diastolic is when the heart relaxes and refills with blood.

**D** **y**: Removal of a portion of liver for donation from a living person.

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

**E** - **LD** (E LD): Irreversible liver failure that requires transplantation as hepatic replacement therapy.

**F** **y** : A buildup of excess fat in liver cells.

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

**F** (FHF): Acute liver failure with no pre-existing liver disease.

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

**G** : A liver transplant is sometimes referred to as a graft.

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

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

**H** **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.

**H** **B**: An inflammation of the liver caused by the hepatitis B virus, or HBV. Hepatitis B is transmitted through blood and infected bodily fluids.

**H** **C**: An inflammation of the liver caused by the hepatitis C virus, or HCV. HCV is transmitted primarily through direct exposure to infected blood.

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

**H** **y** : Another word for high blood pressure.

**I**mmunosuppressants: These medications are taken daily to help prevent the transplant recipient's immune system from rejecting the new liver. Also known as antirejection medicine.

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

**J**aundice: A symptom of many disorders, including liver disease. Jaundice causes the skin and the whites of the eyes to turn yellow.

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

**L**iver: 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.

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

**M**odel for End-Stage Liver Disease (MELD): The scoring system used to measure the illness severity in liver transplant candidates. This system prioritizes the distribution 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 six (less ill) to 40 (gravely ill). The individual score determines how urgently a patient needs a liver transplant within the next three months.

**R**ejection: The process by which the body responds to a "foreign object," such as a transplanted liver. Rejection can be acute or chronic.

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

**S**ystolic blood pressure: The top blood pressure number. It measures the force of the heart muscle as blood is pumped out of the heart chambers.

**T**ransplant: Transferring an organ from a donor to a recipient.

# Beaumont

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