Preparing for a Liver Transplant
Preparing for a Liver Transplant

Table of Contents

Welcome ......................................................................................................................................... 3

About the Liver and Liver Disease

About the Liver ...................................................................................................................... 4
Liver Disease and Cirrhosis ................................................................................................ 5

Transplant Process

Starting the Transplant Process ................................................................................................. 6
Transplant Waiting List .............................................................................................................9
Getting the Call .......................................................................................................................11
Transplant Surgery and After Care .......................................................................................12
What if Transplant Isn’t Right for Me? ............................................................................. 14
My Notes ............................................................................................................................... 15

Comprehensive Transplant Center
300 West 10th Avenue, 11th floor
Columbus, Ohio 43210

Phone: 614-293-6724 or 1-800-293-8965
Fax:  614-293-6710

Talk to your doctor or health care team if you have any questions about your care.
The Library for Health Information is available to help you find more health information at (614) 293-3707 or e-mail: health-info@osu.edu.
Welcome

The Ohio State Comprehensive Transplant Center’s doctors and staff welcome you as a possible liver transplant candidate.

As you begin this journey, you and your family may have many questions and concerns. We hope that this book may help you learn about the process for liver transplant, so you know what to expect.

The goal of a transplant is to allow you to live a more normal life, but there are changes you will need to make after transplant to have the best outcome.

If you have any questions or concerns, please talk to your liver specialist or contact the Comprehensive Transplant Center at 1-800-293-8965 or 614-293-6724.

For more information

It is common to feel both concerned and excited as you consider a liver transplant. Please call to talk with our Pre-Transplant Coordinators to get more information and address your questions and concerns.

• Call 614-293-6724 or 1-800-293-8965, Monday through Friday from 8:00 AM to 4:00 PM.

After regular hours, a phone tree will direct you to the right person to leave a message.

• The fax number is 614-293-6710.

Ohio State Hepatology Clinic

• 2nd floor, Doan Hall, 410 W. 10th Avenue, Columbus, OH 43210
• Phone: 614-293-6255
• Fax: 614-293-8518
About the Liver

The liver is the largest internal organ and weighs about 2 to 4 pounds. It lies in the right side of the upper abdomen, next to the stomach. The rib cage covers most of the liver, except the area just below the breast bone. Under the liver is the stomach, large intestine, the right kidney and the gallbladder. A healthy liver does many things to keep your body working well, such as:

- Helps your body fight infection and destroying germs in your blood.
- Removes or changes almost every hormone, drug, and chemical that enters or is already present in your body.
- Makes and stores substances that help clot blood, called clotting factors.
- Stores glucose, vitamins, and minerals like iron and releases them when your body needs them.
- Produces bile to help digest food.

Blood is supplied to the liver by 2 large blood vessels. The hepatic artery supplies blood that is rich with oxygen to the liver. The portal vein brings blood from the stomach, small intestines, spleen, and pancreas to the liver to supply nutrients to the liver.
Liver Disease and Cirrhosis

There are many diseases that can damage your liver, causing cirrhosis. Your liver doctor, called a hepatologist, can help you understand your liver disease.

Liver disease causes scarring in the liver, called cirrhosis. The scar tissue blocks the flow of blood through the liver. This blockage causes the liver to be slow in breaking down food products, hormones, medicine, and waste products in the body. It also slows the liver's ability to make proteins and other substances.

Causes of cirrhosis

- Alcoholism
- Chronic hepatitis (type B and C are more common)
- Non-Alcoholic Fatty Liver Disease (NAFLD) which is related to insulin resistance and diabetes
- Inherited diseases, such as Wilson’s disease, alpha-1 anti-trypsin (AAT) deficiency Auto-immune disorders:
  - Primary biliary cirrhosis (PBC)
  - Primary Sclerosing Cholangitis (PSC)
  - Auto-immune hepatitis
- Reactions to prescribed medicines and exposure to environmental toxins are less common causes
- Heart failure with liver involvement
- Hemochromatosis

Signs of cirrhosis

Damage to the liver cannot be repaired, but treatment can slow or stop more damage. Problems or signs that are often seen include:

- Feeling tired or weak.
- Loss of appetite, nausea, and weight loss.

- Portal hypertension - High blood pressure in the portal vein system that carries blood from the digestive organs to the liver.
- Pruritus - Itchy skin.
- Jaundice - Yellowing of your skin caused by too much bilirubin in your blood.
- Ascites - Swelling in the abdomen due to a buildup of fluid. If your protein is low in your blood vessels, fluid can leak into your belly to cause ascites.
- Hepatic encephalopathy (HE) - Changes in alertness, confusion, forgetfulness, problems concentrating or increased sleepiness. Increased amounts of ammonia in your body can cause these changes in thinking. If you have HE, avoid use of opioid or narcotic pain medicines, sleeping pills, and anti-anxiety medicines.
- Varices - Swollen blood vessels in the stomach or esophagus. May have black tarry stools or vomit blood if these vessels bleed. Sometimes the bleeding is severe and can be life-threatening.

Infections in the abdomen and damage to the gall bladder and kidneys can also occur, along with many other problems.
Starting the Transplant Process

We strongly encourage you to **have a support person attend all your office visits, testing appointments and education sessions** with you. Because of your liver disease, you may have problems remembering and thinking, so your support person can be a second set of eyes and ears to help you.

**Transplant process steps**
The journey through the process of organ transplant requires several steps.
- Referral for transplant
- Transplant education
- Testing and evaluation
- Selection committee decision
- Waiting list
- Getting the call
- Transplant surgery
- Living with the transplant

We will review each of these steps to help you know what you can expect. Please ask any questions you may have and let us know if there is anything that you do not understand.

**Referral for transplant**
Your doctor may have talked to you about having a liver transplant because of the amount of damage you have to your liver.

If you want to be considered for a transplant, you will need to be seen by a **transplant hepatologist**, a doctor who treats liver disease patients. This doctor will review your records and may do other testing to determine the amount of damage you have to your liver, and if transplant is a good treatment option for you.

If you are a candidate for transplant, this doctor will **refer you to the transplant program** for more information and testing, and continue to work with the transplant team. This liver specialist will manage your liver disease treatment and medicines, whether or not you become a transplant candidate.

**Transplant team**
You will be seen by many members of the transplant team to help you understand the process and what to expect. Some of the team includes:
- **Transplant surgeon** - doctor involved in reviewing your history and doing an exam. This doctor, or another transplant surgeon may do the transplant surgery.
- **Pre-transplant coordinator** - registered nurse (RN) who will work with you through the process from your referral until transplant surgery. You will need to let this coordinator know about any hospital stays, changes in your health, or any changes in your contact information. After surgery, you will have a **post-transplant coordinator**, who is also a nurse.
- **Transplant financial coordinator** - works with you to help you understand the costs of transplant and any benefits you may be eligible for to help you.
• **Transplant social worker** - will work with you to check that you have support and coping skills to deal with the transplant process. Will work with you to meet transplant guidelines if you have a history of drug or alcohol use problems. You may be referred to the transplant psychologist if needed.

• **Transplant psychologist** - doctor who will work with you, if needed, to be sure you have the support and coping skills to handle the stress of the transplant process, or coordinate alcohol or drug counseling.

• **Transplant dietitian** - will work with you to review your eating habits and diet and help you make adjustments to manage your health.

**Evaluation day**

When all of the results of your testing are in, you will be scheduled for an evaluation day. It may take **up to 6 hours** for this appointment, so please **bring a snack and something to drink** with you. You are also expected to **bring at least 1 support person with you to this appointment**.

You should expect to meet with members of the transplant team, such as the:

- **Dietitian** to review your current diet and nutrition status to create a plan to keep you healthy. Changes to cooking and food prep and use of nutrition supplements may be discussed.
- **Social worker** to check your living situation, mental health, social system, work history, and any issues with drug or alcohol abuse. Based on this review, you may also need to meet with the psychologist. You must have a support person with you for this review.
- **Pre-transplant coordinator** will meet to review your medical history.

**Testing**

You will be scheduled to have tests done to check your current health and whether you would be able to have transplant surgery. These tests may be scheduled at Ohio State Wexner Medical Center, or you may be able to have some of the testing done at your primary care doctor’s office or local lab.

Tests may include:

- Abdominal imaging by ultrasound, CT, or MRI
- Blood tests
- Electrocardiogram (EKG or ECG) to check your heart beat patterns
- Cardiac echo to check the pressures in your heart and lungs and to check blood flow through your heart
- Pulmonary function testing to check how well your lungs are working
- Arterial blood gas (ABG) to check oxygen levels in your blood
- 6-minute walk test to check your heart and lungs when you are active
- Chest x-ray
- Dental clearance (within 1 year)
- Cancer screening that may include:
  - Colonoscopy if older than 50
  - Mammogram for women over 40
  - PSA for men
  - PAP smear for women

**Transplant education**

At Ohio State Wexner Medical Center, we start **people considering transplant and their support person(s) out with a class to explain the transplant process**. There is much to think about before an organ transplant. The class is scheduled through the transplant center office.

After you attend the class, if you decide you want to continue, you will be scheduled for testing and then an evaluation day.
• **Surgeon** will talk with you about the plan for liver transplant and review the results of your tests. You will have a physical exam and the risks and benefits of the surgery will be reviewed with you.

• **Financial coordinator** will talk about your health insurance benefits and other financial resources, including your income and savings. We will help you create a financial plan to cover the cost of the transplant and follow up care, as needed.

You will also need to be seen by other doctors. **These appointments may not happen on the same day as the rest of your evaluation.**

• **Cardiologist (heart specialist)** will review the results of some of your test to determine if you have any heart issues.

• **Infectious disease doctor** will review your vaccination history and recommend vaccines that may be needed before transplant.

Based on the findings from your evaluation, you may need other tests, or you may be given other guidelines that you need to meet before you are able to proceed to the committee review.

If your evaluation is complete, your case will be presented to the Liver Patient Selection Committee.

### Alcohol and drug use

Alcohol and illegal drug use can cause more liver damage.

• If you drink alcohol or use drugs, you will be sent for counseling and 3 months of treatment to help you meet requirements for the transplant waiting list.

• If you are on the liver transplant waiting list, and you test positive for alcohol or illegal drugs, you may be placed on inactive status, or you may be removed from the waiting list.

• Random drug and alcohol screening is done for all liver transplant patients. If you are called to have drug or alcohol screening, you have **24 hours to complete the needed test**, or it will be assumed that your results are positive and actions will be taken.

### Patient selection committee (PSC) review

This committee meets weekly to review new patients and to discuss updates for those patients who are either on or waiting to be placed on the transplant waiting list. Many members of the transplant team are on the committee. They determine if you are a good candidate for transplant or if there are other treatment options for your care.

All aspects of your health, testing, and evaluations will be discussed and a decision will be made about your case. There are 3 possible decisions:

• You are an acceptable candidate. We will seek approval from the state organ transplant consortium and final approval from your health insurance.

• We require more testing to decide whether it is safe for you to have a transplant.

• At this time, you are not a candidate. This may be a permanent or temporary decision. Continue your care with your liver specialist doctor. You may be referred back for transplant evaluation in the future.

The pre-transplant coordinator will contact you to let you know the decision from PSC about your case.

If you are an acceptable candidate, the transplant center will work to get your insurance approval for the surgery. They will also contact OSOTC (Ohio Solid Organ Transplant Consortium) to get approval to have you added to the liver transplant waiting list.
The number is calculated by a formula using 4 routine lab test results:

- **Bilirubin**: Measures how well your liver gets rid of bile, a fluid produced in the liver that helps with absorption and digestion.
- **INR**: Measures your liver’s ability to make blood clotting factors.
- **Creatinine**: Measures kidney function because kidney function is often affected by liver disease.
- **Sodium (Na)**: Measures the fluid balance in your body.

These labs are drawn at certain times based on your current MELD-Na.

You should have 3 tubes of blood drawn for this testing. These labs are required for you to remain on the active waiting list. If you miss a scheduled test, you will be placed on Hold, and you will not be eligible for a transplant until the tests are complete.

If you want to enter your lab values to know your MELD-Na score, you can use a calculator at this link: [https://optn.transplant.hrsa.gov/resources/allocation-calculators/meld-calculator/](https://optn.transplant.hrsa.gov/resources/allocation-calculators/meld-calculator/).

**While waiting**

Make sure that you are available by phone, check your messages, and respond right away. You need to return the call within 1 hour to determine if you are well enough for transplant. If you do not return the phone call in that time, the coordinator will contact the next person on the transplant waiting list, and you will miss the opportunity.
Be sure to **stay in close contact with your transplant coordinator.** Let the coordinator know right away if you have:

- Changes in your health, especially if you are seen in a hospital outside of Ohio State Wexner Medical Center.
- Changes to any of your medicines.
- Changes to your contact information or your family contact information if you listed them as a contact for you.
- Plans to leave the state on vacation or for other reasons. You may be placed on Hold if you are out of range.
- Any changes to your support system.
- Any changes in your insurance.

Have plans ready for child and pet care, if needed.

Have transportation arranged, so you are ready if you get a call.

**You are expected to abstain from using drugs or alcohol while you are on the transplant waiting list.** You may be required to get random drug screening done while you are on the transplant waiting list.

You will need to have **ongoing lab work.**

You also need to have yearly dental exams, heart testing, or other imaging tests, and you must update your psychosocial form each year.

Be sure to keep all of your appointments with your primary care doctor, liver specialist and have your needed lab work completed.

**MELD-Na lab work**

Based on your current MELD-Na score, you will need to have lab work done to keep you active on the waiting list. If your lab work is not done as required, you will go on Hold, and you will not be eligible to receive a transplant until the tests are completed.

You should always have at least 3 tubes of blood drawn for MELD-Na labs. You may have monthly tissue typing labs drawn in addition to the MELD-Na tubes if you need a liver and kidney transplant.

**Frequency of MELD-Na lab tests**

How often you need to be tested is based on your MELD-NA score. If your current MELD-Na is:

- 25 or higher, you need testing every 7 days.
- 19 to 24, you need testing every month.
- 11 to 18, you need testing every 3 months.
- 10 or less, you need testing every 12 months.

**Waiting list Hold**

You may be placed on waiting list Hold for many reasons. You are not able to receive organ offers while on Hold, but you are still on the list. Some of the reasons to be placed on Hold include:

- You are too sick to be safe for transplant surgery.
- You have not been current with your lab work or other testing and appointments.
- You had a positive drug screen.
- Your doctor or the Patient Selection Committee has placed you on Hold because you are not following through with required care.

You would also be called and get a letter if you were to be removed from the waiting list.

**Contact the transplant team**

Your transplant coordinator is available if you have any questions or concerns. All calls are routed to the coordinators and prioritized based on urgency. Calls are most often returned the same day that you called.

If you have an emergency, **do not drive yourself to the emergency room.** Ask the doctor in the emergency room to call the OSU Hepatology Clinic at 614-293-6255. If after hours, leave a message and someone will call back.
You may be offered an organ that is considered to be increased risk, related to test results or behavior of the donor. The transplant team would only offer an organ that they feel would benefit you. The reason the organ is increased risk will not be shared with you when you get the call. You would need to sign another consent after you were able to talk to the doctors at the hospital. For example:

- Hepatitis B core positive organs may be offered if you have been vaccinated against hepatitis B, because the risk of getting the hepatitis B virus would be very small.
- Patients with active hepatitis C may also be offered hepatitis C positive organs, as the benefits of transplant outweigh the risks from the hepatitis C organ. After the transplant, the patient would also be treated for hepatitis C.
- Organ may be available from a donor who dies after cardiac arrest. The doctor would discuss differences with this organ.
- Part of a donated liver, called a split liver, may be offered to certain patients who qualify for this type of transplant.
Transplant Surgery and After Care

Possible risks or problems from surgery
The doctor will talk with you about risks and benefits of transplant surgery before you sign the consent form. There may be other risks, based on the donor organ, and other factors. Ask questions if you do not understand the risks as the doctor explains them to you. The major risks include:

- Bleeding
- Pneumonia
- Blood clots
- Infection
- Heart complications
- Death

Surgery takes 6 to 8 hours
You will have general anesthesia, so you will not be awake through the surgery. The doctors will cut an upside down V, called a chevron incision, on your abdomen. If you still have your gallbladder, it will be removed to reduce possible problems after surgery. The transplanted liver will be placed through this incision.

You will have a breathing tube and several IV lines in place after the surgery is done. You will also have several drains to drain fluid out to help with healing. The incision will be closed with staples. You will likely be on oxygen and a heart monitor, and you will have wraps on your legs that are connected to a pump, called a compression device or SCD. The compression device is used to prevent blood clots from forming in your legs while you are on limited activity.

Care after surgery
Most transplant patients spend a few days in the Surgical intensive care unit (SICU). When you are able to breathe on your own, the breathing tube will be removed. You will then be moved to the transplant unit to continue your recovery.

Most liver transplant patients will be in the hospital about 11 days. Staff will teach you and your support person about your care with an organ transplant, such as:

- Your medicines to prevent rejection of the transplant, also called immunosuppression medicines.
- How to prevent infections.
- How to care for your surgery incision.
- Problems that you should watch for and who to call.
Immunosuppression medicines, also called anti-rejection medicines

Your body’s immune system helps protect your body from infection and fights off things that might be harmful to you. With an organ transplant, your immune system will know the transplanted liver is not part of you, so it may try to rid your body of it by fighting against it. Immunosuppression medicines must be taken after a transplant to reduce your immune system’s ability to recognize the transplanted liver as harmful. You will need to take these medicines 2 to 3 times each day, every day, for the rest of your life. As a transplant patient, you need to learn about your medicines and how to take them, including what side effects you may need to watch for with these medicines.

You will need to have **lab work done often to check the levels of your medicines** to be sure they are in the right range to work best for you. You should **never stop taking these medicines, or change the dose, without first checking with your transplant doctor.**

- Doses will change, and you need to communicate closely with your post-transplant coordinator to be sure you understand your instructions.
- Only an **Ohio State Wexner Medical Center transplant doctor** should be making changes to your transplant medicines.

Protect yourself from infections

Because these immunosuppression medicines weaken your body’s immune system, you need to take extra steps to stay healthy. You will be taught about how to protect yourself, such as:

- Good hand washing.
- Avoiding others who are sick.

Working with your post-transplant coordinator

You will get a call from a post-transplant coordinator in 24 to 48 hours after you leave the hospital after your transplant surgery. The coordinator is your contact for any questions you may have about your care. The coordinator will also work with you to coordinate lab work, medicine managements, and adjustments to your medicines.

Appointments after transplant

- You should plan to have appointments for follow up every week for the first month.
- Lab work will be done 2 times every week for the first 3 months.

Based on your condition, you may see the doctor frequently right after your transplant. Be sure to keep all of your appointments.

Can I contact the donor family?

This is your decision. Every donor family and situation is different. Some donor families want to share about their loved one while others find it too difficult.

Please call Lifeline of Ohio at 1-800-525-5667 to find out more about contacting your donor family.
What if Transplant Isn’t Right for Me?

Treatment options
There is no cure for cirrhosis, other than liver transplant. If transplant is not for you for whatever reason, there are other treatments that may benefit you. Some of these treatments may be used to manage your condition while you wait for a transplant.

Here is some information about possible treatment options. Talk to your liver doctor about treatments to manage your disease.

TIPS (transjugular intrahepatic portosystemic shunt)
During this procedure, a small metal tube, called a shunt or stent, is placed in the liver to connect 2 blood vessels. This is done to improve blood flow through the liver, reducing the pressure in the liver to limit further damage.

Heat ablation or radio frequency ablation
During this procedure, a small probe is inserted through the skin and into the liver. The probe produces heat to burn small growths, called tumors, to slow or stop further growth.
During this procedure, chemotherapy drugs are given directly into the liver while the blood flow feeding the growths or tumors is cut off.

Surgery
Based on the size and location of a liver tumor, surgery may be done to remove part of the liver that has the tumor growing in it.

Palliative care
Some patients decide that transplant is not right for them, and they want different goals in their treatment. Palliative care can help you determine what you want to do, and how you want to have your disease treated for the rest of your life. Do you want treatments to prolong your life, or do you want to be kept comfortable until your death? Palliative care can help you control your pain and ease your symptoms. Hospice services may also be useful to you and your family.