Preparing for a Liver Transplant

After receiving a liver transplant in 2001, Morgan was able to give birth to her son, Graham, 13 years later.
About the Liver

William, liver transplant recipient, with his wife

THE OHIO STATE UNIVERSITY
WEXNER MEDICAL CENTER
The liver is the largest internal organ and weighs about two to four 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 by 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 two 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 it with nutrients.
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 and alpha-1 antitrypsin (AAT) deficiency
- Autoimmune disorders, such as primary biliary cirrhosis (PBC) and primary sclerosing cholangitis (PSC)
- Autoimmune hepatitis
- Heart failure with liver involvement
- Hemochromatosis
- Reactions to prescribed medicines and exposure to environmental toxins are less common causes
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, damage to the gallbladder and kidneys can also occur, along with many other problems.
Liver Transplant Process

Lauren, liver transplant recipient (green shirt), pictured with her mom, Susan, dad, Rick and boyfriend, Nathan
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.

Liver Transplant Process

Transplant Process Steps:

The journey through the process of organ transplant requires several steps.

1. **Referral for Transplant**
2. **Transplant Education**
3. **Testing**
4. **Evaluation Day**
5. **Patient Selection Committee Review**
6. **Transplant Wait List**
7. **Getting the Call**

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.
Step 1: 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.

**Hepatologist**

If you want to consider a transplant, you will need to be seen by a 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 transplantation may be a good treatment option for you.

If you are a candidate for transplant, your hepatologist will refer you to Ohio State’s Comprehensive Transplant Center for more information and testing, plus continue to work with the transplant team. Your hepatologist will manage your liver disease treatment and medicines, whether or not you become a transplant candidate.

**Transplant Team**

Once you have been referred to Ohio State’s transplant center, 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 transplantation and any benefits you may be eligible for.

- **Transplant social worker** — will work with you to check that you have support and coping skills to deal with the transplant process. If you have a history of problems with drug or alcohol use, the social worker will also assist you with meeting transplant guidelines and may refer you to the 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 and/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.
Step 2: Transplant Education

If you are considering a liver transplant, the next step in the process is to attend a class at Ohio State’s Comprehensive Transplant Center. **People considering a liver transplant should attend this class with their support person(s) to learn about 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.

Step 3: 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 or you may be able to have some of the testing done at your primary care doctor’s office or a local lab.

Tests may include:

- Abdominal imaging by ultrasound, CT or MRI
- Blood tests
- Electrocardiogram (EKG or ECG) to check your heartbeat patterns
- Cardiac echo to check the pressure 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
- Six-minute walk test to check your heart and lungs when you are active
- Chest X-ray
- Dental clearance (within one year)
- Cancer screening that may include:
  - Colonoscopy if older than 50
  - Mammogram for women over 40
  - PSA for men
  - Pap smear for women
Step 4: 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 six hours** for this appointment, so please **bring a snack and something to drink** with you. You are also expected to **bring at least one support person with you to this appointment**.

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

- **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.

- **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. You will be helped to 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 tests 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 additional tests or you may be given other guidelines that you need to meet before you are able to proceed to the committee review.

Once your evaluation is complete, your case will be presented to the liver transplant **Patient Selection Committee (PSC)**.

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 three months of treatment to help you meet requirements for transplant listing.

- 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 a 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.
Step 5: Patient Selection Committee Review

The Patient Selection Committee (PSC) 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 wait list. Many members of the transplant team are on the committee, and 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 three possible decisions:

1. You are an acceptable candidate.
2. More testing is required to decide whether it is safe for you to have a transplant.
3. 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.

Your hepatologist or the pre-transplant coordinator will contact you to let you know the decision from the 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 the OSOTC (Ohio Solid Organ Transplantation Consortium) to get approval to have you added to the liver transplant wait list.

Step 6: Transplant Wait List

You will receive a letter and a phone call when you have been placed on the liver transplant list. There are several factors that determine your rank or placement on the wait list:

- Blood type
- Weight range
- MELD-Na score

Blood Type

There are four blood groups on the list: A, AB, B and O.

- O and A are the most common blood types and have a longer wait list, but they also have more donors available.
- AB and B groups have shorter lists, but there are fewer donors in these groups.
Weight Range

The donor liver size can determine the recipient. Each patient on the wait list will have a weight range based on their body size.

MELD-Na Score

The Model for End-Stage Liver Disease (MELD) and sodium (Na) score is a useful tool for both you and your healthcare team as you plan for a transplant. It is a numbered scale that estimates how well your liver is working. The sodium level is an indicator of how serious your liver disease may be. With cirrhosis, the function of the liver can change constantly, even every day. These changes are seen in your blood work, which is used to find your MELD-Na score.

The scores range from six, which means the liver is working well, to 40, which means the liver is working poorly and the person needs an urgent transplant.

The number is calculated by a formula using four routine lab test results:

1. **Bilirubin**: Measures how well your liver gets rid of bile, a fluid produced in the liver that helps with absorption and digestion.

2. **INR**: Measures your liver’s ability to make blood clotting factors.

3. **Creatinine**: Measures kidney function. Kidney function is often affected by liver disease.

4. **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 three tubes of blood drawn for this testing. These labs are required for you to remain on the active wait 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: 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 one hour to determine if you are well enough to transplant. If you do not return the phone call in that time, the coordinator will contact the next person on the transplant 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

- **You should have plans ready for child and pet care, if needed, as well as 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 list.** You may be required to get random drug screenings done while you are on the transplant 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 and 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 wait 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 three 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 seven days
- 19 to 24, you need testing every month
- 11 to 18, you need testing every three months
- 10 or less, you need testing every 12 months
Wait List Hold

You may be placed on a wait 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.

If you are removed from the transplant wait list, you will receive a phone call and a letter of notification.

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 they are received.

If you have an emergency, do not drive yourself to the emergency room. Ask the doctor in the emergency room to call the Ohio State Hepatology Clinic at 614-293-6255. If after hours, leave a message, and someone will call back.

Step 7: Getting the Call

Call from Coordinator

A transplant coordinator will call you when a potential organ is available. Coordinators from different groups make calls to patients to offer organs, so you may not be talking to your assigned liver pre-transplant coordinator.

- Organ offers come at all hours of the day and night. Be sure to keep your phone on at night.
- The phone number that the coordinator is calling from will not always show as an Ohio State number on your caller ID. Please do not screen calls, as you may miss the call for an organ offer.
- You have one hour from the time the coordinator first called you to return the call. You do not have to be at the hospital in an hour, but you do need to return the call.
- The coordinator will keep trying to call you and anyone listed as a contact for you during the hour.
- When the coordinator reaches you, you will need to provide information about any changes to your medical history, infections, fevers and the distance you are away from the hospital.
- You may be asked to come to the hospital and then be sent home if the organ does not appear to be a good match for you or if the organ is of poor quality. This would not change your position on the wait list. You may also be sent home if you have an infection, test positive for drugs or alcohol, or you have a new health problem that would make surgery unsafe for you.
• Be sure to bring these items with you to the hospital:
  - Photo ID
  - Insurance card(s)
  - Current list of all medicines
  - Power of attorney or living will documents
  - Medical history and list of past surgeries
  - List of important phone numbers
  - Personal hygiene items
• Do not bring jewelry, large amounts of money or other valuables with you to the hospital.
• For the safety of all patients on the transplant unit, children age 12 or younger are not permitted to visit. In addition, live plants, fresh fruits and vegetables and fresh flowers are not permitted on the transplant unit.

Increased Risk Organ Offers

You may be offered an organ that is considered to be an increased risk, determined by 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.** If you agree to accept the organ, you will receive more information from the surgeon when you arrive at the hospital and will sign an additional consent to receive the organ. It is important to note that the surgical team would not accept the organ unless they believe the benefits of transplant outweigh the risks.

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.

Other types of organs you may be offered include:

• Liver from a donor who dies after cardiac arrest. The doctor would discuss differences with this organ. This is not an increased risk organ and does not require an additional consent.

• Part of a donated liver, called a split liver, may be offered to certain patients who qualify for this type of transplant. This is not an increased risk organ and does not require an additional consent.
Liver Transplant Surgery

Douglas, liver transplant recipient

THE OHIO STATE UNIVERSITY
WEXNER MEDICAL CENTER
After you receive the call from your transplant coordinator, you will be admitted to the Transplant Unit on the 10th floor of Rhodes Hall at The Ohio State University Wexner Medical Center.

Upon arrival, you will have multiple lab tests done to ensure you are ready for transplant. You will be given a number of medications, including antibiotics, antifungals and immunosuppression medications.

Possible Risks or Problems from Surgery

The doctor will talk with you about risks and benefits of transplant surgery before you sign the surgery 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
- Infection
- Pneumonia
- Heart complications
- Blood clots
- Death

Surgery Takes Six to Eight Hours

Ideally, surgery is performed as soon as the organ is available. However, using the latest perfusion techniques, we are able to transplant livers within 12 to 24 hours after organ recovery. When you are taken to the operating room, 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. The transplanted liver will be placed through this incision. If you still have your gallbladder, it will be removed to reduce possible problems after surgery.

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

Krista, liver transplant recipient (center), pictured with her daughter, Shelbi and husband, Ken
Most transplant patients will 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, and 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. The unit staff will be teaching you and your support person about your care with an organ transplant, such as:

- Your immunosuppression medicines to prevent rejection of the transplant
- How to prevent infections
- How to care for your surgical incision
- Problems that you should watch for and who to call
Immunosuppression Medicines (Also Called Anti-Rejection Medicines)

Your immune system helps protect your body from infection and fights off things that might be harmful to you. After your organ transplant, your immune system will know the transplanted liver is not part of your original body. Because of this, it may try to fight against the liver transplant and reject it or rid your body of the transplanted organ. Immunosuppression medicines (also called anti-rejection medicines) must be taken after transplant surgery to reduce your body’s chances of rejecting your newly transplanted liver. You will need to take these medicines two to three 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 to watch for.

You will also 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 transplant doctor should be making changes to your transplant medicines.

Protect Yourself from Infections

Because 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 and management of 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 two times every week for the first three months.
- Based on your condition, you may see the doctor very 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 800-525-5667 to find out more about contacting your donor family.
Other Treatment Options

April, liver transplant recipient, with her son, Samuel
## 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 two 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, in order to slow or stop further growth.

- **Chemoembolization** — 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 pain and ease symptoms. Hospice services may also be useful to you and your family.
Preparing for a Liver Transplant

Ohio State Comprehensive Transplant Center
Abdominal Transplant Clinic
300 W. 10th Ave., 11th Floor
Columbus, Ohio 43210

800-293-8965

wexnermedical.osu.edu/transplant