

Health Facts for You



*Preparing for your
child's liver transplant
evaluation*

Welcome to the UW Health Liver Transplant Program. The team takes pride in building a care plan tailored to your child's needs. We are committed to your success. UW Health is a national and international leader in the field of transplantation. Our program provides care for both adults and children. We offer both deceased and living donor transplantation.

The Liver

It is good to have basic knowledge of how the liver works. The liver is part of the digestive system. It has more than 500 functions, all of which are needed for life. Some of these functions include:

- Breaking down fats, storing nutrients, and making protein.
- Cleaning poisons and waste from the body.
- Fighting infections.
- Breaking down/processing medicines.
- Blood clotting.

End-stage Liver Disease

This occurs when the liver has been permanently damaged. Causes may include:

- Biliary atresia
- Inherited or autoimmune diseases, such as alpha-1-antitrypsin deficiency and it is Alagille syndrome.

- Infection (such as hepatitis)
- Cancer
- Substance toxicity/abuse
 - Acetaminophen (Tylenol®) overdose
 - Poison

MELD and PELD Scores

These scores tell us how sick your child is. The MELD (Model of End Stage Liver Disease) score is used for those who are 12 years of age or older. Scores range from 6-40. The higher the number, the more severe your child's disease. Death is also more likely without a transplant. Lab values (total bilirubin, creatinine, INR, sodium, and albumin) are used to calculate the MELD score.

The PELD (Pediatric End-stage Liver Disease) score is similar. It is used for those younger than 12 years old. Lab values (bilirubin, INR, albumin, and creatinine), age, height, and weight are used to calculate the score.

Transplant Evaluation Visit

The evaluation visit takes about 6-7 hours. It gives the team a complete overview of your child's liver disease and needs. Since transplant is so complex, both parents or support persons must be present for the evaluation. There are many items you should bring. Use the checklist below to be sure you have what you need.

What to Bring With You

<input type="checkbox"/> This packet	<input type="checkbox"/> Completed Vaccine History form
<input type="checkbox"/> Both parents and/or guardians	<input type="checkbox"/> Your child's social security number
<input type="checkbox"/> Your insurance cards	<input type="checkbox"/> Snacks/sack lunch
<input type="checkbox"/> Completed Transplant Evaluation Checklist (found in this packet)	<input type="checkbox"/> Something to do (tablet, book, etc.)
<input type="checkbox"/> An overnight bag with essential items. Some patients are admitted for conditions found during the evaluation.	<input type="checkbox"/> A list of your child's current medicines and pill bottles. This list should include doses and why your child takes them.
<input type="checkbox"/> A list of questions you or your family have for the transplant team.	<input type="checkbox"/> Other:

Transplant Team Members

Transplant Surgeons

Transplant surgeons meet with you and your family during the evaluation. They review your child's record and test results and explain the surgery. They review the risks and benefits of transplant. The surgeon does the surgery and works with other doctors to manage your care after the transplant.

Medical Specialists

These doctors help to decide if a transplant is the best option for your child. They stay involved while your child is on the waiting list and after the transplant.

Pre-Transplant Nurse Coordinators

These nurses coordinate your child's care before transplant. They are involved from the time of the first referral until a transplant is received. They arrange any tests needed to get your child placed on the waitlist. This nurse helps with the evaluation process. These nurses contact your child's local doctors and other healthcare facilities as needed.

Post-Transplant Nurse Coordinators

These nurses coordinate your child's care after transplant. They are involved from the time of transplant through long-term, post-transplant care. They serve as your link to the rest of the transplant team after surgery. They work with the doctors to coordinate your child's medical needs. They teach you and your family and advocate for your child. These nurses contact your child's local doctors and other healthcare facilities as needed.

Clinical Social Workers

Social workers talk with you about your child's emotional health and social situation. They will discuss community resources and help with financial matters. They help

support you and your child during the transplant process. Social workers can also help to find support groups.

Clinical Dietitians

Clinical dietitians assess your child's nutritional status. They help you to make a plan for good nutrition.

Physician Assistants and Nurse Practitioners

These advanced practice providers care for your child before and after transplant. They check on your child during recovery and help to manage your child's medicines. They also help to plan for your child's discharge needs. You will see them in transplant clinic before and after surgery.

Surgical Residents and Transplant Fellows

These doctors mainly assist with hospital care. This includes getting your child ready for and helping with surgery. They help to manage issues after surgery and prepare your child for discharge. You may also see transplant fellows at transplant clinic visits.

Financial Counselors

These staff work with you and your insurance company before and after transplant. They help to work through matters such as billing, deductibles, and drug coverage. They teach you about the financial aspects of transplant. They are the best resource for any questions about insurance.

Transplant Pharmacists

Pharmacists work with the team to make sure the medicines are used correctly. They watch for side effects and try to minimize them. They also help to manage the timing of the medicines.

Inpatient Nurses

These nurses care for your child in the hospital. Your child will have a primary nurse. This nurse works with the rest of the team to get your child ready for discharge.

Case Managers

Case managers focus on the plan for leaving the hospital. Some patients need skilled nursing care or other services. The case managers can help arrange this care.

Transplant Clinic Nurses

These nurses care for your child during clinic visits. They provide care and support after procedures. They arrange follow-up care and provide education.

Office Support Staff

Support staff answer your phone calls and work with the coordinators and other staff. They help coordinators to manage lab results and patient issues and concerns.

Spiritual Care

Chaplains help people find comfort and meaning from their faith during illness recovery. Our chaplains provide spiritual and emotional support. They also perform sacraments. Faith and medicine offerings are provided in the hospital chapel. Catholic and Protestant services are held on Sundays.

Other Expert Doctors

Other doctors may be involved either during the evaluation or after transplant. UW Health has many specialized doctors who work with the rest of your team. Infectious disease, dental, endocrine, cardiology, hepatology, and urology are just a few of the teams that can assist in your child's care if needed.

Other Services

Other services are available to help you and your family. For example, Interpreter Services help those who need translation. Housing assistance can help if you need short-term housing.

The Transplant Process

Evaluation

- In order to make sure transplant is the best option, you and your child will:
 - Meet with the transplant team.
 - Have tests and labs done.
- This phase can take days, weeks or months.
- When the evaluation is done, you will get written notice of our decision.
- You may also start to seek out potential living donors (for kidney and liver transplant) during this phase.

Waiting Period

- If you and the UW Health transplant team believes transplant is your child's best option, your child will be added to the national waitlist. This is done through the [United Network for Organ Sharing \(UNOS\)](#). UNOS is in charge of all organ allocation.
- This phase can last days or years.
- Find potential living donors (for kidney and liver transplant).
- If a living donor is approved, your child will be scheduled for surgery after the donor work-up is done.

Surgery

- Your child receives the organ transplant and heals in the hospital.
- While healing, you will learn about new medicines, self-care, follow-up tests and clinic visits.

Follow-Up

- This phase starts when your child leaves the hospital. It lasts the rest of their life.
- Medicines, labs tests, clinic visits and follow-up care are needed.
- The transplant team will support you long-term, so your child can lead a normal, active, and healthy life.

Social Work Support

A transplant social worker will meet with you at your child's evaluation. They will ask you questions about:

- You and your family
- How you cope
- You and your child's drug/alcohol use
- Your support systems
- How well you will be able to follow important instructions.

These questions help them learn more about you and your child's needs before the transplant.

Patient and Support Expectations

Expectations will be shared with you.

Parents, guardians, family, friends, and other support persons should read these documents before the evaluation. The transplant process can be long. You will need extra help and support to have a successful experience. **An adult must be with your child at this visit.** This must be at least one parent, preferably both, or could be a guardian, family member, or friend. This person must be willing and able to provide in-person support as your child prepares for and recovers from transplant.

Tips for Talking with Your Health Care Provider

You and your health care team are working toward the same goal - good health for you. Talk together about your health and any problems you may have. Here are a few tips to make the most of your time together.

Use clinic and hospital visits to learn how to best care for your child. Ask questions. Practice new skills. Get advice about what might work best for you.

Be a partner in making decisions. Ask about your options. Find out about pros and cons of any decision. Plan your child's care with the health care team and others who support you.

When you make an appointment, ask if your child needs any tests before you come in. They may need to wait to eat or drink until after a test is done. Ask if your child can do the test before their appointment. You may be able to get the results during your child's clinic visit.

Prepare for your visit. Think about the reason for your child's clinic visit. Write down what you want to tell your provider. Write down any questions you have and consider writing down answers during the visit.

Be clear about your child's health problem and how they feel. Before your child's clinic visit, you may want to write down:

- How long has your child had this health problem?
- What has been done about it?
- How has the problem changed or stayed the same?
- What makes it better or worse?

Share what you have been doing about your child's health problem. If you have provided or changed the treatment, tell your provider. To best help you, your team needs to know how you are caring for your child.

Listen carefully. If you don't understand, ask questions. Ask for more information if you need it. Take notes or ask for a written sheet if this would help you. Ask your child's health care provider:

- What your child's health problem is?
- What caused it?
- What should you do about it?
- When will it improve?
- If your child needs a follow-up visit?

Make sure you know and agree with the plan.

- Repeat what you have heard to make sure you understand what was said.
- Make sure the instructions are right for your child. If they aren't, tell your provider. Ask if the plan can be changed to better meet your child's needs.
- Understand side effects and what to expect from any new medicines.
- Find out who to call for questions after going home.
- Take your after-visit summary sheet at the end of a clinic visit. You can also find it in MyChart.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 5/2022. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8245.