

The background features a large, light-colored triangle pointing downwards from the top left, filled with a pattern of small, light grey dots. To the left of this triangle are overlapping geometric shapes in shades of blue, red, and teal. On the right side, there is a vertical strip of overlapping blue, red, and teal shapes. The main title is centered in a large, bold, dark blue serif font.

# 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 child's 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:

- Infection
- Inherited diseases
- Autoimmune diseases
- Cancer
- Fatty liver and metabolic diseases
- Medicine induced liver disease
- Alcohol abuse
- Poisons

### **MELD and PELD Scores**

These scores tell us how sick your child is. The MELD (Model for 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 liver disease and needs. There are many items you should bring. Use the checklist below to be sure you have what you need.

Since transplant is so complex and a strong support system is important in helping your child have a successful experience, parents or guardians must be present for your child's visits with the team during the evaluation. Your child's support system **must** be willing and able to provide in-person support as they prepare for and recover from transplant.

To prepare for your evaluation, we have enclosed:

### **Patient and Support Expectations**

These are documents that explain how we want patients and their support person to partner with us in their transplant care. Please read these documents with your family, friends, and other support persons.

## What to Bring to Your Evaluation

<input type="checkbox"/> <b>Both parents and/or guardians</b>
<input type="checkbox"/> Your insurance cards
<input type="checkbox"/> Completed Vaccine History form
<input type="checkbox"/> Your child's social security number (for future transplant listing if approved for transplant) if not already provided to AFCH at registration
<input type="checkbox"/> A list of your child's current medicines and supplements or pill bottles. This list should include doses and why they take them. Also bring medicines your child may need to take during the appointment.
<input type="checkbox"/> A list of questions you or your support person have for the transplant team.
<input type="checkbox"/> Phone charger
<input type="checkbox"/> An overnight bag with essential items. Some patients are admitted for conditions found during the evaluation.
<input type="checkbox"/> Snacks/sack lunch
<input type="checkbox"/> Something to do (tablet, book, toys, etc.)
<input type="checkbox"/> If needed, diapers/wipes, bottles/formula, pacifier, extra clothes, any medications needed for that day.

## The Transplant Process

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### Evaluation

- In order to make sure transplant is the best option, over weeks or months, you will:
  - Meet with the transplant team.
  - Complete tests and labs.
- After your evaluation, we will follow up with you about next steps.
- You may also start to seek out potential living donors during this phase.

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### Waiting Period

- If a transplant is considered by the team to be the best option, and you wish to proceed with surgery, 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 placing the donated organ with the right recipient, per UNOS policies.
- This phase can last days or months
- If a living donor is approved, your child will be scheduled for surgery after the donor work-up is done.

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### Surgery

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

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### Follow-up

- This phase begins when you leave the hospital.
  - Medicines, labs tests, clinic visits and follow-up care are needed in order to lead a normal, active, and healthy life.
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## **Team Members**

### **Transplant Surgeons**

Transplant surgeons meet with you 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.

### **Transplant Medicine Doctors**

Transplant medicine doctors may meet with you during the evaluation. These doctors help to decide if a transplant is the best option for your child. They help manage your child's care 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 child's support persons to advocate for your child. These nurses contact your child's local doctors and other healthcare facilities as needed.

### **Transplant Social Workers**

A transplant social worker will meet with you during the evaluation. They will talk with you about your child's support system, emotional health, and how well you will be able to follow important instructions. This helps them learn more about your child's needs before transplant. They can help with connecting you and your child with community resources such as counseling, support groups, and financial support. They are also available for support after transplant.

### **Clinical Dietitians**

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

### **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.

### **Inpatient Nurse Case Managers and Social Workers**

Nurse case managers and social workers are available to help develop your plan for leaving the hospital. Some patients need skilled nursing care or other services. They help arrange this care or connect you to other community resources.

### **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, and endocrine are just a few of the teams that can assist in your child's care if needed.

### **Child Life Specialists**

Certified Child Life Specialists help children, adolescents, and families cope with the fear and anxiety associated with the medical environment and hospitalization. The goal of the Child Life program is to promote positive experiences for children and families throughout hospitalization.

### **Other Services**

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

## Financial Planning

You will need to learn more about your insurance plan. A person who gets a transplant needs life-long follow-up care and medicines. Learn about your co-pays and deductibles for clinic visits and tests. This will help you budget for this expense.

Many plans have a yearly maximum for co-pays or deductibles. When you have reached the limit, your insurance may pay 100%. Refer to your insurance booklet and keep track of your healthcare expenses.

Know the referral guidelines of your health plan. UW Health is a hospital-based clinic. You will get bills from the hospital and the doctors. If guidelines aren't followed, you may need to pay for the bill.

You may need to stay in Madison for some time after your transplant. Most insurance plans require prescriptions to be filled at certain pharmacies. Know your preferred pharmacy in your hometown and in Madison.

### Common Financial Questions

Below are some common questions which other transplant patients have found helpful.

- What would be my monthly total co-pay be if prescribed 15 medicines?  
 $15 \times \$ \underline{\hspace{2cm}}$  (the co-pay amount per prescription) =  
 $\$ \underline{\hspace{2cm}}$
- What are the co-pays and deductibles for clinic visits and procedures?
- What do I need to pay out-of-pocket?  
Monthly clinic and procedure co-pays: \$
- How would this expense fit into my budget?
- What would I do if my insurance was changed? (Notify your coordinator right away!)

- My health plan referral guidelines:

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## Tips for Talking with Your Health Care Provider

You and your health care team are working toward the same goal - good health for your child. Talk together about your child's health and any problems they 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 your child.

**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 you should 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.

### **Learn More**

For more resources about transplant at UW Health, scan the QR code below.



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 © 4/2024. University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#8245.