

I can tell you what to expect before surgery.

How do you decide if my child can get a new liver?

You are here because the doctor felt your child might need a liver transplant. This is the start of many visits, called the **Evaluation**. We will get to know your child and your family. This helps us understand your child's liver disease, and helps us get your child ready for a liver transplant, if it is needed. We will also be ready to move quickly to transplant if this is best for your child.

Your family is invited to come to these Evaluation visits to the hospital. Different people may think of different questions that you have not thought to ask. It is also helpful to have everyone in the family understand the process and get their questions answered. Going through a transplant can be stressful for everyone. It might help to have the support of family to get through the transplant and follow up care.

This Evaluation starts now, and continues even when your child is on the list waiting for a liver.

Here are the steps:

1. We learn about your child. A doctor specializing in children's liver diseases (**pediatric hepatologist**) will ask about your child's medical history, and examine your child. Bring with you the dates of your child's shots (**immunization record**) and other medical records you have. Your child may also have tests and other visits, such as with team members from anesthesiology, palliative care, or cardiology.

2. You learn about a transplant. You and your family will meet with a transplant coordinator to talk about the process of getting a transplant.

3. The surgeon learns about your child. You and your family will meet with a transplant surgeon.
4. We learn about your child's teeth. Your child may need to see a dentist before surgery.
5. Blood tests. Blood is tested for many things, including a check to see if your child has been exposed to certain viruses, such as chicken pox, HIV, or hepatitis.
6. Other medical tests. Your child will have a chest x-ray, CT scan of the liver, and an echocardiogram.
7. You and your family will be checked for TB (**tuberculosis**).
8. We learn about your child's nutritional health. You and your family will meet with a nutritionist, who will learn about your child's diet. We will learn what your child eats, and will tell you if your child needs more or less of some foods to get ready for a transplant. Some children will need to get added nutrients in other ways, such as supplements or tube feedings.
9. We will learn if your family is ready for your child's transplant. You and your family will meet with a social worker, who will talk with you about the feelings that come up with a transplant, and the money issues. You and your family will meet with a child life specialist.
10. You and your family will meet with a financial coordinator, who will learn about your health insurance and tell you how much of the transplant costs will be covered.
11. The decision. Everyone has to decide what to do.

You have now spoken with our team, and your family can decide if you want your child's liver to be transplanted at Phoenix Children's Hospital.

A team called the multidisciplinary selection committee will look at all the information they have about your child and decide if your child has everything in place that would make this a successful liver transplant. They decide

- if your child's name should be put on the liver transplant waiting list
- if they need more information before they can decide, or
- if your child should not get a liver transplant. If this is the team's choice, they will tell you why. It may be that your child is too sick to survive the surgery, or is using

drugs or alcohol. Or it may be that in the past your child did not take medicine as ordered or keep appointments, and the transplant will not work without good after care.

If the team decides your child should not get a transplant, you can take your child to a different center that transplants livers and ask them to evaluate your child.

If the team decides your child should have a transplant, they will tell you, tell your child's doctor, send you a letter, and put your child on the list.

The liver transplant waiting list

When the transplant team decides your child should have a liver transplant, your child's name goes on to the national waiting list. This list is kept by a not-for-profit, private (not government) organization called **UNOS**, the **United Network for Organ Sharing**.

Donated organs are given fairly, without regard to the person's age, sex, ethnicity, religion, or social status. The group that makes sure this is fair is called OPTN, the Organ Procurement and Transplantation Network. Your transplant team will give you more information on these groups or you can read their website at www.unos.org.

Patients are given scores, and these numbers place them in order on the list. The higher on the list, the sooner the transplant. A liver that becomes available has to be the right blood type, quality, and size.

To get these scores, all the lab tests, height, and weight must be done on the same day. Here are the scores they look at:

PELD (Pediatric End Stage' Liver Disease) Score

This score is used for children under 12 years old. Data we can measure are put into a math equation, and calculates a score.

- child's age, if under 1
- albumin level in the blood
- total bilirubin level in the blood
- the liver's ability to help the blood clot (INR)
- growth failure (measured by how far off from normal)

The score can range from -10 to +150, which says how important it is for the child to get a liver within the next 3 months. A higher score means the child is sick, and needs

a liver soon.

MELD (Model for End-Stage Liver Disease) Score

This score is used for patients 12 and older.

Data we can measure are put into a math equation, and calculates a score.

- total bilirubin level in the blood
- the liver's ability to help the blood clot (INR)
- kidney function (creatinine level)

The score can range from 6 to 40, which says how important it is for the child to get a liver within the next 3 months. A higher score means the child is sick, and needs a liver soon.

As your child's bloods test results change, your child's score changes, and place on the list changes. They do not look at how long your child has been on the list, unless there are two patients with the same score.

All ages go on to the same transplant list, using MELD scores. So there is a chart that shows what a PELD score would be in MELD. A PELD score of 40 is about the same as a MELD score of 29.

In addition to a MELD or PELD score, your child is assigned a status. Patients who are Status 1A and Status 1B are the sickest. If they don't get a transplant, they may die in less than 7 days. These may be patients with:

- acute liver failure
- have gotten a liver transplant with 7 days and it is not working (called **primary graft non-function**)
- have gotten a liver transplant within 14 days and they develop a specific blood clot (**hepatic artery thrombosis**)
- acute Wilson's Disease
- chronic liver disease.

Your transplant team will talk to you if your child becomes Status 1A or Status 1B.

Your child will keep the same doctor or pediatrician while waiting for a transplant. The transplant team only looks at your child's transplant status.

How often your child sees the transplant team depends on your child's health and PELD or MELD score. Your child may need to come to the clinic every 1, 3, 6, or 12 months. You may use these visits to talk to the Transplant Coordinator, Transplant Surgeon, and Social Worker if you have questions or concerns.

Your transplant team has to report to UNOS your child's lab test results, height, and weight on schedule for your child to stay on the waiting list for a liver. We will tell you when these tests are needed. You need to make sure your child gets these on time, to stay on the list.

When a liver is available, it is offered to a specific patient on the UNOS list. The transplant team does not decide who gets the liver.

While your child is on the waiting list, we will talk to you about liver transplants and how to take care of your child while waiting. We will closely watch how your child is doing. Your child's MELD or PELD score will change over time. Your child may be too healthy or too sick for a transplant, and may be taken off the list.

What does our family need to do while we are waiting?

Your family can also get ready for the time of surgery.

Make sure we can always reach you

Make sure the Transplant Team has all the telephone numbers to contact your family: home, work, cell phones. We need to be able to reach you quickly if a liver becomes available.

If your child is high on the transplant list and you don't have a cell phone, get one. This way you don't have to stay at home waiting for our phone call.

Tell the Transplant Team right away if your address or phone number changes. If you are going out of town, tell the Transplant Team the dates of your trip and how to reach you when you are away.

Health insurance

If your health insurance changes, tell our financial coordinator right away. This may change the cost of your child's appointments, test, and transplant.

Have a plan

The transplant coordinator will tell you when to pack a bag with a change of clothes for yourself and your child, and personal care items like toothpaste and toothbrush.

Have a plan for how you will bring your child to the hospital when you get that call that a liver is ready for transplant. If you need help making a plan, talk to the Transplant Coordinator and Social Worker.

Have a plan for housing

After the transplant, one family member can stay at your child's bedside. While your child is in the hospital, you will need a plan for who will take care of brothers and sisters. There is no place for siblings to stay at the hospital.

To stay at a Ronald McDonald House:

- The child getting treatment must be under 22 years old.
- The child's permanent residence must be more than 30 miles away from the Ronald McDonald House.
- All children under 18 must be with their legal guardians when at the Ronald McDonald House.

If you would like a room at the Ronald McDonald House, talk to the Transplant Coordinator or Social Worker to learn more about how much it costs and how to plan for it.

Be ready for extra costs

Most of the medical costs of a liver transplant are usually covered by health insurance. Insurance does not cover housing, travel, or food. Your Social worker can tell you about groups that can help you plan for these expenses.

What do we do while we are waiting on the list for a transplant?

While your child is waiting for a transplant, there are some things you child and your family can and should do.

To stay on the list:

Blood tests

The higher the PELD or MELD score, the more often your child must have blood tests done. We must report blood test results to UNOS to keep your child's place on the waiting list. We will tell you when you need to bring your child in for tests.

Immunizations

The shot schedule may be different for children waiting for a liver transplant. We will explain this to your child's doctor. To get a liver, your child must be up to date on all his or her shots, and your child and family all must get flu shots every year before the transplant can be done.

Tell us of changes

Tell us if your child's condition changes or if your child goes into the hospital. This might change your child's place on the waiting list.

To stay ready for surgery:

Prevent infections

Everyone in the family should wash their hands well and often, to prevent spreading germs. Keep your child away from people who are sick. Tell us if your child has been near someone with chickenpox, TB (tuberculosis), or any other disease that spreads from person to person. If you have any questions or concerns, talk to your school nurse and the transplant team.

Skin Care

When you wash your child, check his or her skin. Call the transplant team if you see:

- rashes
- little purple spots (called **petechiae**)
- bruises
- irritation from scratching or diaper

If your child's eyes and skin are yellow (called **jaundice**), your child may feel itchy. Keep your child's nails short and filed to avoid scratches. A lukewarm bath using Aveeno oatmeal bath may soothe the itching. If your child needs more relief from itching, call the transplant team. Medicine may help.

To live as normal a life as possible while waiting for surgery:

School

A child's job is to go to school. Tell the transplant team if you have any concerns about your child going to school. We can talk to your child's school about limits on your child's activity. We can talk to you about education options.

Rest and Sleep

Your child's liver may have trouble clearing waste products from the blood. This can make your child sleepy and confused. Children with jaundice may feel too itchy to fall asleep or stay asleep. If your child needs relief from itching, call the transplant team. Medicine may help.

Stress and Coping

Our Child Life Specialists will help your child get ready for the feelings that come up with surgery. They will give your child a tour of the places in the hospital your child will see before and after surgery. They will play with your child using medical equipment, and explain what to expect. They can answer your child's questions in ways that are right for your child's age, and tell you how you can help your child, too.

It can be stressful to care for a child with a chronic illness. Take care of yourself, too. Ask family and friends for help. Our team's social worker and psychologist can also help you and your family cope. We will tell you what we've learned from other families and tell you what you might expect. We will guide you as your child recovers from surgery, and we will get you more help if you need it. We have resources that can help with financial worries, and information about support groups.

Disclaimer

The information provided at this site is intended to be general information, and is provided for educational purposes only. It is not intended to take the place of examination, treatment, or consultation with a physician. Phoenix Children's Hospital urges you to contact your physician with any questions you may have about a medical condition.