



A patient's guide to  
**PEDIATRIC LIVER TRANSPLANT**

Transplant Institute  
4502 Medical Drive, MS 18-1  
San Antonio, TX 78229  
Mainline: 210-567-5777 or 1-888-336-9633  
Referral Fax: 210-358-0402  
[UniversityTransplant.com](http://UniversityTransplant.com)





# RESOURCES

## United Network for Organ Sharing (UNOS)

888-894-6361 | unos.org

## American Liver Foundation

800-Go-Liver or 212-668-1000

www.liverfoundation.org

## Hepatitis Central

www.hepatitis-central.com

## Transplants for Children

210-949-1212 | transplantforchildren.org

## US Department of Health and Human Services

Access to the Government's information on organ and tissue donation and transplantation.  
organdonor.gov

## Texas Organ Sharing Alliance (TOSA)

210-614-7030 | txogansharing.org

## Transplant Living

A website with information and resources for transplant recipients.  
transplantliving.org | trasplantesyvida.org

## The Scientific Registry of Transplant Recipients

www.srtr.org



## A PATIENT'S GUIDE TO PEDIATRIC LIVER TRANSPLANT

Welcome to the University Health Transplant Institute at University Hospital in partnership with UT Health San Antonio.

This guidebook was created to help provide you and your family with a better understanding of the transplant process. Please read this information carefully and write down any additional questions you may have for our team.

### Our History

The Liver Transplant Program was started in 1992 by Dr. Glenn A. Halff. Since then, we have performed over 2,000 liver transplants. Dr. Francisco G. Cigarroa, Director of University Health Transplant Institute, performed South Texas's first civilian pediatric liver transplant in 1997. We were the first in South Texas to perform both a split-liver transplant from a deceased donor (allowing us to transplant both a child and an adult from the same donated organ) and a living donor liver transplant (when a living person donates a portion of their liver to someone in need of a liver transplant).

Please refer to the Scientific Registry for Transplant Recipients website to view our patient outcomes and survival rates. New reports are available every six months at [www.srtr.org](http://www.srtr.org).

# THE LIVER

# GENERAL INFORMATION

The liver is the largest internal organ in the human body. It is located on the right side and is protected by the ribs.

### The Liver:

- Helps with digestion of food
- Helps distribute nutrients such as vitamins and minerals
- Helps clean the blood by removing substances that could harm your body called toxins
- Produces natural chemicals to help your blood clot and promote healing
- Makes bile (a yellow fluid) your intestines use to digest food
- Stores iron, vitamins, minerals, fats and sugars until your body needs them

### What happens when the liver is not working properly?

- Absorption of vitamins and nutrients is decreased
- Waste products (toxins) are not efficiently removed from the body
- Proteins that help the blood clot are reduced and increase risk for bleeding
- The body is unable to get needed nutrients to provide energy and promote healing

### Signs and Symptoms of Liver Disease:

- **Fatigue** – extreme tiredness
- **Ascites** – fluid build-up in the abdomen
- **Encephalopathy** – inability to concentrate from high ammonia level in the blood; sleepiness, irritability
- **Jaundice** – yellow color seen in the eyes and/or skin
- **Pruritis** – very itchy skin
- **Edema** – swelling in the hands, feet and legs
- **Anemia** – low blood cell count, low hemoglobin
- **Bleeding** – from the esophagus, stomach or rectum; bruising easily, nosebleeds



Early evaluation and testing for transplant is key.  
Life is not possible without the liver.

### University Health Transplant Institute

4502 Medical Drive, MS 18-1  
San Antonio, Texas 78229

### Office Telephone Numbers:

210-567-5777 | 888-336-9633  
Fax: 210-358-0408

### Office Hours

Monday through Friday  
8 a.m. to 4:30 p.m.  
Closed on holidays and weekends

### Transplant Institute Pediatric Clinic

4502 Medical Drive, Rio Tower, 5th Floor  
San Antonio, Texas 78229

### Clinic Mainline:

210-358-5437  
Fax: 210-702-4143

### Clinic Hours:

Monday through Friday  
8 a.m. to 4:00 p.m.  
Closed on holidays and weekends

### After Hours, Weekends, or Holidays

Main Hospital Line: 210-358-4000  
NurseLink: 210-358-3000  
For medical emergencies, please call 911.

### Other Important Phone Numbers

Pediatric Intensive Care Unit: 210-743-3190  
Pediatric Immediate Care: 210-743-2252  
Hematology/Oncology Transplant Unit: 210-743-2182  
Chaplain Services: 210-743-3300

### Living Donor Health Questionnaire:

UTCLivingDonor.com

[UniversityTransplant.com](http://UniversityTransplant.com)







# MEETING THE TRANSPLANT TEAM

The transplant team is a group of healthcare professionals who are here to help care for your child before and after transplant.

Professional:	Description
<b>Transplant Hepatologists</b>	Our pediatric hepatologist (sometimes called gastroenterologist or "GI doctor") specializes in diagnosing and treating liver diseases.
<b>Transplant Surgeons</b>	A transplant surgeon will go over the surgical procedure with you and your child. They can also answer any questions you may have about the operation.
<b>Transplant Nurse Coordinator</b>	Your child's nurse coordinator is a registered nurse responsible for managing your child's transplant evaluation schedule and keeping you informed of your child's progress toward transplantation. They also provide additional education and support while your child is in the hospital. <b>You have access to a transplant nurse coordinator in all phases of transplant.</b>
<b>Transplant Pharmacists</b>	Transplant pharmacists help make sure your child is on the best medications to avoid unwanted side effects and medication interactions. They will educate you and your child about the medications they will be taking. They work with local specialty pharmacies which carry the transplant medications your child will need after transplant.
<b>Dietitian</b>	Our pediatric dietitian provides nutritional advice and closely monitors and manages nutritional status in all phases of transplant. What your child eats and drinks is very important to their overall health and healing.
<b>Transplant Social Worker</b>	A social worker will assist you with any non-medical issues. They will also provide important information regarding various insurance and assistance programs. Your child's social worker helps also with discharge planning and counseling support, if needed.
<b>Transplant Financial Coordinators</b>	Financial coordinators will help you obtain preauthorization for your child's evaluation exams, kidney transplant surgery and follow-up care. They can also answer any questions you may have regarding your child's healthcare coverage.

# SPREADING AWARENESS

Transplantation provides hope to thousands of children and adults with organ failure by giving them a new chance at a healthy and normal life. Transplantation is made possible by the commitment from organ, eye and tissue donors. Unfortunately, the need for donors is much greater than the number of people who donate. You can help spread awareness by sharing your story with those around you and encouraging them to register to become a life-saving donor.

You have the power to save lives. Here is how.

### Steps to Sharing Your Story:

- Introduce yourself and speak about how personal transplantation is to you and your family.
- On average, 17 people die each day waiting for a life-saving transplant due to a shortage of donors. Share the facts about donation.
- Make a point to share how important donation is to "life" and how it affects your child and your family.
- Encourage others to register online at [www.donatelife.net](http://www.donatelife.net) or by completing the donation section on their driver's license or renewal application form at the DMV.

### Facts About Donation:

- Organ donation is only considered after all efforts to save your life have failed and death has been declared.
- Anyone can register, regardless of age, gender, ethnic background or current health status.
- All major religions support donation.
- There is no cost directly related to donation.
- Donation does not prevent an open casket funeral.

A single donor can improve the lives of more than 50 people through organ, eye and tissue donation.



# CONGRATULATIONS!

Your child is ready to be discharged from the hospital and return to living a full life with family and friends.

**We will follow them closely in the Pediatric Transplant Clinic. Here are a couple of points to keep in mind:**

- You will receive an appointment for your child's first post-transplant clinic visit prior to discharge.
- Medications are monitored and will be changed as needed.
- Follow-up appointments are frequent at first (twice a week for the first two weeks).
- Follow-up appointments will eventually be less frequent (every six months to once a year).
- Annual follow-up appointment will be close to the transplant anniversary date.
- You should bring your child's medications and your transplant manual to ALL of your child's appointments.
- We will give you instructions for lab work or other tests that your child might need. The purpose of these tests is to monitor your child's progress and identify complications as soon as possible.
- We strongly encourage you and your child's doctor to contact us with any questions or concerns.
- It is vital that you maintain good contact with your child's primary care doctor and gastroenterologist before transplant so they can better help your child after transplant.

**Returning to School:**

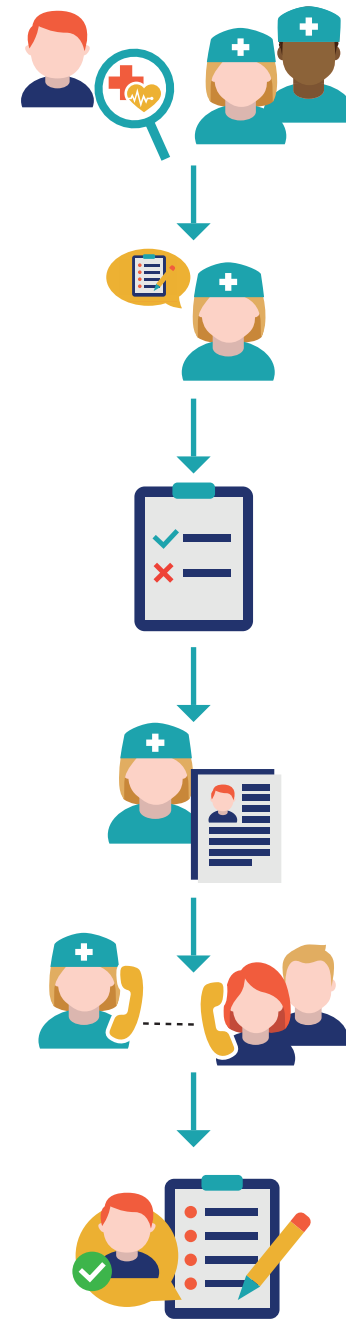
- Your child's health at the time of transplant will determine how quickly they may return to school.
- The transplant team will help you arrange to have a teacher come to your house. Most children return to school approximately eight weeks after discharge.
- Your transplant physician will let you know when your child can resume normal activities.
- It is your responsibility to contact your child's school prior to and at the time of transplant.
- The school will provide you necessary forms to complete.
- Once your child returns to school, they should avoid contact with sick children.
- Please instruct them NOT to share drinking glasses or eating utensils with others at home or at school.
- Physical Education (PE) is acceptable. Contact sports like football or wrestling are **NOT** recommended.

Professional:	Description
<b>Primary Care Physician (PCP) or Pediatrician</b>	Your child should continue keeping appointments with their primary doctor before and after their liver transplant. Your child's primary care physician or pediatrician is a very important part of your child's healthcare team and will manage your child's non-transplant related health issues, such as ear aches, immunizations, wellness checks and the common cold. We will be available to answer any questions your child's primary doctor may have regarding their transplant plan of care.
<b>Intensivist</b>	An intensivist is a physician who specializes in the care and treatment of patients in intensive care.
<b>Anesthesiologist</b>	The anesthesiologist will be monitoring your child and administering special medicine (anesthesia) that allows them to be in a deep sleep so they do not see, hear or feel pain during surgery.
<b>Spiritual Services</b>	University Hospital's Peveto Center for Pastoral Care offers spiritual services to help promote healing and to meet the spiritual, emotional and religious needs of all patients and their families. The Peveto Center is open 24 hours a day and may be reached at <b>210-358-4000</b> .
<b>Child Life Specialist</b>	Child life specialists are clinical staff members who assist children and families in the hospital cope with the experience of transplant, child development and emotional well-being.
<b>Family and Friends</b>	You and your child cannot go through this process alone. Everyone will come to a point where they will need help and encouragement to make the journey. A strong support system produces the best outcome. This means you must have family or friends who are willing and available to help you drive your child to and from appointments, and help take care of them before and after transplant.
<b>Along the way, you and your child will also meet:</b>	<ul style="list-style-type: none"> <li>• Patient Care Coordinator</li> <li>• Financial Coordinator</li> <li>• Transplant Nurse Practitioner</li> <li>• Resident Physicians</li> <li>• Respiratory Therapist</li> <li>• Physical Therapist</li> <li>• Transplant Clinic Staff</li> <li>• Staff Nurse</li> <li>• Living Donor Team</li> <li>• Living Donor Champion Coordinator</li> </ul>

# WHAT HAPPENS NEXT?

Once your child's transplant evaluation is complete and all test results have been received, the transplant team will have a selection committee meeting to determine the risks and benefits of transplantation.

- The selection committee will make one of the following three decisions:
  - › **Accept** - the committee recommends your child be placed on the waiting list and/or proceed with living donor liver transplantation.
  - › **Defer** - the committee decides to request additional information or testing before a decision can be made.
  - › **Decline** - the committee decides transplantation is not a treatment option for your child at this time.
- The referring physician will continue to monitor your child. A summary of your child's evaluation will be sent directly to them as they continue to be involved in your child's care.
- Some children are too well for transplant but may be seen again by the team if their condition changes.
- If transplantation is recommended, you will have the final decision on whether your child's name is added to the waiting list.
- Your child's transplant coordinator will contact you by phone and/or correspondence to inform you that your child has been placed on the list. ONLY after you receive such correspondence is your child officially on the transplant list.
- Your child has the option to also be placed on the waiting list at other centers (multiple listings).
- Patients have the option to refuse transplantation at any time.



# TRANSPLANT MEDICATIONS

The body tries to get rid of anything that it considers foreign. After your child's transplant, their body will try to reject/attack the transplant liver. In order to prevent this rejection, we will give your child important medication that has to be taken every day for the rest of their lives, even when your child is feeling well.

## Here is a list of medications your child may take:

- **Immunosuppressants** – or "anti-rejection" – special medications that are designed to weaken their immune system
- **Steroids** – first line of defense for rejection
- **Antibiotics** – help prevent bacterial infections
- **Antivirals** – help prevent viral infections
- **Antifungals** – help prevent fungal infections
- **Antihypertensives** – help control high blood pressure
- **Diuretics** – "water pill" helps control fluid
- **Vitamins and minerals**
- **Medications to help prevent stomach ulcers**

Don't forget to consult with the various prescription programs available from local pharmacies.

**Please remember, patients who do not take their medications correctly are not considered for another transplant if their liver fails.**

Your child/family's willingness to work hard and follow the transplant team plan of care is directly related to how well your child will do after transplant.

### After Surgery

- Your child will likely spend the night on a breathing machine in the Pediatric Intensive Care Unit (PICU). They will be woken up and the breathing tube will be removed when they are ready.
- Your child will have some pain around the incision/ surgical site.
- Your child will receive medication to relieve their pain.
- In order to clear your child's lungs, the transplant staff will ask them to take deep breaths and cough.
- Medications and fluid will be given to your child through an IV for the first few days after transplant.
- A catheter will be inserted in your child's bladder to help him/her pass urine, even if they are in diapers.
- The transplant team will go over your child's medications and how to care for the transplanted liver.
- The average time in the hospital after an uncomplicated liver transplant is about two weeks.

### Complications From Surgery

Most transplant surgeries are successful; however, some complications may occur after a liver transplant, including:

- Infection
- Bleeding (that may require a blood transfusion)
- Bile duct narrowing or leak
- Rejection
- Need for additional surgery
- Non-functioning donor liver which may require re-transplantation
- Clotted vessels
- Problems breathing
- Death

### During Your Child's Hospital Stay

A multidisciplinary team will be responsible for your child's care. They meet daily and will visit your child each weekday in their hospital room. They are dedicated to answering you and your family's questions and to help your child recover as quickly as possible.

The transplant team will teach you and your family the following before discharge:

- How to care for your child at home
- Explain each medication and how important they are to take even when your child is feeling well
- Medication side effects
- Outpatient follow-up and frequency of lab draw to check your child's newly transplanted organ
- Life after transplant

You will be given a new, in-depth transplant education book to help you and your child through their hospital stay and after transplant care.



### Contacting your transplant team

You may contact any member of the transplant team at any time. Continue to see your child's local doctor or specialist who can also communicate with our transplant team. We will work together to provide your child the best care.

Please remember that you or a family member must inform the transplant nurse coordinator or transplant team if your child becomes ill or is admitted into a hospital. Clear, direct and honest communication among all family members and your transplant team will help the transplant process run smoother.

#### Contacting Your Coordinator—Call 210-567-5777

The administrative staff in the main transplant office answers all calls between 8 a.m. and 4:30 p.m., Monday through Friday, except holidays and will transfer your call where necessary.

For non-emergencies, during weekends, holidays or after hours your call will be answered by our voicemail. Leave your name and telephone number plus a detailed message on the recorder. Your call will be returned as soon as your child's coordinator becomes available.

#### NurseLink

For medical questions or concerns after hours, weekends or holidays, contact NurseLink at **210-358-3000**.

#### In an Emergency—Call 911

In the event your child is experiencing a life-threatening emergency, such as chest pain, unresponsiveness, breathing problems or bleeding, **call 911** immediately and they will take your child to the nearest hospital emergency room. You may ask the physicians in the emergency room to call University Health Transplant Institute to inform the transplant team of the incident.



## OTHER TREATMENT OPTIONS

Prior to liver transplant, your child may be considered for other treatment depending on the severity of their disease. The transplant team will determine which options are recommended for your child on a case-to-case basis.

### TIPS\* (Transjugular Intrahepatic Portosystemic Shunt)

This is a radiology procedure that re-routes blood flow in the liver and decreases portal blood pressure, which causes varicities and ascites (helps decrease internal bleeding) by placing a shunt between two major blood vessels in the liver. Before the TIPS, your child will have an abdominal ultrasound to make sure vessels in the liver are open. Before this procedure, your child will be given medications that will help them relax.

**Hospital Stay:** One to two days

**Recovery Time:** Two to six weeks

**Follow-Up:** Every three to six months with sonogram and possible adjustment of stent

**Complications:** May cause bleeding and/or increased ammonia levels which can lead to confusion, sleepiness, coma and death.

*\*This procedure is sometimes used as a "bridge" to decrease liver failure complications.*



## TIME FOR TRANSPLANT

Once your child arrives at University Hospital, report to the Emergency Center for further assistance.

**Your child will be given a temporary room to prepare for surgery. Members of our transplant team will administer the following:**

- Physical examination & evaluation review
- Blood work
- Chest X-ray
- Electrocardiogram (EKG)



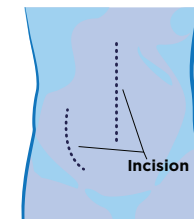
- Provide fluids and medicines through an IV
- Final cross match
- Testing for infection



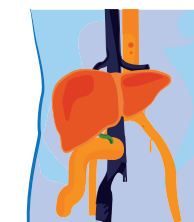
The doctor will answer your questions prior to surgery and ask you to sign a surgical consent.

### About the Surgery

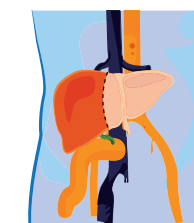
Your child will be under general anesthesia. Anesthesia is special medicine that allows your child to be in a deep sleep so they do not see, hear or feel anything during surgery, not even pain. Surgery may last from six to 12 hours.



The surgical incision is shaped like a boomerang under your child's rib cage. Your child may need to have blood products during surgery.



The artery, veins and bile duct of the new liver will be attached to your child's arteries and veins.



In some cases, a split liver transplant will be performed.

### What to Expect:

- **The donor liver size is important when considering for your child's body size.**
- Most livers come from deceased donors with the same or compatible blood type.
- It is possible that the donated liver may not be suitable for transplant; in this case the surgery is cancelled. If this happens, your child will be sent home. Once confirmed that the liver is suitable for transplant, your child will be taken to the operating room.
- The old liver is removed and the new donor liver is attached to your child's blood vessels and bile ducts.
- You and your family will wait in a room close to the operating room and someone from the staff will keep you informed of your child's progress.
- The transplant surgeon will speak to you and your family once the surgery is complete.

# GETTING THE CALL

- A transplant nurse coordinator will call you with specific instructions.
- Have a designated driver and a back-up plan on how to get your child to the hospital.
- Bring their medications, medical records, medical equipment such as feeding pump and health insurance information.
- Your child will be instructed to not have anything to eat or drink once they are called for a transplant unless the transplant nurse coordinator advises otherwise.
- Assign one family member the task of calling the rest of your family and friends.



**Please arrive as quickly and safely as possible.**

### Changes After the Call

Your child's transplant could be cancelled or postponed if:

- Your child has any signs of infection or test positive for infection even if they show no symptoms.
- The donor liver is not suitable for transplant.
- A new medical problem exists.

It is important to inform our center if your child develops a new medical problem as soon as it occurs.

**Remember**, if we cannot find you, the liver will go to another person. Provide us with as many contact numbers as possible.

### What to Bring:

#### For your Child:

- Two sets of comfortable clothing (such as: extra large T-shirts, pajamas, pull on pants, socks, underwear, shoes/slippers and robe)
- Favorite blanket, stuffed animal or toy - make sure the item has been washed well (Child Life can provide other toys, crafts, books, games, etc.)
- Personal hygiene items
- Family photos (be sure to include the pets)
- Hand-held electronic devices/games
- List and bottles of all current medications your child currently takes
- List of important medical conditions, prior surgery(s) or hospitalization(s)

#### For Parents or Caregiver:

- All insurance cards and current photo identification
- Keep extra checks, deposit slips and your ATM/ debit/credit card on hand (do not leave these items in the hospital room or hotel room)
- Comfortable clothing and shoes
- Prescription medications
- Phone numbers and addresses of family, friends, employers, neighbors, your child's school and medical care providers
- A good book, magazines or small craft project
- A camera, phone, laptop, and/or iPad (University Hospital offers free Wi-Fi)
- Chargers for your electronic devices

### What NOT to Bring

- Jewelry
- Flowers/plants/pets
- Latex balloons are not allowed; mylar balloons are okay

**Remember: All valuables should be kept with a caregiver at all times and not kept in the hospital room.**

## Children who need a liver transplant due to a tumor.

### Stereotactic Body Radiotherapy (SBRT)

This high-precision technique delivers a large dose of radiation to a tumor while avoiding nearby normal tissues. It is a painless, non-invasive outpatient procedure. Treatment is given in three to five sessions of approximately one hour each. Sessions are scheduled two times each week. During each session the patient is held very still in a custom fitting body mold. Every detail of treatment is directly verified by the physician and a medical physicist at each session. SBRT can be used for selected primary or metastatic tumors in the liver that are up to six cm in size. SBRT can be used to control small tumors and extend the window of opportunity for receiving a liver transplant.

**Hospital Stay:** None

**Recovery Time:** One day

**Follow-Up:** CAT scans and blood work at one month and then every three months

**Complications:** A few hours after a treatment session some patients experience mild nausea. Fatigue is common on the day following treatment. Rare complications would be bowel perforation, pain with swallowing or worsening of liver function in patients with viral hepatitis which could result in death.



### Chemoembolization

Chemoembolization delivers a high dose of cancer-killing drugs (chemotherapy) directly to the liver while depriving the tumor of its blood supply by blocking or embolizing, the arteries feeding the tumor. Using imaging for guidance, the interventional radiologist threads a tiny catheter up the femoral artery in the groin into the blood vessels supplying the liver tumor. The embolic agents keep the chemotherapy drugs in the tumor by blocking the flow to other areas of the body. This allows for a higher dose of chemotherapy drugs to be used because less of the drug is able to circulate to the healthy cells in the body. Chemoembolization usually involves a hospital stay of two to four days. Patients typically have lower than normal energy levels for about a month afterwards.

**Hospital Stay:** Two to four days

**Recovery Time:** One month

**Follow-Up:** CAT scans and blood work every three months

**Complications:** Infection, bleeding, or death

# WAITING FOR A TRANSPLANT

The most difficult part of the transplant process is the waiting period. It is unknown when an organ will become available. Please be prepared for the call at any time. In the meantime, your child should be living a healthy, active, normal life as possible. This may be a stressful time. Stay calm and don't be afraid to discuss these issues with your child's transplant team, clergy, social worker or counselor. There are support groups and people who are willing to help.

## Finding a donor

The waiting list is a national computerized network. This list is managed by the United Network for Organ Sharing (UNOS). You may contact them at **888-894-6361** or visit their website at [www.unos.org](http://www.unos.org) for more information. Several factors are considered when determining who will receive the available liver:

- Blood Type – Every person is a blood type A, B, AB, or O. For deceased donors and living donors, the blood type must be compatible.
- Size match is very important
- Medical urgency
- Donor's age, history and lab results
- Availability of suitable organ and geographical proximity to the donor
- Visual exam and in some cases, biopsy of the donated organ

## What will affect my child's transplant wait time?

The time your child must wait for a transplant depends on their MELD/PELD score, blood type, donor's age, availability of suitable organs in our donation service area and their adherence in keeping up with scheduled appointments and lab work.

- Your child could wait for several months or several years. We cannot predict how long they will have to wait for a suitable liver to become available.
- Remember, your child may feel very bad and still have a low MELD/PELD score. The score is based on your child's lab results only and does not always reflect how bad they feel.

- In certain diseases, exception points can be requested as a MELD/PELD score may not reflect actual mortality risk.

## What is MELD?

The Model for End-Stage Liver Disease (MELD) is a numerical scale, ranging from 6 (less ill) to 40 (gravely ill), used for liver transplant candidates age 12 and older. It gives a score (number) based on how urgently they need a liver transplant within the next three months. The number is calculated by a formula using three routine lab test results:

- Bilirubin - measures how effectively the liver excretes bile
- INR (prothrombin time) - measures the liver's ability to make blood clotting factors
- Creatinine - measures kidney function (impaired kidney function is often associated with severe liver disease)
- NA (sodium)

## What is PELD?

The Pediatric End-Stage Liver Disease (PELD) is a numerical scale, ranging from 6 (less ill) to 40 (gravely ill), used for liver transplant candidates under age 12. It gives a score (number) based on how urgently they need a liver transplant within the next three months. The number is calculated by a formula using the following:

- Age
- Gender
- Height
- Weight
- Bilirubin
- Albumin
- INR
- NA (sodium)

For additional information on MELD/PELD scoring, you may go to [www.unos.org](http://www.unos.org).

## Plan Ahead

Answer the following questions as a family:

1. How will your child get to the hospital once you get the call?

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2. Who will be the primary care giver after transplant?

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3. Where will your family stay while your child is in the hospital?

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4. How will your child get to follow-up appointments?

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5. Who will care for your child while they cannot attend school for eight weeks?

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6. How will you pay for expenses while out of work?

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7. Who will pay the bills and take care of the household chores while you are away?

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8. Who will take care of the pets?

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# WHILE ON THE WAITING LIST



- Make sure your child stays as healthy as possible.



- Have your child see the dentist regularly to keep teeth and gums healthy.



- Keep appointments with their primary gastroenterologist and primary care physician.



- Have your child follow their recommended diet.



- Keep your child's follow-up appointments with the transplant clinic.



- Adhere to frequent lab draws for your child depending on MELD/PELD score.



- Notify your child's transplant coordinator of any telephone, address and/or before any insurance changes.



- Contact the transplant team if you are going out of town and how you can be reached, even for one-day trips.



- Contact the transplant team if your child has had a blood transfusion, immunizations or is being treated for an infection.



- Have a small suitcase packed and ready for you and your child with toiletries, robe, slippers, etc. (see page 20).



- Plan for financial expenses during the time your child is in the hospital. This includes accommodations, food, transportation and initial medication cost upon discharge.



- If from out of town, please make flight arrangements. A social worker or coordinator can further assist.

## Most Important

Find interesting activities to keep you and your child occupied and busy: Play, relax, read, listen to music, create crafts, visit a museum, attend school activities, plan fun things to do, spend time with friends and family and **live life!**

**Keep your child's vaccines up-to-date.**

## Changes in Listing Status

After your child is placed on the waiting list, there are things that could change their listing status, including:

- Loss or change in insurance
- Non-adherence/compliance
- Outdated MELD/PELD lab testing
- Loss of contact with the program
- An illness that would result in a poor transplant outcome
- A new medical problem exists. It is important to inform the transplant team if your child develops a new medical problem as soon as it occurs.

## Nutrition

Poor nutrition is a common problem for patients with liver disease, and almost all patients are malnourished at the time of transplant. Children who are better nourished generally have fewer complications, spend less time in the Pediatric Intensive Care Unit after surgery and have a shorter recovery time. In addition, good nutrition combined with an exercise program helps your child maintain a reasonable quality of life during the waiting period.



Your child may have problems with fluid build-up in the abdomen (ascites) and legs (edema). It's recommended that your child follow a low-salt diet to help prevent fluid from building up. The transplant dietitian will help assess your child's food habits and suggest strategies for symptom management together with general nutritional advice.

## Exercise

Physical fitness is very important for your child as they wait for a liver transplant. It is difficult to remain active when they are feeling bad, but this must remain a priority. Children who are in better condition generally have shorter recovery times and fewer complications following surgery.



- Simple age-appropriate activities such as walking are generally safe for children with health problems, including liver disease. Your child should not walk immediately following a big meal or on days that are extremely cold, hot or humid. Please contact your primary care physician or pediatrician to discuss if your child qualifies for an early childhood intervention program (ECI).
- At school, your child should participate in physical education class. They should NOT participate in any contact sports like football or wrestling. Your child should stop exercising if they feel dizzy, nauseated, or unusually short of breath. Maintaining physical health is important before transplantation. Your child will benefit physically and mentally by keeping their body in good shape.
- Try your best to incorporate age-appropriate exercise into their daily routine and get family and friends involved.
- Please remember, you must consult with your child's primary care physician or pediatrician before starting any new exercise program.

# LIVING DONATION

## Living Donation

Living donation is when a person donates either a kidney or a portion of their liver to someone in need of a transplant. Due to the shortage of deceased donors, living donation is the quickest way to transplantation. There are currently over 122,000 people waiting for a life-saving organ transplant in the United States. An organ from a living donor lasts longer and can extend a patient's life span compared to an individual who received an organ from a deceased donor.

## Living Donor Team

At the Transplant Institute, we have a designated Living Donor Team made up of specialists committed to the safety and health of donor candidates before and after donation. This group works separate from the recipient's team to ensure confidentiality and suitability.



## Who can be a donor?

- A donor can be a family member, distant relative or friend.
- Donors do not have to be a "blood relative" of the recipient
- A donor can also be someone who chooses to donate to someone in need without knowing the person they are donating to. They are called "Altruistic", "Good Samaritan" or "Non-Directed" donors.

Living donors must be compatible with the recipient. There are two types of blood test checks to determine the blood type compatibility of the donor and recipient: tissue typing and cross matching. The tissue typing blood test checks the tissue match between six codes on the donor and recipient's white blood cells. The cross matching blood test determines how the transplant candidate will react to the organ.

If you have a potential donor, they can visit [utclivingdonor.com](http://utclivingdonor.com) to fill out the health questionnaire or contact the living donor team at **210-567-5777**.

## When the Donor Is Not a Match

If a donor is not a match with the intended recipient, there are alternative options. Other donor-recipient pairs across the country find themselves in the same situation. Because of this, our transplant institute participates in two national programs for paired exchange. This option allows hospitals to coordinate an exchange between compatible pairs. By donating through a paired exchange, several lives could be saved.



## Ineligible Donors

If an intended donor is not eligible to become a living donor, there is another way for them to help the recipient who is in need of a transplant. University Health Transplant Institute has developed a program called Champion For Life. This program is designed to help family members and friends learn how to create a campaign for their loved one. Studies have shown patients who share their story have an increased chance of finding a living donor.

For more information on the Champion for Life program, please contact [ChampionForLife@uhs-sa.com](mailto:ChampionForLife@uhs-sa.com) or call **210-743-9799**.

# MEDICATIONS BEFORE TRANSPLANTATION

Before transplant, your child may be on a wide variety of medications. These medications are used to control the symptoms associated with liver disease. Generally, children who have liver disease may be on the following medications:

## Diuretics

These medications will help remove extra fluid from the body. They are used to control ascites and swelling in the legs and feet.

**Examples:** Aldactone (Spironolactone®), Lasix (Furosemide®)

## High Blood Pressure

Although your child may not have high blood pressure, patients with liver disease often have increased pressure in the circulation of blood in the gastrointestinal tract. This may cause small blood vessels to burst inside the stomach. Your child may vomit blood or pass blood in their stool. Certain medications decrease the blood pressure in the GI tract.

**Example:** Inderal (Propranolol®)

## Antibiotics

If your child has ascites, they may be at risk of developing an infection in the fluid and may be started on antibiotics to reduce the risk.

**Example:** Cipro®

## Ulcer medications

These medications control the over production of stomach acids.

**Examples:** Protonix®, Prilosec®, Prevacid®, Zantac®, and Nexium®

## Vitamins

With liver disease, your child may have difficulty absorbing vitamins and minerals; therefore, we often recommend supplemental vitamins.

## Medications to Decrease Confusion (per doctor's discretion)

When the liver is damaged, the body is unable to remove toxins (poison), especially ammonia. Increased ammonia levels can cause confusion, fatigue, disorientation and in extreme cases even coma and death. We give certain laxatives to decrease ammonia levels in the intestine.

**Examples:** Lactulose®, Enulose®, Kristalose®, Flagyl®, Xiphaxin®

## DO NOT TAKE

The following over the counter or prescription medications should NOT be used for patients with liver disease:

### Over the Counter

- Fenoprofen (Nalfon®)
- Flurbiprofen (Ansaid®)
- Ibuprofen (Motrin®, Advil®)
- Ketoprofen (Orudis®)
- Naproxen (Naprosyn®)
- Naproxen Sodium (Aleve®, Anaprox®)
- Herbal drugs that have not been approved by the transplant doctors

### Prescription

Your child can take Tylenol® and Tylenol® with codeine (Vicodin®) at **recommended doses only**. You should inform your child's doctor of all the medications they take and bring a list of the medications to every doctor's appointment.