A Guide to Pediatric Liver Transplant

Welcome to the University Transplant Center at University Hospital in partnership with the 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, Director of the University Transplant Center and Professor of Surgery at UT Health San Antonio. Since then, we have performed over 1,500 liver transplants.

Dr. Francisco G. Cigarroa, surgical director of the pediatric transplant program, 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). Our program is one of the largest in Texas with a commitment to providing excellent care to our patients and their families.

According to data reports, our patient survival rates have consistently met or exceeded national expectations. 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.
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.
A liver transplant is a treatment option to improve your child’s quality of life and will not necessarily cure the underlying cause of liver disease.

Common causes of end-stage liver disease in children:

- Biliary atresia and other defects of the liver and biliary system
- Autoimmune hepatitis
- Metabolic liver diseases such as Alpha-1 antitrypsin deficiency, Wilson's disease, Alagille's syndrome, progressive familial intrahepatic cholestasis (PFIC) and mitochondrial diseases
- Liver complications from chronic conditions, such as short gut syndrome or cystic fibrosis
- Hepatoblastoma and other liver tumors
- Primary biliary cirrhosis (PBC)
- Primary sclerosing cholangitis (PSC)
- Sudden acute liver failure (possible causes could be overdose of prescription or nonprescription drugs, toxins or poison, infection caused by viruses, Wilson's disease, or the cause may not be known)
- Cryptogenic cirrhosis
- Hepatitis A, B, & C
- Toxic liver failure caused by chemotherapy, antibiotics or acetaminophen

TYPES OF LIVER TRANSPLANT
Reduced Size • Whole-liver Transplant • Split-liver Transplant
YOUR CHILD’S FIRST VISIT

Your child has been referred for a liver transplant evaluation because he or she is experiencing symptoms of advanced liver failure.

The process begins with an initial visit with the transplant team to determine what plan of care is right for your child. An evaluation will only start if the transplant team feels your child will need a transplant soon. You will be asked to discuss the dates your child will be available for his/her evaluation and testing. If you live a long distance from the transplant center, please be prepared to stay three to four consecutive days for testing as instructed by your child’s transplant team. We encourage you to bring another adult along to help write notes and help you remember what was said.

The purpose of the evaluation is to:

• Complete testing to determine if a liver transplant will be an option for your child
• Confirm the cause of your child’s liver disease (in most cases, the referring doctor already has made the diagnosis.)
• Determine the severity of your child’s liver disease
• Determine if your child would benefit from a liver transplant, or discuss other treatment options
• Explain liver disease, transplant surgical risks and benefits

We ask that you not bring other children to this visit. You will need to pay close attention to the information provided by many team members.

Please bring the following with you to the evaluation:

• All insurance cards including prescription/medication coverage plan
• Your child’s medications and medication list
• Any test results not sent to the transplant team
• Up-to-date immunization records
• Contact information for all of your child’s doctors including: dentist, eye doctor and pediatrician
• Contact information for your child’s school
• List of questions to ask the transplant team
Preparing for the Evaluation

Children and adults alike feel better when they know what to expect. Learning as much as you can about transplant and the process may help your child with a speedier recovery. Please arrive on time and keep all appointments as scheduled. Missed, rescheduled or canceled appointments may delay your child from being placed on the transplant list if he or she qualifies. The transplant committee also weights their decision heavily on your commitment to keeping appointments.

Here is a list of tests and exams that may be performed during your child’s liver transplant evaluation:

- Complete medical assessment.
- Chest X-ray – Determines if your child’s lungs and heart are healthy.
- Electrocardiogram (EKG or ECG) – Evaluates the electrical system of the heart that controls rate and rhythm.
- Echocardiogram – An ultrasound of the heart that will show how well your child’s heart “pumps.”
- CAT (CT) scan – A computerized image showing the size and shape of the liver and major blood vessels.
- Magnetic Resonance Imaging (MRI) – Used for detecting abnormalities in the liver and blood vessels as needed.
- Upper Endoscopy – A scope which looks at the esophagus and stomach if indicated.
- Colonoscopy – A scope which examines the rectum and colon as needed.
- Liver biopsy (not always performed) - Helps doctors diagnose various disorders and diseases in the liver.
- Extensive lab work screening – Blood draw to determine your child’s blood type, liver function and immune system function. Screening for infections, to include Hepatitis and HIV.
- Dental consult – A dentist must check your child’s teeth and gums to make sure they are healthy before transplantation. (This may or may not be covered by your child’s insurance.)
- Cardiology consults – A heart doctor will examine your child, to make sure transplant surgery will be safe for your child if indicated.
- Social Work consult – Helps family understand the emotional and psychological stressors that a transplant process can place on a family and also help provide resources for issues that come up during the process.
- Psychiatric consult – Evaluates your child to determine suitability for transplant if indicated.
- Nutrition assessment – A dietitian will ask questions to determine your child’s eating and exercise habits. They want to help your child be as healthy as possible before and after transplant.

Additional tests may be requested by your child’s transplant team.
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.

Transplant Hepatologists
Our pediatric hepatologist (sometimes called gastroenterologist or “GI doctor”) specializes in diagnosing and treating liver diseases.

Transplant Surgeons
A transplant surgeon will go over the surgical procedure with you and your child and answer any questions you may have about the operation.

Transplant Social Workers
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.

Dietitian
Our pediatric dietitian provides nutritional advice to help your child remain as healthy as possible. What your child eats and drinks is very important to his or her overall health and healing.

Transplant Nurse Coordinator
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.

After your child’s transplant, he/she will meet his/her post-transplant coordinator who will manage your child’s care.

Transplant Pharmacists
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 he or she will be taking.

They work with local specialty pharmacies which carry the transplant medications your child will need after transplant.
Primary Care Physician (PCP) or Pediatrician
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.

Intensivist
An intensivist is a physician who specializes in the care and treatment of patients in intensive care.

Anesthesiologist
The anesthesiologist will be monitoring your child and administering special medicine (anesthesia) that allows him/her to be in a deep sleep so they do not see, hear, or feel anything during surgery, not even pain.

Spiritual Services
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 (210) 358-4000.

Child Life Specialist
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.

Family and Friends
You and your child cannot go through this process alone. Everyone will come to a point where he or she needs 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 him/her before and after transplant.

Along the way, you and your child will also meet:
- Patient Care Coordinator
- Financial Coordinator
- Transplant Nurse Practitioner
- Resident Physicians
- Respiratory Therapist
- Physical Therapist
- Transplant Clinic Staff
- Staff Nurse

Receiving a liver transplant is a gift of life and a lifetime commitment. The success of a transplant is directly related to how well you and your child follow the care plan given by the transplant team.
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 listing).

- Patients have the option to refuse transplantation at any time.
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 5 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 Transplant Center to inform the transplant team of the incident.

Elizabeth Melendez
Split-liver Recipient, 2000
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.

Alan and Morelia Rangel
Siblings and Liver Recipients, 2000 and 2001
**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 varices 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:** 1 to 2 days  
**Recovery Time:** 2 to 6 weeks  
**Follow-up:** Every 3 to 6 months with sonogram and possible adjustment of stent  
**Complications:** May cause bleeding and/or increased ammonia levels which can lead to confusion and sleepiness. In some cases coma or even death can occur.  
*This procedure is sometimes used as a “bridge” to decrease liver failure complications.*
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, as 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 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 case 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 his or her 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 he or she 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 he or she feels.
- In certain diseases, exception points can be requested as a PELD scores’ 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 he/she needs a liver transplant within the next three months. The number is calculated by a formula using three routine lab test results:

- Bilirubin, measures how effective 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)

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 he/she needs 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

For additional information on MELD/PELD scoring, you may go to www.UNOS.org.

Changes in Listing Status

After your child is placed on the waiting list, there are things that could change his or her 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. He or she should NOT participate in any contact sports like football or wrestling. Your child should stop exercising if he or she feels dizzy, nauseated, or unusually short of breath. Maintaining physical health is important before transplantation. Your child will benefit physically and mentally by keeping his/her body in good shape.

- Try your best to incorporate age-appropriate exercise into his or her 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.
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 (Propanolol*).

**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* once a week.

**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 he or she takes and bring a list of the medications to every doctor’s appointment.
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 his/her primary gastroenterologist and primary care physician.
- Have your child follow his or her 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 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 19)
- 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, and 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.
PLAN AHEAD

Answer the following questions as a family:

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

2. Who will be the primary caregiver after transplant?

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

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

5. Who will care for your child while he/she cannot attend school for 8 weeks?

6. How will you pay for expenses while out of work to care for your child?

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

8. Who will take care of other children, elderly relatives, and/or pets?
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 his or her 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.
- The donor liver is not suitable for transplant.
- A new medical problem exists.

It is important to inform our center if you 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

Pack a Small Suitcase

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 – select “attwifi”)
- Chargers for your electronic devices

What Not to Bring

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

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

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

Starcie Demay
Liver Recipient, 2010
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 he/she does not see, hear, or feel anything during surgery, not even pain. Surgery is about 3 to 4 hours long.

The incision is approximately ____ inches long in the mid abdomen. The surgical incision is shaped like a boomerang under your child’s rib cage. Your child may need to have blood products during surgery.

**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.
AFTER SURGERY

- Your child will wake up in the Pediatric Intensive Care Unit (PICU).
- Your child will have some pain around the incision/surgical site.
- Your child will receive medication to relieve his/her pain.
- In order to clear your child’s lungs, the transplant staff will ask him/her 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 for 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 of the complications that may occur after a liver transplant, including:

- Infection
- Bleeding (that may require a blood transfusion)
- Bile duct narrowing or leak
- Rejection
- 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 week day in his/her 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 transplant organ, and
- life after transplant.

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

TRANSPLANT MEDICATIONS

The body tries to get rid of anything that it considers foreign. After your child’s transplant, his/her body will try to reject/attack the transplant liver. In order to prevent this rejection, we will give your child important medication that have 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:

- **Immunosuppressant** – or “anti-rejection” – special medications that are designed to weaken his/her immune system
- **Steroids** – first line of defense for rejection.
- **Antibiotics** – help prevent bacterial infections
- **Antiviral** – help prevent viral infections
- **Antifungals** – help prevent fungal infections
- **Antihypertensive** – 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 that 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.
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 him/her 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 8 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.
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.
• In 2015, 21 people died each day awaiting 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 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.
RESOURCES

United Network for Organ Sharing (UNOS)
(888) 894-6361 or UNOS.org

American Liver Foundation
(800) Go-Liver or (212) 668-1000 or LiverFoundation.org

Hepatitis Central
Hepatitis-Central.com

Transplants for Children
(210) 949-1212 or transplantforchildren.org

US Department of Health and Human Services
Access to the Government’s information on organ, eye, and tissue donation.
OrganDonor.gov

Texas Organ Sharing Alliance (TOSA)
(210) 614-7030 or TXOrganSharing.org

Transplant Living
A website with information and resources for transplant recipients
TransplantLiving.org or TrasplantesYVida.org

The Scientific Registry of Transplant Recipients
SRTR.org

Stay Connected with University Transplant Center
University Transplant Center
4502 Medical Drive MS 18
San Antonio, Texas 78229
UniversityTransplantCenter.com
Phone: (210) 567-5777 or Toll free (888) 336-9633
Fax: (210) 702-4146
Office Hours
8:00 a.m. to 4:30 p.m.
Monday through Friday
Closed on holidays and weekends

University Transplant Center
Pediatric Clinic
Phone: (210) 358-8309
Clinic Hours
8:00 a.m. to 4:30 p.m.
Monday through Friday
Closed on holidays and weekends

After Hours / Weekends
NurseLink (210) 358-3000