



Children'sSM
Healthcare of Atlanta
Dedicated to All Better

Liver Transplant

Patient family handbook

Table of Contents

Welcome	1
Our promise to you	1
About the handbook.....	1
Important phone numbers.....	2
General information sheet.....	3
Why Your Child May Need a Transplant	5
What is the liver?	5
What does the liver do?	6
Liver failure	6
Common causes of liver failure.....	7
The Liver Transplant	9
Steps for your child's liver transplant	10
Pre-transplant evaluation	11
Lab tests	14
Deceased donor transplant.....	14
Living donor transplant.....	16
Important questions	19
Preparing for your child's transplant.....	20
Transplant surgery	21
After the Transplant	23
In the hospital	23
Complications	24
Clinic visits	26
Routine lab work	27
Viral infections.....	27
Teen clinic.....	27
Caring for Your Child	29
At home tips.....	29
Travel tips	32
When to call the transplant coordinator.....	32
Medicines.....	33

Helping Your Child Cope.....	37
Guidelines to support your child.....	37
Talking to your child about a transplant	40
Disciplining my child	41
Caring for the Whole Family	43
Coping with your feelings.....	43
Impact of a transplant on a marriage	44
Suggestions for divorced parents.....	44
Impact of a transplant on siblings.....	45
Impact of a transplant on grandparents	45
Programs and events.....	46
Resources	47
Financial resources.....	47
Resources available at Children’s.....	49
Area lodging.....	50
Other transplant resources	51
Websites	53
Glossary	55
Helpful definitions.....	55
Helpful abbreviations	60
Important Documents	61
My child’s medical records	61
My child’s immunization record	63
My child’s current medication list	65
Additional notes and questions	67
Liver Transplant Evaluation	69

Welcome

Welcome to the Children's Healthcare of Atlanta Carlos and Marguerite Mason Transplant Center. We offer full pre- and post-transplant outpatient services for liver, heart and kidney transplant patients in one central location. At Children's, our focus is on our patients. We want to create a friendly, family-centered experience for you and your child. In addition to our medical areas, our Center includes:

- A parent lounge
- A family library
- A playroom
- A teen room
- A parent business center
- A family consult room

The Transplant Center is located at our Egleston hospital on the sixth floor.

Our promise to you

The Children's liver transplant team wants to provide you and your child with high quality, family-centered care. Together, our team can give you the support you need during your child's treatment. At each admission and clinic visit, you will experience a nurturing, caring environment.

If you have any questions, please feel free to call us. We look forward to helping your child have a healthy future.

About the handbook

This handbook is meant to help you learn more about liver transplant. It can help you explore the best options for your child. It also contains information about resources that can help you.

This handbook should NOT replace instruction given to you by your child's healthcare team. It is not meant to be medical advice or a complete resource for all information on this subject. Your child's doctor is the best source of information about what is right for your child's treatment. If you have any questions about this handbook, please ask the liver transplant team.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Important phone numbers

Liver Transplant office (Monday-Friday, 8 a.m. to 4 p.m.)	404-785-1807*
After hours emergencies (ask for the liver transplant coordinator to be paged)	404-785-6000
Billing and finance	404-785-6478
Liver transplant social worker	404-785-1132
Clinic appointments	404-785-1807

If your child has NOT received a transplant yet, please call us if he has:

- Skin that is more itchy
- Skin or eyes are more yellow
- A belly that is bigger
- Any blood in vomit or stool, nosebleeds or other source of bleeding
- Increased sleepiness or confusion
- Weight loss or weight gain of 1-2 pounds in two days
- A fever of 101.5 F (38.5 C) or higher
- Problems taking medication
- Issues obtaining medication from your pharmacy

Visit our website at choa.org/livertransplant for more information about our Liver Transplant program.

**All transplant questions should be addressed by the liver transplant team.*

General information sheet

Child's Name _____

Medical Condition _____

Your Child's Transplant Team

These are some of the team members you that may be included on your child's transplant team. Please write down the name of each person you meet. Ask them how to spell their name and what they do.

Transplant surgeon: The doctor who performs the transplant surgery.

Liver doctor (hepatologist): A doctor who works with the transplant surgeon to care for your child's digestive system (stomach, liver and intestines).

Fellow: A doctor who is in additional training in liver transplantation, hepatology or gastrointestinal specialties. Fellows have already completed their residency.

Anesthesiologist: A medical doctor who monitors your child during surgery. Your child will be given a special medicine (anesthesia) that allows him to be in a deep sleep so he cannot see, hear or feel anything, not even pain.

Physician assistant and nurse practitioner: Clinical staff who assist your child's doctor in surgery. They are supervised by doctors and help take care of your child before, during and after his transplant.

Transplant coordinator: A nurse who helps you and your family arrange your child's care and treatment before and after a transplant.

Intensive Care Unit (ICU) and TSU nurses: Nurses who care for your child while he is in the ICU and on the Transplant Step-down Unit.

Respiratory care or respiratory therapist: Clinical staff who help your child with his breathing. They give breathing treatments, oxygen and monitor how your child breathes.

Registered dietitian/nutritionist: Clinical staff who will help your child with food and nutritional needs.

Transplant pharmacist: A pharmacist who has special training with transplant medicines. This person arranges for your child's medicines, teaches you what you need to know about them and helps with research studies.

Psychologist: A medical professional who helps you and your child cope with feelings about having a liver transplant. The psychologist helps with the transplant evaluation.

Child life specialist: Clinical staff who help you, your child and your family learn about why your child is in the hospital. They can answer questions, show you medical supplies, teach you about your child's hospital stay and talk with your child about his feelings. Child life specialists can also be an encouragement and support for your child during procedures or treatments that may be scary for your child.

Social worker: A healthcare professional that can help provide guidance, counseling and coping skills for you and your family. The social worker helps you get the services and resources you and your child need while in and out of the hospital.

Physical therapist: Clinical staff who help your child with exercises to make him stronger before and after transplant. The physical therapist can also teach you what you can do at home to help your child regain strength.

Chaplain: A person who helps meet your family's spiritual needs. A chaplain can work with your pastor or religious leader to provide needed spiritual support. Hospital chaplains also conduct interfaith services in the hospital chapel on the ground floor at Egleston.

School program teacher: Certified teachers who help your child keep up with his schoolwork so the transition between hospital, home and school will be easier. The schoolroom is located on the first floor at Egleston.

Transplant financial counselor: A person that helps you learn about your insurance plan and how to reduce your family's out-of-pocket expenses for your child's care. A financial counselor can help your family set up a long-term payment plan, if needed.

Why Your Child May Need a Transplant

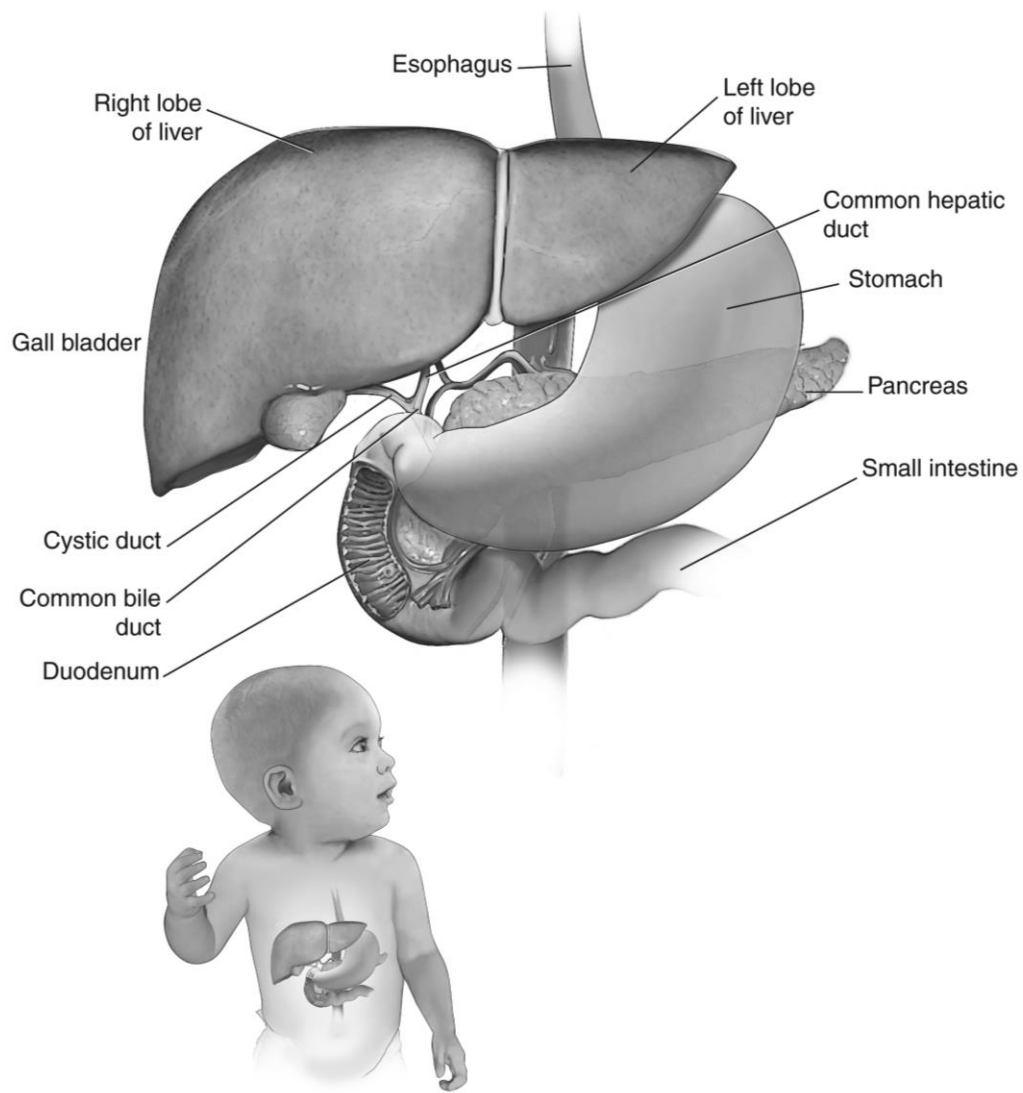
Why Your Child May Need a Transplant

What is the liver?

The liver is:

- The largest solid organ in the body.
- Divided into right and left sections, called lobes.
- On the right side of the body, behind the lower ribs and below the lungs. It is located to the right of the stomach.
- The only organ in the body that can regenerate, or grow back. When part of the liver is removed, the rest of the organ will grow back to its original size.

The Liver, Gall Bladder
and Biliary System



What does the liver do?

The liver is a very complex organ with many functions. It is needed for good health. You cannot live without a working liver. Some of the main functions of the liver are listed in the chart below.

What the liver does	What this does for the body
Helps the body digest, absorb and store food and nutrients	The liver makes liquid called bile. Bile helps to digest food and absorb nutrients that nourish the body, such as vitamins and minerals. The liver also stores sugar, iron and vitamins for the body to use later.
Filters harmful chemicals	The liver acts as a filter for the body and cleans the blood of harmful chemicals.
Produces albumin	Albumin is one type of blood protein. It helps to carry some medicines and other substances through the blood. It is needed for tissue growth and healing. When albumin levels drop, fluid may collect in the ankles, lungs or abdomen.
Helps with clotting	The liver makes proteins that help the blood to clot normally. Clotting happens when blood changes from a liquid into a solid, such as when a scab forms over a cut or wound.

Liver failure

When the liver fails, these things can happen:

- Your child may not grow and develop normally.
- The liver does not take in or store enough nutrients and vitamins from food.
- Blood does not clot as quickly as it should. This can cause your child to bruise easily or bleed longer after an injury.
- Your child's eyes or skin may begin to look yellow if his liver cannot filter out harmful substances. The yellow coloring is called *jaundice*.
- Your child's stomach may get larger because of extra fluid in the abdomen (the area between the chest and hips). This is known as ascites.
- Fluid may collect in your child's feet and legs. This is known as edema.
- Your child's skin may itch.
- Your child may be weak or tired.
- Your child may have a loss of appetite, upset stomach or lose weight.
- Your child may develop cirrhosis, which is the result of chronic liver disease. It can lead to scarring of the liver and liver failure.

Common causes of liver failure

Some of the causes of liver failure are listed on the chart below.

Medical condition	What this means	How this hurts the liver
Alpha -1– Antitrypsin Deficiency (A1AD)	This is an inherited disease (passed from parent to child) caused by low levels of a protein called alpha-1-antitrypsin (A1AT). A1AT is found in the blood.	When the body lacks A1AT, substances that break down protein attack other tissue in the body. This causes liver damage.
Autoimmune hepatitis	Due to a problem with the immune system, immune cells attack healthy liver cells.	Liver cells are damaged by the body's own immune system.
Biliary atresia	Tubes (bile ducts) that carry bile from the liver do not form normally before birth.	Bile carries waste away from the liver and breaks down fats in the small intestine. Bile is not able to leave the liver through the bile ducts. This causes liver damage.
Intrahepatic Cholestasis	Bile ducts within the liver do not form normally. They become blocked, which causes a build-up of bile in the liver.	Bile is not able to leave the liver through the bile ducts. This causes liver damage.
Cystic fibrosis (CF)	CF is a disease that affects the body's breathing and digestive systems. It causes the body to produce an excess of thick mucus.	Excess mucous from CF causes the bile ducts to become blocked and inflamed. This causes liver damage.
Acute Liver Failure	The liver begins to fail because of severe damage to liver cells. The cause is unknown.	Acute Liver Failure causes the liver to suddenly be unable to perform all of its important functions. Jaundice, poor blood clotting as measured by blood tests and altered awareness are symptoms.
Gestational Alloimmune Liver Disease	Iron builds up in the liver prior to birth.	Gestational Alloimmune Liver Disease is when the liver becomes diseased while a baby is in his mother's womb. This can lead to end stage liver disease at birth.
Hemochromatosis	The body has a problem breaking down iron. Iron builds up in the liver.	Small amounts of iron are normally stored in the liver, kidneys and heart. Excess iron can damage these organs.
Hepatitis A (viral hepatitis)	A virus that is carried by contaminated food or water.	The liver becomes inflamed. This causes short-term mild to severe symptoms.
Hepatitis B (viral hepatitis)	A virus that is carried by infected blood or body fluids.	The liver becomes inflamed. This causes severe or long-term symptoms.

Hepatitis C (viral hepatitis)	A virus that is carried by infected blood or body fluids.	The liver becomes inflamed. This causes severe or long-term symptoms.
Liver cancer	Cancer develops when cells in the body begin to grow out of control. Normal cells grow, divide and die. Instead of dying, cancer cells continue to grow and form new abnormal cells.	Because the liver is made of different types of cells, several types of tumors can form in the liver. Some of these are cancerous (malignant) and some are not cancerous (benign).
Tyrosinemia	Tyrosinemia is a disease caused when a vital enzyme that breaks down amino acids is missing from the body. An enzyme is a protein that helps the body make certain chemicals.	When amino acids do not break down, a build-up of toxic chemicals can occur. This leads to liver disease.
Wilson disease	A rare inherited illness (passed from parent to child) that causes copper to be stored in excess and leads to several organs working poorly.	Extra copper in the liver cause's tissue damage, scarring and liver failure.

If you do not know why your child's liver is failing, ask his nurse or doctor to write down the name of the problem below. Ask the doctor or nurse to explain it to you in a way that you can understand.

The Liver Transplant

A liver transplant provides your child with a healthy liver from a donor. The donor is a person who gives your child a liver. There are two main types of liver transplants:

1. Deceased donor (Also known as cadaveric donor)

A *deceased donor* transplant provides your child with a liver from a person who has recently died.

- This is the most common type of liver transplant.
- To receive a deceased donor liver, your child is placed on the *United Network for Organ Sharing (UNOS)* list. UNOS matches deceased donors and patients waiting for a liver. The organs are sent across the country.

Visit unos.org to learn more about UNOS.

2. Living donor

A *living donor* is a person who gives your child part of his liver.

- A living donor transplant takes only a part of a person's liver for your child.
- The liver is the only organ that can regenerate, or grow back. When doctors remove part of a donor's liver, the rest of the liver will grow back within a few weeks. Even when more than half of the liver is removed, the donor can recover well.

Note: Your child is placed on the UNOS list even if there is a living donor available. This increases his chances of getting a liver as soon as possible.

Other types of liver transplants:

- **Reduced graft:** A liver is "cut down" to a smaller size and then given to your child.
- **Split liver transplant:** A deceased donor liver is cut into two parts. The larger part is given to an adult or larger child. The smaller part is given to a small child or infant.

Steps for your child's liver transplant

The liver transplant team will discuss each step with you, your child and your family.

- Step 1** Your child's doctor refers him to Children's. Your child's doctor must state the medical need for a transplant and send medical records.
- Step 2** Children's financial counselor will work with you to get approval for your child's pre-transplant evaluation from your insurance company. A pre-transplant evaluation is a series of tests. These tests help the liver transplant team decide if a transplant is the best option for your child. The liver transplant team will help you through this process. If you do not have insurance, our financial counselor will work with you to set up a payment plan.
- Step 3** The liver transplant team will call you to schedule your child's pre-transplant evaluation with the transplant coordinator.
- Step 4** Your child has a pre-transplant evaluation at Egleston. This will be a one- or two-day outpatient visit. Rarely, this may be an inpatient evaluation.
- Step 5** Based on the evaluation, the liver transplant surgeon and team will decide if a transplant is the best option for your child.
- If your child meets all of the standards from the pre-transplant evaluation and your insurance company approves, your child's name is placed on the UNOS list.
 - During this time, the liver transplant team will decide if there are living donors who might be a good match for your child.
 - If a person wants to be a living donor, the donor should call the liver transplant coordinator. The liver transplant team will not contact a donor unless asked to do so by the potential donor.
- Step 6** If there is no living donor, your child waits to be matched with a liver from the UNOS list.
- Step 7** If there is a living donor, the donor's surgery is scheduled at Emory University Hospital. Your child's surgery will take place at Egleston.
- Step 8** Your child has his transplant surgery. The average time your child will stay in the hospital is about two weeks after transplantation but can vary depending on their age and condition.
- Step 9** Your child will receive follow-up care at Egleston. Your child's needs will determine how often he needs to come in for checkups. (Refer to section under the tab labeled "After the Transplant" about clinic visits).

Pre-transplant evaluation

The pre-transplant evaluation (also called an evaluation) is a series of tests that helps decide if a liver transplant is the best option for your child.

- The liver transplant coordinator will schedule the evaluation. This will most often be an outpatient visit to Egleston that can take up to two days.
- The coordinator will schedule tests and meetings with the liver transplant team during your visit.
- Your family will meet the liver transplant team. They will work closely with you during the entire process.
- Please plan to stay for the entire one or two days of evaluation.
- If you need help with hotel arrangements or getting a room at the Ronald McDonald House, please let us know so we can help.

How does my family prepare for the transplant evaluation?

To help ensure that the pre-transplant evaluation goes as smoothly as possible:

- Make sure your insurance company has approved the evaluation. Bring a copy of your insurance benefits and insurance ID card with your deductible and co-payment. [See section Resources: Financial resources]
- Please arrive on time. Allow ample time for parking and walking to the clinic. If you are late, we may need to reschedule your visit.
- Please leave young siblings at home. Your focus needs to be learning about the transplant. We do want your family to take part in follow-up clinic visits.
- **Call your pediatrician to make sure your child's immunization (shot) records are up-to-date. Please bring his records to the evaluation.**
- Write a list of questions to ask the team. Share your concerns and fears with them.

Egleston parking garage rates for Children's families

- | | |
|------------------------|--|
| • 0 - 30 minutes | Free |
| • 31 - 60 minutes | \$1 |
| • 61 - 90 minutes | \$2 |
| • 91 minutes - 2 hours | \$3 |
| • 2 - 24 hours | \$5 |
| • Exit Pass | \$5 (valid for 5 separate exits from garage) |

Bring your parking ticket you receive in the garage to your appointment so we can validate it.

What happens during my child's transplant evaluation?

You will spend most of the day on the sixth floor at the Children's Transplant Center. Your child will have some routine tests but be aware; **your child may not require all of these tests listed.** The liver transplant team will decide which tests your child needs. We will discuss the plan with you prior to any testing. If anesthesia is necessary or available, we will let you know.

1. A routine medical exam

- This includes your child's height and weight, family history of long-term diseases, and discussion of any surgery your child has had in the past.
 - Please keep a written record of your child's medical history and have it ready before you come to the evaluation to share with the doctors.
 - Bring your child's immunization records with you.

2. Blood tests that check your child's:

- Blood type: This test checks your child's blood to see if it is type A, B, AB or O.
- Blood chemistries, such as sodium and potassium.
- Blood counts, such as red and white blood cell counts.
- *Liver enzymes*: An enzyme is a protein that helps the body make certain chemicals.
- Blood for viruses, such as EBV and CMV [See section After the Transplant: Viral infections]

3. Radiology and imaging tests

- Chest X-ray: This test checks your child's lungs.
- Ultrasound with Doppler exam: This test checks the bile ducts and major blood vessels. It is often done before and after a liver transplant.
- CT scan: This computerized image checks the size and shape of your child's liver and major blood vessels.
- MRI (magnetic resonance imaging): This test may be used in place of a CT scan or ultrasound to check the liver and major blood vessels.

4. Other imaging tests may include:

- Total body bone scan: If your child has a liver tumor, he may need this test.
- Upper gastrointestinal (GI) series: This test checks your child's esophagus (tube between the mouth and stomach) and stomach.
- Lower GI series: This test checks your child's intestines (colon).
- Angiogram: This test checks the size of the blood vessels outside of the liver or if there are any blockages. Dye is injected into an artery so that the blood vessels show up on X-ray.
- Cholangiogram (co-lan-gee-o-gram): If needed, this test checks for any blockages or growths in your child's bile ducts.
- Gallium, colloidal gold or technetium scan: These tests show your child's liver, gallbladder and pancreas.

5. Breathing and heart function tests

- Pulmonary function test: This test checks how well your child's lungs work.
- Electrocardiogram or echocardiogram (EKG or ECG): This test checks your child's heart.

6. Surgery

- Peritoneoscopy (pair-i-to-nee-os-co-pee): A flexible tube is placed through a tiny incision in your child's abdomen. The transplant doctor can see changes in the liver.
- Liver biopsy: This test checks the liver tissue itself. A needle is placed between two of the right lower ribs to take a sample of the liver. The tissue sample goes to a lab for testing.

Lab tests

Below is a list of the most common blood tests that doctors use to find out how well the liver works. The liver transplant team will check these lab tests during your child's pre-transplant evaluation and during and after his transplant. Call **404-785-1807** if you have any questions about your child's lab results.

Common blood tests:

<p>Albumin Albumin is a protein in the blood that is made by the liver.</p>	<p>Glutamyltransferase (GGTP) GGTP is an enzyme mostly found in the bile ducts of the liver. An enzyme is a protein that helps the body make certain chemicals.</p>
<p>Ammonia Ammonia is made when proteins break down. Normally, the liver removes ammonia from the blood and turns the ammonia into waste (urea). Urea leaves the body through the urine.</p>	<p>Hemoglobin Hemoglobin carries oxygen to the body in red blood cells. Hemoglobin is low when iron in the blood is low. This is anemia.</p>
<p>Aspartate transaminase (AST) AST is an enzyme found in the liver. An enzyme is a protein that helps the body make certain chemicals. When the liver is diseased or damaged, more AST is released into the bloodstream.</p>	<p>Hematocrit Hematocrit measures the number of red blood cells in the blood. A low hematocrit level can show anemia or blood loss.</p>
<p>Aminotransferase (ALT) ALT is an enzyme that is measured to find out if the liver is damaged or diseased. An enzyme is a protein that helps the body make certain chemicals. When the liver is diseased, it releases ALT into the bloodstream.</p>	<p>International ratio (INR) INR is the difference between the PT and the control used to calibrate the machine.</p>
<p>Bilirubin <i>Bilirubin</i> is made when red blood cells die. The liver repackages it and it is then removed from the body in the form of bile.</p>	<p>Prothrombin time (PT) and international ratio (INR) PT measures how long it takes your child's blood to clot. The liver makes proteins (factors) that help blood to clot. When the liver fails, blood takes longer to clot.</p>

Liver tests include the ALT, AST, GGTP, Albumin and Bilirubin.

Deceased donor transplant

There are several steps for a deceased donor transplant. The liver transplant team can answer your questions during the process.

1. Your child is placed on the UNOS *waiting list* to receive a deceased donor liver.
 - You will receive a phone call from your liver transplant coordinator immediately after your child is added to the transplant waiting list.
 - You will also receive a letter when your child is listed on the transplant waiting list.
 - Your child's name is placed on the UNOS list before a living donor is evaluated.
 - Your child may receive a deceased donor liver before a living donor is found.

2. UNOS works with an agency to obtain organs and keeps a national list of people waiting for transplants. Your child will stay on the list until he receives a liver.
3. UNOS gives your child a Pediatric End Stage Liver Disease (PELD) score based on a formula that looks at his age, weight and lab test results.
4. Your child is matched with a liver based on the PELD score and his blood type. We can review our average wait time for a deceased donor with you with the SRTR data. Visit srtr.org for more information.

How does the UNOS donor matching process work?

1. A liver is donated from a person who just passed away but had consented to be an organ donor.
2. The donor's medical information is put into the UNOS database.
3. UNOS notifies the Children's Organ Call Center that a liver is available.
4. The transplant surgeon and team review whether to accept or decline the organ. This is based on whether the liver is the best match for your child.
5. The liver transplant coordinator calls you when a liver is available.
6. To understand how patients are matched on the national waiting list: Think of the list as a "pool" of patients.
 - When an organ is available, UNOS searches the entire "pool" for a match.
 - The liver is given to the child with the highest PELD score and with the same blood type and size.

Other factors include:

- The patient's current medical status.
- Location of the liver and the child.
- Amount of time that the child has been on the waiting list.
- Blood type: Your child can receive a liver from a person with the same or with a different blood type.
 - The same blood type: The four most common blood types are O, A, B and AB.
 - Liver transplants are typically performed with the same blood type. This also includes type O, which is a "universal donor" and can be given to types A or B.
 - A different blood type: Under urgent conditions your child may receive a different blood type liver, such as a blood type A or type B.

About the deceased donor

Families often want to know the age of the donor and how the donor died. Information about the donor cannot be shared. Likewise, information about you and your family will not be given to the donor's family. You may write a letter to the donor's family. If you write a letter, the Liver Transplant coordinator will send it to the donor agency, which will forward it to the donor family. If you have any questions about how to write this letter, your transplant coordinators will be happy to help you.

Living donor transplant

In a *living donor transplant*, doctors take a lobe or part of the liver from a living person to replace your child's unhealthy (diseased) liver. The liver transplant doctor will decide which lobe your child will need.

How a living donor liver transplant works

The liver is made up of lobes. Lobes are divided into sections.

- The left lobe makes up about 40 percent of the liver. The right lobe makes up about 60 percent of the liver's volume.
- The surgeon decides on the amount of liver tissue to be removed from the donor during surgery.

Who can be a living donor?

A living donor can be anyone—a parent, family member or friend. A donor has to meet certain health standards and have a donor evaluation done by a separate Liver Transplant Team. Based on these results, the other team's Liver Transplant surgeon and team will decide if a donor is a good *match* for your child. A donor must also:

- Be older than 18 years of age or age of majority (the age when a person has all of the rights and responsibilities of being an adult). In most states, including Georgia, the age is 18.
- Be in good health. Certain medical conditions can prevent a person from being a living donor. This is up to the liver transplant surgeon to decide. Examples include:
 - Liver disease
 - High blood pressure
 - Diabetes
 - Heart, lung or breathing problems
 - Cancer
 - Urinary tract problems
 - Contagious diseases (a disease able to be passed from one person to another) such as HIV, hepatitis or tuberculosis (TB)
 - Obesity (very overweight)
- Be willing to donate part of his liver. The decision to donate must be made freely and without pressure from anyone.
- Be admitted to Emory University Hospital for the evaluation and surgery.
- Stay in the hospital for an average of seven to 10 days. The donor may not be able to work for up to two months.

Steps to becoming a living donor

Before anyone can be a living donor, he must have a series of tests to make sure he is the best match for your child.

- Step 1** A person wishing to be a donor for your child's transplant calls the Children's liver transplant coordinator.
- Step 2** The liver transplant financial counselor asks your insurance company for approval for the donor evaluation (evaluation). The recipient's insurance may pay for this. If you do not have insurance, our financial counselors will work with you to set up a payment plan. [See section Resources: Financial resources]
- Step 3** Your insurance company approves the donor evaluation for both the recipient and the potential donor. The Emory liver transplant coordinator and living donor advocate sets up the donor evaluation at Emory University Hospital
- Every person has one of four blood types: O, A, B or AB. Type O is the most common. Type B is the least common.
 - If you do not know your blood type, you can donate blood or call your local Red Cross to have a blood type test done. If you have had surgery or a baby, your doctor may have a record of your blood type.
- Step 4** If the donor's blood type is a good match with your child's, the evaluation can take place.
- Step 5** The donor will have a two-day, outpatient evaluation at Emory University Hospital. The donor's test results may take more than six weeks.
- Based on the donor's evaluation and test results, the liver transplant team decides if the donor is a good match.
 - If the donor is not a good match, the process will begin again with the insurance company (see Step 1).

What if I want to become a living donor?

A person must clearly express his interest to be a living donor.

- Before a donor evaluation (evaluation) is scheduled, your child must be listed on the UNOS list.
- Set up an appointment with the transplant surgeon. Schedule a complete donor evaluation, which can be done as an outpatient.
- Your insurance company has to approve a donor evaluation. If the insurance company does not give Children's pre-certification or authorize these tests, you may need to pay for the charges.
- Only one person at a time will be accepted for a donor evaluation. If that person is not accepted, the process will begin again starting with the insurance company (see Step 2).
- Exercise often. Activities such as walking, swimming or biking are strongly advised for donors. This will help the donor recover better after surgery.
- Follow a healthy diet and stop drinking alcohol or smoking. This allows your liver to work better. You will also need to stop some medicines if you are taking them. Talk with your doctor and the Liver Transplant team before you stop any medicine. Herbs, vitamins and nutritional supplements are medicines.

The living donor evaluation

During the living donor evaluation (evaluation), the donor may have some of these tests:

- Screening tests before the evaluation: All female donors must also have a Pap smear and mammogram. Men must have a prostate specific antigen (PSA test). These tests are not included in the regular evaluation.
- A routine medical exam: This includes the donor's height and weight, blood pressure, family history of heart, kidney or other chronic diseases, history of smoking or obesity, alcohol or drug use, and whether the donor has had any prior surgery.
- Lab tests: These may include a complete blood count and tests for hepatitis, drugs, HIV and pregnancy. The transplant surgeon decides which lab tests the donor needs.
- Chest X-ray and electrocardiogram (ECG): These tests check the donor's lungs and heart.
- Liver biopsy: This test checks the health of the liver. A needle is placed between two of the right lower ribs to take a sample of liver tissue. The tissue sample goes to a lab for testing.
- CT scan: This computerized image checks the size and shape of the donor's liver and the amount of liver tissue in each lobe.
- Angiogram: This test checks the size of the donor's blood vessels outside the liver to see if there are any blockages. Dye is injected into the artery so the blood vessels show up on X-ray.
- A psychosocial evaluation: The donor will talk to a social worker and psychologist to make sure the donor knows about the emotional aspects of a transplant. The psychosocial exam also makes sure that the donor wants to have a transplant free of any outside pressures from family or friends.

Based on his medical history, a donor may need more tests than those listed here. If there are no problems, the next step is to schedule the transplant surgery.

Important questions

You should be able to answer the questions below after meeting with the liver transplant team. Please ask the team to explain any that you do not understand.

Questions to ask the liver transplant team

What are the reasons for a transplant?

What are the risks of a transplant?

Are there other alternatives to transplant for my child?

How long is the transplant process from beginning to end?

What is the process for a living donation?

Addition questions or notes:

Preparing for your child's transplant

While you wait

Here are some simple steps you and your family can take while your child waits for a transplant.

Stay in touch and be ready at all times.

- Make sure the liver transplant coordinator can reach you at all times. Provide us with your home, cell, school, work, family and vacation phone numbers; as well as email addresses or any other contact information you have. This ensures that the transplant team can contact you right away.
- Tell us if your phone number, address, or any other contact information changes immediately. If we can't make contact, the liver will be given to another patient waiting for a transplant.
- Call the liver transplant coordinator before you leave for vacation. Be sure your cell phone is working so we can contact you at all times.
- Contact the liver transplant financial counselor if your family has a change in work status or insurance coverage.

Have a plan to get to the hospital the day of the transplant.

- The liver transplant coordinator will tell you when your child must arrive at Egleston.
- Make sure your car or truck is working well and is ready for your trip at any time.
- Have a plan to take care of siblings during the transplant.

Make sure your child is ready.

- Call the liver transplant coordinator if your child has any illness or infection, including something as common as a cold or sore throat.
- If your child becomes ill, get treatment right away. This helps ensure he will be ready for transplant when a donor liver is ready.
- Make sure the liver transplant team is aware of any changes in your child's health.
- Help your child get in good physical shape for the transplant.
- Have him eat healthy foods, as allowed by his diet guidelines. Keep him as active as possible.
- Spend time with your child. Talk with him about his transplant. Let him express feelings, fears or concerns. Let him ask questions and be truthful with your answers. The liver transplant team will be happy to help you if concerns or questions arise.

School

- Keep your child in school and involved in activities, if possible. Try to keep your child's routines normal and balanced.
- Your child's school should be aware that your child has been listed for a transplant. Please ask them to tell you immediately if there is even one case of a contagious infection (ex. Chicken pox, shingles, measles, etc.). Call your liver transplant coordinator at 404-785-1807 if this happens.
- Individualized Education Program (IEP) is something your child may require. The IEP is intended to help children reach educational goals. It will be tailored to your child's specific needs.

When the call comes

The liver transplant coordinator will call you when UNOS finds a donor liver. When the call comes, your child must get to Egleston as quickly and safely as possible. As soon as you are called, have your child stop eating and drinking so that his stomach will be empty.

When you receive the call, bring:

- A list of your child's medicines
- A list of drug allergies
- Your child's health information
- Your health insurance card
- Make sure your child takes all of his medicine as prescribed to prevent problems. It is okay to swallow small sips of water with his medicine.

Transportation

You need to get to the hospital as quickly and safely as possible. If you live far from Atlanta, you and your family should be ready to fly here for the transplant if needed. We may need to plan with your insurance company prior to transplant if flight may be necessary to ensure that the payment will be covered and you will not be billed for that.

Transplant surgery

If your child has a deceased donor transplant

- Step 1** When a donor liver is ready, the liver transplant coordinator will call you at home. If no one is home, you will be paged (if you have a transplant pager). **Be sure to call us back as quickly as possible.** We will advise you on when to get to the hospital.
- Step 2** Your liver transplant coordinator will tell you where to report. You will go to admissions to check in.
- Step 3** Your child will be admitted and staff will direct you to your child's room. He will be prepped for surgery.
- Step 4** The liver transplant team will do a medical review of your child in the next few hours that might include:
- A complete history and physical exam.
 - Blood tests.
 - A review of your child's current medicines. Please have a complete list of all medicines your child is taking.
 - A review of any health problems that your child has had lately such as a sore throat, cold, peritonitis (infection of the fluid in the abdomen), ear infection, rashes, cold sores or contact with people who have infections.
 - A chest X-ray.
 - Urine tests.
- Note: If your child is sick or if an emergency occurs, your child's surgery may be cancelled.
- Step 5** The anesthesiologist will come to your child's room to discuss his allergies and types of anesthesia. An anesthesiologist is a medical doctor who monitors your child during surgery. Anesthesia is medicine that allows your child to be in a deep sleep so he cannot see, hear or feel anything, not even pain.

Step 6 The liver transplant surgeon will come and talk to you about your child's surgery. You must sign consent for surgery after the surgeon has explained the operation and its possible risks.

Step 7 The transplant surgery will take place.

- The surgery may take from four to 12 hours.
- During surgery, there is a room for you and your family to wait.
- The liver transplant coordinator, an operating room (OR) nurse or a child life specialist will give you updates about your child.
- The surgeon will talk to you after your child's surgery.
- If you need to leave the hospital, please tell your coordinator. Be sure to leave a number where you can be reached.

Step 8 Right after your child's surgery, he will go to the Pediatric Intensive Care Unit (PICU) at Egleston.

Step 9 When his doctor feels he is ready, your child will go to our transplant floor (6th floor, Transplant Step-down Unit) at Egleston.

If your child has a living donor transplant

Step 1 The transplant surgery is scheduled. Your child may be admitted to Egleston the afternoon before surgery.

- The transplant surgery will be cancelled if your child is sick.
- If another emergency occurs, the surgery may be postponed, including if the donor is sick.

Step 2 The anesthesiologist will come to your child's room to discuss his allergies and types of anesthesia. An anesthesiologist is a medical doctor who takes care of your child's body functions during surgery. Anesthesia is medicine that allows your child to be in a deep sleep so he cannot see, hear or feel anything, not even pain.

Step 3 The liver transplant surgeon will talk to you about your child's surgery. You must sign consent for surgery after the liver transplant surgeon has explained the operation and its possible risks.

Step 4 The transplant surgery will take place.

- The surgery may take from four to 12 hours.
- During surgery, there is a room for you and your family to wait.
- The transplant coordinator, an operating room (OR) nurse or a child life specialist will give you updates about your child.
- The surgeon will talk to you after your child's surgery.
- If you need to leave the hospital, please tell your coordinator. Be sure to leave a number where you can be reached.

Step 5 Right after your child's surgery, he will go to the Pediatric Intensive Care Unit (PICU).

Step 6 When his doctor feels he is ready, your child will go to our transplant floor at Egleston

The donor's transplant surgery

Step 1 Once the donor evaluation is complete, the donor's surgery is scheduled at Emory University Hospital.

Step 2 The Emory transplant coordinator will give the donor information about preregistration and when to stop eating and drinking the day before surgery.

Step 3 The donor will be admitted to Emory University Hospital.

Step 4 The transplant surgery will take place the next morning and may take from three to eight hours.

Step 5 After surgery, the donor will recover at Emory University Hospital.

After the Transplant

In the hospital

PICU

After surgery, your child will go to the Pediatric Intensive Care Unit (PICU) for approximately two to three days. While in the PICU; the liver transplant team and the PICU team will work together to take care of your child after surgery.

- Your child will be sleepy from the *anesthesia* (a medicine that puts your child to sleep during surgery) for up to several days, but he will be aware of your presence.
- Your child may have different medical devices after transplantation. Your child may have:
 - NG Tube: a soft thin tube inserted into your child's nose to remove excess fluid or provide nutrition.
 - CVL: a soft tube that is inserted into a large vein leading into the heart. It can be used to give nutrition, fluids and medicine, and can be used to take blood for lab work.
 - Foley catheter: a small flexible tube that drains urine from the bladder, used to measure his urine
 - T Tube: A tube placed in the bile duct that allows bile to drain into a bag outside the body
 - Intubation tubes: a tube inserted into your child's mouth and down his airway to assist with breathing
 - Oxygen: via mask or short tubes in your child's nostrils providing additional oxygen
 - Other I.V.s: a flexible tubes that deliver medication through his veins

These different types of medical devices will stay in place for a couple of days and will be removed as your child recovers from surgery.

- A Family Center is available for families with children in the PICU on the fourth floor of Tower One. It contains parent sleep areas and other amenities. Visitors should use the lobby or public waiting areas.
- A play area is available for children. A space for patient activities is located on each floor.
- Children younger than 18 must have an adult with them when using the center.
- Contact a service ambassador or your child's nurse for more information.

Patient floor (Transplant Step-down Unit—TSU, 6th floor)

When appropriate, your child will be taken to a patient care area.

- The nurses and staff will help your child recover and prepare him to go home.
- Your child can usually go home about 18 to 24 days after surgery.
- The liver transplant coordinator and nursing staff will teach you how to care for your child at home.

Guidelines for visiting Egleston (PICU and TSU)

- Wash your hands each time you enter and leave your child's room.
- Tell your child's nurse if any visitors are sick. The nurse will give them protective clothing to keep your child healthy and prevent infections.
- Due to limited space, only two visitors at a time are allowed in the PICU.

- Please stay in your child’s room when doctors do daily rounds. Rounds are times when doctors, nurses and the liver transplant team talk about the care of your child. Your child’s nurse will tell you when the doctor will make rounds.
- It is best to stay with your child at all times. A family member or friend who is at least 18 years old is allowed if the parent cannot stay.
- One parent can stay with your child overnight. Your social worker can help you with accommodations.
- Please be aware that child visitors under 10 years old must be with an adult and cannot visit the PICU at any time and cannot visit anywhere in the hospital during flu season.

Taking care of you and your family

The liver transplant team knows that you have a great need to be near your child during his hospital stay. We also know that it is easy to become tired from worry or lack of restful sleep. This means you should take regular breaks, eat well and get plenty of rest. You will be better able to make care decisions for your child. Also, the transplant social worker can assist with providing light meals if necessary. Please let us know if there is anything we can do to help you.

Getting ready to go home

Taking your child home with a new liver can be very stressful. The liver transplant coordinator and team will prepare you for discharge. They will give you information to help care for your child at home.

Complications

Some children who receive a liver transplant have complications or problems following the transplant. Be aware that infection and rejection are two of the most common complications after a liver transplant. Your child’s transplant team will help you learn about the early signs of complications. They can also discuss your child’s care and advise further treatment when needed.

Rejection

Rejection is a natural response of your child’s *immune system*. The immune system is the body’s defense against “unknown” material such as *viruses*, *bacteria* and some types of cancers. Your child’s body treats a transplanted organ as an “unknown,” so it tries to reject the new liver.

Immunosuppressants

Your child will take medicines called **immunosuppressants** to help prevent rejection.

- These medicines can reduce the risk of severe rejection that damages the liver.
- They also decrease the actions of your child’s immune system. This places him at greater risk for infections.
- Give these medicines on time and as ordered by the doctor.
- Most children take an immunosuppressant after receiving a transplant for the rest of his life.

Tacrolimus and Cyclosporine

Tacrolimus and Cyclosporine are immunosuppressants. Your child may take either medicine. They should be given on time every day as ordered by your child’s doctor.

- Levels of the two medicines are drawn with every set of blood work.

- Blood should be drawn about 30 minutes to one hour before your child takes the medicine.
- We can change your child's medicine schedule to fit your needs. (See page 32 for more information about medicine)
- If you have any questions about your child's medicine, call the Liver Transplant coordinator right away.

Liver biopsy

Rejection can still occur even though your child is taking medicine. The only way to detect rejection is with a lab test or biopsy. Many children require a liver biopsy after having a liver transplant at some point. This is a procedure that your child's doctor may decide to do. This test checks the liver tissue itself:

- Your child will receive anesthesia so he will not feel the procedure
- A needle is used to take a sample of the liver.
- The tissue sample is checked under a microscope to look for rejection.

Infection

Your child is more likely to get an infection when taking immunosuppressants. The risk of infection is greatest in the first three to six months after transplant. Some ways to help prevent infection include:

- Hand washing: Wash your hands often and teach your child to wash his hands after:
 - Going to the bathroom
 - Eating and drinking
 - Taking medicine
 - Handling uncooked food
 - Touching garbage or anything that might have germs
 - Blowing his nose, coughing or sneezing
 - Wiping your child's nose
 - Caring for someone who is sick
 - Playing with or touching pets
 - Leaving a public place
- Avoid large crowds and other children. Avoid people with colds, measles, mumps, chicken pox or the flu. Use common sense. For example, your child may attend church and go to the mall.
- Clean your child's cuts and scrapes with soap and water.
- Cover cuts with antibiotic ointment and a clean, dry dressing.

Infection warning signs

If your child has any of these symptoms, call the liver transplant coordinator at 404-785-1807 right away.

- Fever over 101.5° F
- His hands, fingers or toes are cold
- If your child is sleepy and doesn't want to wake up (lethargy)
- Wound redness, swelling, excess warmth or tenderness or yellowish drainage

Other infection warning signs:

- Cold or flu symptoms
- Tiredness
- Nausea, vomiting or diarrhea that lasts more than 24 hours
- Abdominal pain either over the new liver or in the stomach area
- Headache with increased sinus drainage or a change in the color of the drainage
- Recurring cough, with or without mucus
- Pain or burning while passing urine
- Rash
- Snoring or breathing through the mouth while sleeping

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away, we will manage transfer to Egleston if necessary after stabilized in the nearest emergency department.

Clinic visits

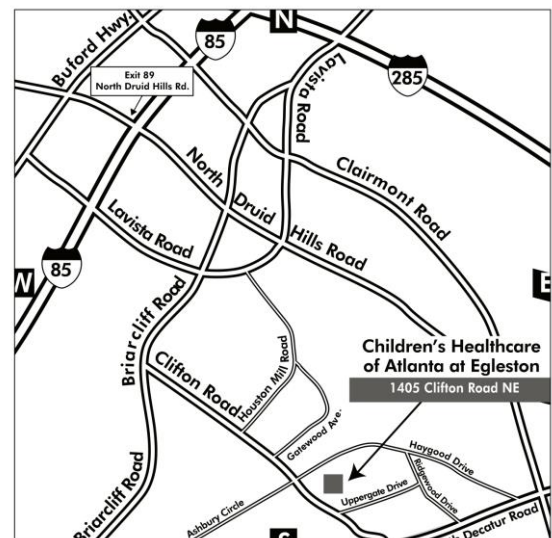
Follow-up clinic visits and lab tests are vital to your child's care when he is well or ill. Even when your child is well, infection and rejection can occur. There are not always signs or complaints to show a problem. Every child is different. Talk to your child's doctor so you can learn about the treatment plan and any problems that may arise. Blood work is the most certain tool a doctor can use.

The liver transplant team will follow your child closely after his transplant. During the first few months, you will see your liver transplant doctor and team each week. As your child's health improves, your visits will decrease.

- Transplant clinic is every Wednesday on the sixth floor at Egleston. To schedule appointments, please call 404-785-1807.
- Please call the clinic as early as possible to schedule routine visits.
- A review of your child's medicines will be done with each visit. Bring all bottles of medicine your child takes to each visit and a dose of all medications to be taken after lab work has been completed.

Your liver transplant coordinator will set up your first visit at the Children's Transplant Clinic. Each visit may include:

- Seeing the liver transplant doctor, coordinator and transplant team as listed on page 3 and 4.
- A check of your child's vital signs (blood pressure, heart rate and breathing), energy level, appetite, weight and activity level.
- A physical exam.
- Blood work.
- This is also a great time for you to ask questions.
- Please be aware that members of the liver transplant team are available at clinic visits and on an outpatient basis as well. Call 404-785-1807 if you need to speak with anyone from the liver transplant team.



Routine lab work post-transplant

- Lab work is one way to make sure your child is on the right amount of medicine.
- After discharge, your child will need lab work often. As time goes by, the lab schedule will vary based on how your child is doing.
- Have all lab tests done as your doctor orders.
- Call the transplant office if you forget to have lab tests done or need to have them done at a time other than scheduled.
- Often immediately after transplant your child will have a CVL or PICC line. We may use it to take blood samples for lab work.

Viral infections

Epstein Barr Virus (EBV) and Cytomegalovirus (CMV) are common viral infections that affect many people. These viruses are everywhere and since your child's immune system is weak, they can be serious for your child.

- If your child picks up EBV or CMV, he may show no signs, or he may show signs of tiredness, muscle aches or fever. Young children may complain of stomach pain, cramping and diarrhea. Call your doctor **right away** if your child shows any of these signs.
- If your child shows signs of EBV or CMV, he may need to come to the hospital. Your doctor will talk with you about treatment. This may include anti-viral medicine or stopping your child's immunosuppressants for a while.
- A test for EBV and CMV is done every week for the first six months after transplant to monitor for these viruses. The test has to be shipped overnight to a special lab for processing. For this reason, EBV tests are collected on Mondays.

Teen clinic

The teen years, right before adulthood, can be challenging, especially after a transplant. The Children's Teen Liver Transplant Clinic helps make the transition to adulthood as smooth as possible by giving teens:

- Guidance and support
- Education
- Resources

Teens can learn how to be responsible for their own healthcare, the importance of taking their medicine, having regular checkups and eating healthy.

Our teen clinic is for Liver Transplant adolescents between the ages of 14 and 21 who are one year post-transplant. Call 404-785-1807 for more information.

Caring for Your Child

At home tips

Vital signs

Many children have high blood pressure after their transplant. Anti-rejection medicine may increase blood pressure. It is vital to take blood pressure medicines as ordered by the transplant doctor.

- When you get home, you may be asked to keep a daily record of your child's blood pressure, weight and temperature.
- You may be asked to check your child's blood pressure. If this is necessary, you will be taught how to do this prior to discharge from the hospital.
- Let the liver transplant coordinator know if you are in need of a scale, thermometer or any other additional equipment you may need to help your child.
- Call the coordinator if the reading is not normal for your child at 404-785-1807.

Immunizations (Vaccines)

- When possible, your child should receive all needed vaccines before the transplant.
- Talk with your child's doctor about the vaccines your child needs. In general, your child should receive these vaccines before a transplant:
 - Diphtheria, pertussis and typhoid (DPT)
 - Polio
 - Measles, mumps and rubella (MMR)
 - Influenza type B (inactivated)
 - Haemophilus flu type B
 - Chicken pox
 - Hepatitis B

After transplant, your child cannot receive any live vaccines because his immune system will be weak. He could get the disease the vaccine is trying to prevent. Live vaccines include the measles, mumps and rubella (MMR), smallpox, rotavirus and chicken pox.

- Transplant patients have weakened immune systems should only receive inactivated immunizations.
- You, your child and family members older than 6 months old should receive a flu shot each year.
- If your child is exposed to chicken pox or shingles, call the transplant doctor or coordinator right away. He might need intravenous (IV) medicine. If your child has not had chicken pox or a chicken pox vaccine and is exposed, he will need a varicella zoster immunoglobulin (VZIG) shot within 72 hours of exposure.

Pediatrician

After transplant, make an appointment with your local pediatrician or family doctor. This gives your local doctor a chance to check your child and update his chart with his new medicines.

- Have your local doctor keep your child's vaccines up-to-date and give him a flu shot each year.
- This doctor can also treat your child for any routine problems such as ear infections, colds or rashes.

Car seats

All states have laws that require babies and toddlers to be properly restrained in a car safety seat that is correct for their age and weight. Have your child ride in the back seat. Use your seat belt to set a good example.

Medical alert identification

Your child should wear a medical identification (ID) bracelet or necklace. In case of a car accident or other emergency, health workers will know he has had a liver transplant, his allergies, who his emergency contact is, blood type as well as anything you feel is pertinent to his care in an emergency. Ask your child's doctor or nurse for this order form. Please complete and mail this form right away.

Nutrition

Eating healthy food helps your child's body grow and heal. The body needs protein, carbohydrates, fats, vitamins and minerals. Your child's appetite can change after a transplant. Be sure to listen to your child and make changes based on his appetite.

The dietitian will check your child's nutritional status and teach your family about the right foods or formulas for your child's special needs. The dietitian will also check your child's diet and growth after transplant.

Before a liver transplant, most children are on special diets. Your child may need to eat less sodium, potassium, protein or phosphorus. The amount your child can have may change over time. We will review changes with you if they are needed.

After the transplant:

- Have your child avoid any uncooked or raw foods such as clams, oysters or sushi.
- Help your child eat a balanced diet that includes fruits and vegetables. Adopt a no added salt rule.
- Avoid chips, sodas, excess fruit juice and other snack foods. They are empty calories and do not provide good nutrition.
- Have your child eat more healthful foods by eating them yourself and setting a good example.
- Your child's weight will be checked during clinic visits to make sure he is growing well. Our goal is for your child to reach the ideal body weight for his age and height.
- Your child may dislike foods he once enjoyed. He may begin to like new foods. Be sure to support your child during this time of change.
- Avoid force-feeding any food. This may cause your child to dislike food, even after treatment.
- If your baby is bottle-fed, give him formula or milk in his bottles. Do not give your baby soda or juice in the bottle.

Tube feedings

Some children need so many calories to grow and heal that they cannot eat enough during the day.

- Tube feedings help a child receive needed formula or supplements. They are given through a thin, flexible tube that passes through the nose and into the stomach.
- Tube feedings can boost calories and enhance weight gain. The tube feedings can even be given at night during sleep.
- Many parents say that their child has more energy when on tube feedings.
- Your child's doctors and nutritionist may advise tube feedings before or after the transplant. The nurses will help you learn more about tube feedings if your child needs them.

Exercise

As your child feels better, his activity level will increase. He can do any activities he feels up to, except contact sports. Please feel free to call the transplant office or ask us questions during clinic visits about your child's activity or energy level.

Sunscreen

Because of side effects with your child's medicine, he must use sunscreen. Choose one with an SPF of 15 or higher. Use it freely and often, even if your child will only be in the sun a short time. To prevent sunburn, your child should:

- Wear clothing that protects his skin, such as a hat, long pants and long sleeves.
- Put sunscreen on exposed skin 30 minutes before going outdoors. Put it on again as the package directs. This usually means you need to put it on every two hours and after playing in the water.
- Use sunscreen for children of all ethnic backgrounds, regardless of skin color.
- Sun exposure happens all year, not just during the summer.
- The best way to prevent skin damage is to limit time spent in the sun.

Dental

Your dentist must be aware that your child has had a transplant. Medicine such as Cyclosporine can cause overgrowth of gum tissue. Keep your child's teeth, mouth and gums clean. This helps reduce the chance of an infection.

- Make sure your child brushes and flosses his teeth two times a day.
- Use a soft toothbrush and gently brush up and down. This may help keep his gums from overgrowing.
- Your child should also see a dentist regularly. He may require prophylaxis (preventative antibiotics) before all dental procedures.
- You can have your dentist contact us at 404-785-1807 for additional information.

Ear/body piercings and tattoos

Your child should not get any ear or body piercings or tattoos until you talk to the liver transplant doctor. We do not advise this procedure because it can cause infection. Please contact your team at 404-785-1807 with further questions.

School and daycare

Talk to your liver transplant doctor about when your child will be ready to return to school, preschool or daycare. He can also advise you of any special plans that may be needed. The goal for all transplant children is to attend school full-time. This helps your child keep up with learning, socializing and physical activities.

Children's also offers a Hospital School program to help with studies when your child is in the hospital. Your liver transplant coordinator, social worker or hospital school program coordinator can help you with plans for your child's return to school.

This may include letters, guidelines and options to help explain why your child may:

- Need to return to school part-time.
- Not be able to receive certain vaccines that are needed to enroll in school.
- Have limits on contact sports.
- Need home-care school options for when he is ill or unable to attend school full-time.

Travel tips

As your child feels better and returns to a regular schedule, you may want to travel or take a vacation. Please call your Liver Transplant coordinator before you travel.

- If you fly, take your child's medicines with you in your purse or carry-on bags. This is helpful in case your checked luggage gets lost in flight.
- Bring extra medicine in case of travel delays.
- Carry an up-to-date list of all of your child's medicine in case of an emergency.
- Always have a copy of your child's health insurance card.
- Have your child wear a medic alert bracelet and carry an identification (ID) card.
- Include the phone number of the liver transplant team (404-785-1807).

Notes

When to call the transplant coordinator

Please call **404-785-1807** to reach the liver transplant office or the on-call liver transplant coordinator any time you have questions or concerns about your child's health. Call the liver transplant coordinator right away if your child has:

- Redness, swelling, drainage or pain at the incision site or other sites
- Any redness, drainage, swelling or damage to the drain, if your child has one
- Any fever over 101.5°
- Diarrhea or vomiting that lasts more than two to three hours
- Weight gain or swelling
- Headaches or dizziness
- Exposure to chicken pox or shingles
- Any rashes
- Stomach pain
- Any decrease or darkening of urine
- Poor appetite or fluid intake
- Cold hands, fingers or toes

Also call if your child:

- Is not able to take his medicine
- Is sleepy and doesn't want to wake up (lethargy)

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Medicines

After a liver transplant, your child will take many medicines. These medicines are very important. They will help keep your child from rejecting his new liver and keep him in the best possible health. It is important to keep a chart or reference to help make sure medications are given as instructed. (A helpful resource for creating medication charts is www.mymedschedule.com). As time passes, your child's doctor may decide that some of the medicines may be decreased or stopped. Until your doctor makes any changes, give your child all of his medicines on a regular schedule.

- Do not skip doses, even if they are several hours late.
- Do not double doses. If you accidentally give the wrong dose of medicine, call the liver transplant coordinator to see if you need to take any action to prevent a bad reaction.
- Call the liver transplant financial counselor if there are any financial concerns in getting your child's medicines.

Examples of medicine your child may take:

NAME OF MEDICINE	WHAT IT DOES
Immunosuppressants Tacrolimus (Prograf), Everlimus, Cyclosporine, Prednisone, Mycophenolate Mofetil (Cellcept)	Help prevent rejection
Blood pressure medicines (antihypertensives) Amlodipine, Nifedipine	Control blood pressure and help keep it from getting too high
Antivirals Acyclovir, Famciclovir, Ganciclovir, Valganciclovir	Help the body fight viruses such as chicken pox
Antibiotics Ciprofloxacin, Sulfamethoxazole (Bactrim), Trimethoprim, Penicillin	Fight infections
Antipyretics Acetaminophen and Aspirin	Reduce fever

NOTE: Your child should NOT take Ibuprofen (Advil) after receiving a liver transplant.

Immunosuppressant drugs

NOTE: All of these medicines cause an increased risk of infection.

DRUG	REASONS FOR TAKING	SOME COMMON SIDE EFFECTS
Tacrolimus (Prograf)	Suppresses immune system, prevents organ rejection	Mouth sores, diarrhea, diabetes, Post-Transplant Lymphoproliferative Disease (PTLD)
Everolimus	Suppresses immune system, prevents organ rejection	Belly pain, diarrhea, decreased appetite, delayed wound healing
Cyclosporine	Suppresses immune system, prevents organ rejection	Nausea, hair growth, gum growth
Prednisone	Prevents inflammation	Moon face, nausea, weight gain, insomnia, high blood sugar
Mychophenolate Mofetil (Cellcept)	Suppresses immune system, prevents organ rejection	Nausea, diarrhea, weakness, tremors

Medication helpful hints

Time to give medicine:

- Ask your child's doctor or pharmacist for the best time to take each medicine.
- Call the transplant coordinator or your doctor if your child vomits the medicine less than 30 minutes after it was taken.

Ways to give medicine:

- Check with your child's pharmacist or doctor to find out if your child is taking any time-released medicine. Some time-release medicine cannot be crushed or opened.
- Some medicine can be crushed and put in a small amount of food, such as applesauce, ice cream, juice or flavored syrup. Use a small amount because your child may not want to finish all the food.
- Some medicine can be crushed and put in a gel cap for older children who can swallow a capsule.

Other medicine:

- Some over-the-counter medicine can change the effects of prescription medicines. Be sure to keep track of all medicines given to your child.
- Ask the liver transplant coordinator before you give your child any medicine for coughs or colds.
- Call the coordinator if a pediatrician or other doctor starts any medicine. The liver transplant team needs to keep a complete record of all of your child's medicine and illnesses.
- Ask staff to call the liver transplant coordinator if you take your child to a local doctor or emergency center. This will help your child's doctor provide the best care by having a complete picture of his health.
- Do not give your child any herbal medicine, teas, nutritional supplements or any other natural or herbal treatments without checking with your liver transplant doctor or liver transplant coordinator. If you have any questions about any medicines or treatments, please call the liver transplant office.

Maintaining an accurate medication list:

- Transplant medications must be given regularly and at the correct times to help prevent rejection or other complications.
- It is important to keep a chart to help make sure your child is getting his medications as prescribed. A helpful resource for creating medication charts is www.mymedschedule.com

Medicine refills:

- Call the liver transplant coordinator when you need medicine refilled. Be sure to call a month ahead so you do not run out.
- Some medicine must have insurance prior approval before they can be filled at the pharmacy. Your child's clinical nurse coordinator can submit this prior approval information to his insurance company, but this process may take several days.
- Call your pharmacy a few days ahead to refill your prescriptions. This ensures the pharmacy has enough medicine in stock for your child.
- Check the bottle for the correct dose and strength each time your child's medicine is refilled. The dose may change if the prescription is filled with a different strength tablet or a more concentrated liquid.
- Your child needs his blood work checked often right after the transplant. His medicine may need to be changed based on blood work results. The liver transplant coordinator or doctor may contact you to change your child's dose.
- A refill from the pharmacy may not be the same as your child's current dose. If you have questions about the dose of any medicine, call the liver transplant office or have your pharmacist contact the office.

Helping Your Child Cope

A transplant changes the life of your child and family. You may ask:

- What does my child know or understand about his transplant?
- How will my child feel about treatment?
- How can I support my child?

Your child's personality, age, support system and treatment will affect how he copes with a transplant. When children are faced with stress, their normal behaviors may change. They may become more dependent on adults and act younger than their age. Your child may not know how to handle his feelings. You know how your child handles stress. Work with your healthcare team to find new ways to help your child cope. Child life specialists can also help.

Guidelines to support your child

Infants (birth to 12 months)

Your baby expects you to meet his needs. He does not understand a liver transplant. An infant will:

- Rely on you for food, comfort, play and care
- Learn about his world through senses such as smells, colors and tastes
- Develop trust in familiar people and things
- Respond to new people and surroundings

COMMON ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR BABY:
Separation from familiar people	<ul style="list-style-type: none">• Be with your baby as much as possible• Leave something of yours when you go, like a picture or shirt• Rock or hold your baby—keep familiar blankets and toys in the room
Fear of strangers	<ul style="list-style-type: none">• Have the same people care for your baby inside and outside the hospital as much as possible• Limit the number of people and voices in the room
Development	<ul style="list-style-type: none">• Allow your baby to explore toys with his hands and mouth. Be sure toys are clean and no small pieces could make him choke• Use gentle touch and massage to comfort him• Play games with your baby like you would at home
Sense of safety	<ul style="list-style-type: none">• Keep your baby's crib as a safe place. Ask if staff can use the treatment room for painful procedures (This may not be possible every time)• Wake your baby before a painful procedure• Continue or develop the same type of feeding, bedtime and bathing routines you have at home

Toddlers (12 months to 3 years)

Toddlers begin to do more on their own.

- Your child may say, “me do” or “no.”
- Let him do things on his own. He may show feelings by his actions.
- Help him learn about how his body works.
- Explain the transplant in his terms. Toddlers think they make things happen. He may think he did something to cause his illness.

SOME ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR TODDLER:
Fear of separation or fear of strangers	<ul style="list-style-type: none"> • Be with your child as much as possible • Have the same people care for your child when possible • Provide security objects such as a blanket or stuffed animal • When leaving, tell him where you are going and when you will be back • Leave something of yours when you, go like a picture or shirt
Loss of control	<ul style="list-style-type: none"> • Allow your child to make choices but do not offer a choice when there is not one • Give your toddler a job to do • Allow him to play and be in control of the game or activity
Loss of normal routine	<ul style="list-style-type: none"> • Maintain normal eating, sleeping and bathing routines as much as possible • Let him play with favorite and familiar toys
Behavior changes	<ul style="list-style-type: none"> • Give him safe ways to express anger and other feelings such as painting or blocks • Tell your child it is okay to feel mad or sad • Spend time with him and offer reassurance • Set limits with your child and give discipline when needed. He needs limits to feel safe • Praise him whenever possible
Fear of treatment	<ul style="list-style-type: none"> • Ensure your child that he did nothing wrong • Keep security objects nearby such as blanket, pacifier or stuffed animal • Use simple words, pictures or books to tell what will happen • Tell him what will happen just before the treatment

Preschoolers (3 years to 5 years)

Preschoolers take pride in being able to do things for themselves.

- Preschoolers learn more words to say what they think and feel. Your child might use play to express himself.
- Your child may think the hospital is punishment for something he did wrong.
- He may get confused by adult words and make up reasons for what happens.

SOME ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR PRESCHOOLER:
Explain what happens	<ul style="list-style-type: none"> • Use simple words, pictures or books to tell what will happen • Tell your child what will happen before treatment • Let your child play with doctor kits and safe medical supplies
Loss of control	<ul style="list-style-type: none"> • Allow your child to make choices, but do not offer a choice when there is not one • Give him a job to do
Loss of normal routine or behavior changes	<ul style="list-style-type: none"> • Praise your child for doing things for himself • Give him time to adjust to change • Use play to help him show feelings

School-age (6 years to 12 years)

School-age children take pride in doing things themselves.

- Your child enjoys school because it helps him learn new things.
- Friends are very important.
- School-age children are able to think in terms of cause and effect. Your child has a better sense of time.
- Your child may have more words to describe his body, thoughts and feelings.
- Your child understands how his body works. He may not understand medical words.

SOME ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR SCHOOL-AGE CHILD:
Loss of control	<ul style="list-style-type: none"> • Allow him to make choices, but do not offer a choice when there is not one • Give your child a job to do • Let him practice new things • Let him go to school or do school work • Provide games and activities
Being away from friends and school	<ul style="list-style-type: none"> • Let friends visit • Have him write letters to friends and family
Fear of harm to body or fear of unknown	<ul style="list-style-type: none"> • Use simple words, pictures or books to tell your child what will happen • Tell him what will happen a few days before treatment • Let your child play with safe medical supplies

Teenagers (13 years to 18 years)

- Teens see themselves as individuals and want to be independent
- Friends and peers are important
- Your teen wants to be like his friends and is concerned with how others view him
- Illness and treatment cause teens to be different
- Teens are able to see things from many points of view

SOME ISSUES AND FEARS:	HOW YOU CAN SUPPORT YOUR TEEN:
Loss of control or independence	<ul style="list-style-type: none"> • Allow your teen to make choices • Let him be active in school and social activities • Involve him in the treatment plan • Include him when talking to the medical team • Have him do his own self-care as much as possible
Body image or self-esteem	<ul style="list-style-type: none"> • Give your teen chances to talk about physical and emotional changes • Talk with him about his feelings • Point out things he does well • Allow your teen to do things that make him feel good about himself
Loss of privacy	<ul style="list-style-type: none"> • Respect his need to do things by himself • Knock before entering his room • Offer him private time
Separation from peers	<ul style="list-style-type: none"> • Provide time with peers • Allow friends to visit and call
Concern for the future	<ul style="list-style-type: none"> • Answer questions openly and honestly • Help your teen plan for the future • Have your teen keep doing normal activities
Behavior changes	<ul style="list-style-type: none"> • Offer your teen safe ways to express feelings, especially anger • Ensure your teen that his feelings are normal

Talking to your child about a transplant

Many parents want to protect their child by not telling them things that could be scary. Your child is more afraid when he does not know what is happening. Benefits to talking to your child about his transplant include:

- He can build trust in you and hospital staff
- He will know what to expect
- Honest information corrects false ideas about transplants
- It can help him cooperate during treatment
- It can help give him a sense of control
- He can learn how to get through hard situations

It may be hard to tell your child about his transplant. Children know when something is wrong. They may feel lonely and separated from family and friends.

- Think about your child's age when choosing words to explain his transplant. Your child life specialist can help you find ways to explain tests and treatments.
- Children learn from doing, seeing and hearing things many times. You may need to explain the transplant several times.
- The child life team can also help provide books and other resources for your child.
- Support groups are also available. The transplant social worker can provide additional information if you would like.

Why should I talk to my child about his transplant?

The items below can help you talk with your child and answer his questions about the transplant. Be honest when you talk with him.

- A transplant is no one's fault. Many children believe a transplant is caused by something they did, said or thought. Explain that what your child thinks, says and does did not cause his transplant. It is no one's fault.
- A transplant is not contagious. Your child did not catch the need for a transplant from someone else.
- Surgery is when a doctor takes out all or part of the liver and replaces it with a donor liver. Your child will be given special medicine (anesthesia) that puts him in a deep sleep so he does not feel or see anything, not even pain.
- Tell your child how healthy bodies work. Avoid using words like bad and good. Instead use words such as sick and healthy.
- Talk to your child about his feelings. Let him know that his feelings are normal. Many times children feel angry, guilty, sad, lonely, scared and sometimes even happy. Please be honest with your child about your feelings, without scaring your child.

Disciplining my child

A transplant can disrupt your family routine. Your child may be the center of attention and may receive gifts. Although he may feel sick, gifts and attention are fun. It is easy for him to feel special and want the special treatment to last. Discipline can be a problem when special attention stops.

Your child's illness can make discipline hard. Pain and side effects of treatment can make any child short-tempered. He may act more helpless when he feels sick. Medicines may also cause your child to feel ill-tempered. You may feel helpless when you see your child suffer. You want to help him by giving special rewards. These feelings are normal. Keep the same rules he had before his transplant.

Keep these ideas in mind to provide limits:

- Set clear limits your child can understand.
- Realize limits may need to change as your child receives treatment.
- Praise him and give rewards for good behavior.

Caring for the Whole Family

Coping with your feelings

Since you found out about your child's illness, your lives have changed. A transplant brings changes to your home life, including new stresses. Every family is unique. Your family may feel fear, anger, depression and guilt. By sharing these feelings, you may find it easier to cope with change. Your child's healthcare team is here to listen to your concerns and help you in any way that they can.

Fear

The time that you find out about your child's illness is often the hardest. The fear of the unknown may be overwhelming. This may be the first time your child has been in the hospital. This can be stressful for you and your child. You may also have fears about treatment, cost or how to help your child cope with a transplant. Talk about these fears and get them out in the open.

Anger

You may feel very angry. This is a normal reaction. Find a way to express your anger— take a walk or talk with someone.

Guilt

Parents may feel guilty because they did not know their child was sick. Some families feel that they caused their child's liver failure. Other family members may feel guilty that they are healthy. Children may also feel that they caused the illness. Let your family know they did not cause your child's liver failure.

Depression or grief

Depression is used to describe a range of emotions and behaviors. Feeling sad is a normal reaction. It may cause changes in family routine and feelings of loneliness and change can also cause grief and depression. Common symptoms are:

- Crying spells
- Decreased or increased eating
- Lack of interest
- Lack of energy
- Tightness in the chest
- Headaches

All of these feelings are common human emotions. You are not alone. With the support of family, friends and your child's healthcare team, most families are able to work through these emotions. They are able to regain the coping skills needed to meet your child's care demands.

Suggestions to help you cope with your child's illness:

- Find a private time to talk with your spouse or a close friend. Try not to talk only about your sick child.
- Avoid talking about your child in his presence unless he is included.
- Find ways to reduce stress. You know what works best for you. Ideas include exercising or reading.
- Take turns with your spouse or another person who can stay with your child in the hospital or go to clinic visits. This helps everyone be involved in your child's treatment. It also reduces the gap that may grow between parents when one is more involved in treatment than the other.

- Ask a member of your child's healthcare team for help and support.
- Talk with other parents of children with transplants.
- Talk with your spiritual leader.
- Attend a support group.

Sometimes emotions become so overwhelming that it can be hard to regain balance. This is very true when there were stresses before your child's illness. If there have been other family strains or losses, mental health problems or substance abuse, counseling and medicine may be needed. Discuss your feelings with the healthcare team so you can get the help that you need.

Impact of a transplant on a marriage

An illness can upset a family's life. You may become emotionally and physically tired. Parents often continue to work while trying to keep a normal home routine. Many couples feel the strain on their marriage. They feel angry and upset and do not have time for each other. Suggestions that can help include:

- Assess your coping styles. It is important to know and accept how your spouse deals with stress. Each person shows feelings in different ways. Some people withdraw, others cry or get angry and some try to learn as much as possible.
- Talk to each other. The key to a good relationship is talking. The need to discuss feelings, fears and information is even more important in times of stress. Silence can make you feel distant from your partner. Sharing feelings and facts can help. This will help you make decisions.
- Change roles when needed. The stress of an illness can change the roles of family members:
 - The mother who once took care of the home may now be too busy.
 - Another family member may need to help out in the home.
 - The father may have made decisions in the past. Now the mother is with the sick child and may be the one who helps make decisions with the healthcare team.

Changes in roles can cause stress in a marriage or a family. Some short-term role changes may be needed to help the ill child. Other changes may be long term if they help the family work together.

Suggestions for divorced parents

While divorce is hard on most families, problems can get worse when your child is ill. Your child may use his illness to bring divorced parents closer. In other cases, he may play parents against each other to feel in control. Do not let divorce affect your child's care. You both are still parents and good communication is key.

Tips to help avoid problems include:

- Talk with a member of the healthcare team if your child is having behavior problems.
- Provide copies of divorce decrees, custody and visitation rights for your child's medical records.
- Meet together with your child's healthcare team to help avoid confusion about his plan of care.
- Ask for two copies of all teaching materials so both parents have the same information.

Impact of a transplant on siblings

Siblings (brothers and sisters) also have feelings about your child's liver disease. They may feel upset, scared and unsure of what will happen. Children of any age will sense a change in their family life. Other children may feel resentment or anger since Mom and Dad are spending more time with the sick child. They may have problems of their own, such as depression, trouble sleeping, physical complaints or school problems.

How to help siblings

- It is normal to spend more time with your sick child. Set aside time to spend with your other children.
- Tell them you love them and they are special.
- Talk about the transplant so they understand. Help them understand the illness and how it affects their brother or sister. Tell them liver disease is not contagious (catchy) and they are not to blame.
- Take them to the hospital. Help them feel involved in the care of your sick child. This may help decrease fears and help them feel closer to their brother or sister.
- Ask a friend or relative to stay in your home, rather than send your children elsewhere.
- Ask your children to help with chores. This makes them feel needed.
- Talk with their teachers. Teachers can support your children and let you know about any problems at school.
- Ask for help from a member of the healthcare team such as a child life specialist, social worker or child psychiatrist.
- Books are available for check-out for your child's sibling in the Family Library on the 3rd floor of Egleston.

Impact of a transplant on grandparents

Grandparents have many responses when they hear their grandchild has liver disease. They may feel shock and disbelief or feel guilty for living a long life. They may also feel blame, thinking they passed liver disease through the family. Grandparents may also feel sadness, not just for their grandchild, but also for their son or daughter. Include grandparents in meetings with the healthcare team. This can help them understand the treatment plan.

Grandparents can be a great help to you. If they are still in good health, they can:

- Relieve you in the hospital or help at home.
- Give your other children attention, comfort and love.
- Serve as a contact person, giving others information, so you don't have to spend as much time on the phone.
- It is important to give a copy of your child's insurance card to his grandparents or other support persons in case of emergency.

Programs and events

The Children's liver transplant team knows there is more to treating your child than just taking care of his health. It is about treating the whole patient. This means enhancing your child's quality of life while in our care. We also understand your child's life is centered on his family. We offer programs that involve the entire family, including:

Teen program

- This program is open to transplant recipients and candidates between ages 14 to 21.
- Teens participate in two outings in the spring and fall. The program lets teens socialize with peers in a fun and relaxing environment.

Parent support groups

- Groups are scheduled for parents to gain support from each other and members of the transplant staff.
- Guest speakers talk about many interesting topics. Meals are provided.
- Children (patients and siblings) are welcome to attend. They can take part in activities with a child life specialist to help them cope.

Spring evening with the Atlanta Braves

- Transplant recipients, families and staff are invited to a picnic and a parade around the bases at Turner Field before the first pitch.
- Your family can meet and have their pictures taken with Atlanta Braves players before the game.

Family Camp

- This weekend camp gives the whole family the chance to experience camp, build friendship and make lifetime memories.
- Camp is at Camp Twin Lakes in Rutledge, Ga.
- Families take part in educational seminars on different transplant topics.
- Activities are centered on family-friendly themes, including:
 - Canoeing
 - Mountain biking
 - Swimming
 - Fishing
 - Square dancing
 - Archery
 - Music
 - Wall climbing
 - African dancers
 - Arts and crafts

Camp Independence

- This week-long camp is for children ages 8 to 16 with chronic kidney conditions and organ transplants.
- Camp is at Camp Twin Lakes in Rutledge, Ga.

Holiday party

- A festive party in early December at different locations in metro Atlanta.
- Meet and mingle with family and friends, take pictures with Santa and his elves and enjoy many other holiday activities.

Call the liver transplant program manager at 404-785-6735 for more information about our programs and events.

Resources

Financial resources

At times, the cost of a transplant may seem overwhelming. The Children's liver transplant team is here to help you. A financial coordinator can help you learn about your insurance benefits and payment options. A Liver Transplant financial coordinator can:

- Contact your insurance company and find out about your child's benefits.
- Get approval for the evaluation and transplant.
- Meet with you through the transplant evaluation to review your insurance benefits.
- Answer questions about your benefits.
- Help assess your financial needs.
- Talk about making a long-term financial plan for your child's healthcare needs.
- Help get your child into a case management program if your insurance company has this service.
- Help you learn about government programs for which you may qualify.
- Teach you about hospital and doctor billing practices.

Financial coordinators at Children's can also help you with:

- Financial aid packets for the Charitable Hospitable Fund. Aid is based on federal poverty guidelines and other financial guidelines.
- Questions regarding Medicare, Medicaid, Georgia's Peach Care program and hospital and doctor payment plans.
- Find out what government assistance your child can receive. The coordinator can help you fill out forms and paperwork. There may be a lot of paperwork to complete. Fill out all the forms as soon as possible. The sooner the papers are sent, the sooner you may receive benefits. This process may take weeks, or even months, to complete.

Contact our financial coordinator or registration office if your insurance coverage has changed. Medical bills can be confusing. Please let the financial coordinator know if you are having any financial trouble regarding your child's medical costs.

Insurance companies

It is important that you know about your insurance coverage.

Helpful hints:

- Ask someone in the human resources department where you work to explain your benefits.
- If your doctor or hospital is not in network, please contact your insurance company to discuss your co-insurance rates and out-of-pocket costs. The transplant financial coordinator can help assist you with this as well, to contact please call 404-785-6478 or 404-785-0924.
- Your insurance company may ask you to give them a letter of medical necessity so your child can be treated at Children's. Please contact the hospital financial coordinator to help you get this information from your transplant surgeon.

- Bring a copy of your insurance card to each of your child's appointments. It lists your benefits, deductible and copayment amounts.
- Be sure to tell the Liver Transplant office right away of any changes in your address, phone number or insurance coverage.

Helpful hints about the billing process

You will receive bills from several places: hospital bills known as technical or facility fees, and doctor bills known as professional fees.

- If you have a question about a bill, please call the phone numbers listed on your billing statement.
- Make a file for hospital bills and insurance forms. This will help you to track payments, denials and requests for more information.
- You may need to call your insurance company to ask questions about the transplant. Ask to speak to someone that can answer transplant benefits questions.

Below is a list of common offices that will send you bills:

- Children's Healthcare of Atlanta for all services received at any Children's hospital or satellite location
- Emory Clinic for any radiology, pathology and anesthesiology services
- Other staff or doctors who care for your child

Read bills closely. You may receive statements that are still pending payment. These statements are for your records and are not bills. If your caregiver's billing offices or your insurance company contacts you, please respond quickly.

Medicaid

Medicaid is a state medical assistance program that covers most costs for hospital stays, clinic visits and medicines. There are some procedures or exams not covered by Medicaid and some must be pre-approved. Some Medicaid programs are based on family income and others are based on medical needs. You may be able to get coverage for medical services that occur three months prior to the month your child becomes eligible for Medicaid.

Medicaid may be able to pay for:

- Doctor and hospital bills
- Up to five prescriptions a month
- Physical, occupational and speech therapy
- Adaptive equipment

If your child has Medicaid through Peachcare, Peachstate, Wellcare, Amerigroup, or any other Georgia Medicaid CMO, they are eligible to keep this Medicaid coverage until the end of the month of their 19th birthday. It is important that you maintain your child's Medicaid coverage after age 18 because if it is cancelled for any reason, it will not be reinstated between their 18th and 19th birthday.

If your child has SSI Medicaid and was approved for this as a child (under the age of 18), you will need to have your child re-apply for adult SSI benefits as he/she approaches his/her 18th birthday. If your child SSI is denied, you can appeal the denial and be sure to request that the SSI Medicaid remains active during the appeals process (which can take up to four months).

Feel free to contact your social worker for additional information about the programs offered through Georgia Medicaid. Children's also has an onsite Medicaid office located on the first floor at Egleston and Scottish Rite. A DeKalb or Fulton county case manager staffs each office.

Resources available at Children's

PICU sleep rooms

- All sleep rooms accommodate two people and can have either two twin beds or two sleep chairs or one twin bed and one sleep chair.
- Only the parents or legal guardians of children in the intensive care unit (ICU) can use the sleep rooms.
- Only two family members may sleep in a room at one time. Children are not allowed in sleep rooms.
- Sleep rooms should be used only for sleeping. Meetings and visitors are not allowed.
- Cleaning takes place each day between 9 a.m. and 2 p.m. Bed linens and towels are provided.
- Families must be out of sleep rooms by 9 a.m. You must remove all of your personal items.
- You cannot use a sleep room once your child has been discharged from the ICU.
- Sleep rooms are assigned each day based on a lottery system.
- Contact the front desk in the Family Center or a service ambassador for more information.

Showers and restrooms (each non-PICU patient room or in the family lounge on the 2nd floor)

- Private showers and restrooms are available for parents and guardians.
- Toiletries, such as soap, razors and shaving cream are donated. If you need toiletries, talk with a service ambassador, the liver transplant social worker or your child's nurse.

Washers and dryers (3rd floor)

- Washers and dryers are available to your family.
- Laundry can be done between 7 a.m. and 10:30 p.m.

Exercise room (ground floor)

- Includes a treadmill and stationary bike
- Open 8 a.m. to 10 p.m.

Family kitchen/lounge (on each unit)

- Vending machines
- Ice machine
- Family refrigerator

Lactation/feeding rooms (2nd floor)

- Breast pumps are available for any admitted patient family
- There is a lactation consultant onsite Monday to Friday, ask your nurse for more information

Food services

- Cafeteria
 - Breakfast: 6:30 a.m. to 9:30 a.m.
 - Lunch: 11 a.m. to 2 p.m.
 - Dinner: 3:30 p.m. to 8:30 p.m.

- Room Service
 - Dial ext. 56262 from your child's room
 - Available from 7 a.m. to 8 p.m.

Chapel (1st floor)

Garden (entrance on 1st floor)

Family library (2nd floor)

- Open Monday through Friday from 10 a.m. to 6 p.m. and Saturday and Sunday noon to 6 p.m.
- Consumer health collection
- Recreational books and movies for all ages
- One-hour digital camera checkout
- Laptop checkout for long-term patients (laptops are locked in the patient's room)
- Four computers for adults, two for children and two for adolescents and young adults
- Access to the Internet for email and medical information searches
- Library staff to assist you

Business center (2nd floor)

- Open 8 a.m. to 10 p.m., seven days a week
- Four computers with Internet access and printing available from 10 a.m. to 6 p.m.

Area lodging

The social work office keeps a list of area hotels that offer reduced rates to families. The Liver Transplant social worker can make reservations for you. The social work office is located on the sixth floor (Butterfly elevators) of Tower Two at Egleston.

Gatewood Ronald McDonald House

795 Gatewood Road NE
 Atlanta, GA 30329-4200
 Phone: 404-315-1133

The Ronald McDonald House provides temporary lodging for families of hospitalized children who live outside of Atlanta. An adult family member or guardian must be present with children at all times. New guests must have a referral from a hospital social worker.

Mason Guest House

1555 Shoup Court
 Decatur, GA 30033-4607
 Phone: 404-712-5110

The Mason Guest House offers low-cost lodging for transplant candidates, recipients and their families for Atlanta's four transplant hospitals. Please call 24 hours in advance to check availability.

Other transplant resources

There are many family resources that can help with transplant costs. Each one has its own rules. Make sure to pick one that suits your needs.

- For example, some require families to count money raised as income. That is not the case with all of them.
- Some match funds raised at a rate set by the organization.
- The most success with fundraising is usually done before a transplant.

Some of the more common resources include:

American Liver Foundation (Southeast)

2250 North Druid Hills Road NE, #285

Atlanta, GA 30329

888-443-7872

www.liverfoundation.org

National, nonprofit organization that provides research, education and advocacy for those affected by liver-related disease.

Children's Organ Transplant Association (COTA)

2501 West COTA Drive

Bloomington, IN 47403-4204

800-366-2682

www.cota.org

National, nonprofit agency that helps organize community resources in fundraising on behalf of patients who need or have had organ transplants.

Georgia Transplant Foundation, Inc.

6600 Peachtree-Dunwoody Road NE

600 Embassy Row, Suite 250

Atlanta, GA 30328

770-457-3796 or 866-428-9411

www.gatransplant.org

Private, nonprofit organization that financially assists Georgia residents who are transplant candidates or recipients.

Make a Wish Foundation of Georgia and Alabama

1775 The Exchange SE, Suite 200

Atlanta, GA 30339

770-916-9474

www.ga-al.wish.org

National, nonprofit organization that grants wishes for seriously ill children from 2 to 17. Contact your child life specialist or the organization for more information.

National Organization for Rare Disorders (NORD)

55 Kenosia Avenue
P.O. Box 1968
Danbury, CT 06813-1968
800-999-6673 or 203-744-0100
www.rarediseases.org

Manages drug cost share program for individuals who cannot afford Cyclosporine.

National Foundation for Transplants (NFT)

NFT Corporate Headquarters
5350 Poplar Ave., Suite 430
Memphis, TN 38119-3665
800-489-3863 or 901-684-1697
www.transplants.org

Limited emergency grants available for medicine.

Pharmaceutical Research and Manufacturers of America (PhRMA)

950 F Street NW, Suite 300
Washington, DC 20004-1440
202-835-3400
www.phrma.org

Publishes the Directory of Prescription Drug Indigent Programs. You can get a copy by writing to the company.

United Network for Organ Sharing (UNOS)

P.O. Box 2484
Richmond, VA 23218-2484
888-894-6361 or 804-782-4800
www.unos.org

The United Network for Organ Sharing (UNOS) is the national agency that oversees organ transplants.

These resources are provided to you for informational purposes only. Children's Healthcare of Atlanta is not associated with any of these organizations and does not make any representations regarding their services. We do not recommend or endorse any particular products, services or organizations or make any determination that such products, services or organizations are appropriate for you or your child. Children's assumes no liability or responsibility for acts or omissions of these organizations.

Websites

The following is a list of informative websites on pediatric liver transplants. Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and makes no claim regarding their content or accuracy. Children's does not recommend or endorse any particular products, services or the content or use of any third-party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's is not responsible for the content of any of the sites. Use of these links is at your sole risk.

Liver Related Websites

American Liver Foundation

www.liverfoundation.org

Partnership for Organ Donation

www.transweb.org/index.shtml

CDC National Immunizations Program

Schedule

www.cdc.gov/vaccines

Sandrine's Gift of Life

<http://sandrinesgift.org>

Children's Organ Transplant Association

www.cota.org

United Network for Organ Sharing (UNOS)

www.unos.org

Georgia Liver Foundation

www.liverfoundation.org/chapters/georgia

Scientific Registry of Transplant Recipients

www.srtr.org

Hepatitis Foundation

www.hepfi.org

Hepwatch

www.hepwatch.com

Immunizations Contraindication

<http://www.cdc.gov/vaccines/recs/vacadmin/contraindications.htm>

LifeLink of Georgia

www.lifelinkfound.org/organdonation

National Immunization Program

www.cdc.gov/vaccines

National Transplant Assistance Fund & Catastrophic Injury Program

www.ntafund.org

Local Georgia Resources

Atlanta Chamber of Commerce

www.metroatlantachamber.com

Atlanta Hotel Guide

<http://atlanta.hotelguide.net>

Children's Healthcare of Atlanta

www.choa.org

Georgia Department of Human Resources

www.dhr.georgia.gov/portal/site/DHR

MapQuest

www.mapquest.com

Medicaid

www.cms.gov/Medicaid/GenInfo

Medicare

www.medicare.gov

PeachCare for Kids

www.peachcare.org

Glossary

Helpful definitions

Absorption The degree and speed at which a drug enters the bloodstream.

Alkaline phosphatase An enzyme produced by liver and other cells. High blood levels of this substance may show problems with the liver or other organs.

Allograft (allogenic graft or homograft) A graft or transplant between two people.

Antibiotics A medicine used to fight infections.

Antibody A protein made by the body to fight foreign matter, such as germs.

Antigen A type of foreign matter in the body, such as a transplant, that triggers a reaction by the immune system. This action leads to the production of antibodies.

Antibodies then try to destroy the antigen (transplanted organ).

Anesthetic (anesthesia) Medicine that reduces pain in a specific area, such as Novocaine for pulling teeth, is called a local anesthetic. General anesthetics are used to put people into a deep sleep during surgery.

Arteriogram An X-ray of the arteries. A dye is used to help the arteries show up on the X-ray.

Ascites Excess fluid in the stomach area.

Atherosclerosis A buildup of fats in the lining of the arteries that can interfere with the flow of blood.

Autoantibody (ies) A type of antibody that reacts against a person's own organs.

B Cell A type of white blood cell that helps the immune system with antibody production.

Bacteria Germs that can cause disease.

Bile A fluid made by the liver and stored in the gallbladder. It is released to help digest and absorb fats.

Bile ducts The tubes that carry the bile.

Bile leak A hole in the bile-duct system that causes bile to spill into the stomach cavity.

Biliary stenosis Narrowing of a bile duct.

Biliary tract A pathway for bile to flow from the liver, through the bile duct and into the small intestine.

Biliary tree All of the passageways inside and outside the liver that carry bile to the intestines.

Bilirubin An orange-colored substance in bile made by the breakdown of red blood cells. Bilirubin levels are often high with liver disease.

Bioavailability A measure of how much of a drug dose is absorbed into the bloodstream. This helps doctors know how much of the drug gets to the part of the body it is intended for.

Biopsy A piece of tissue removed from the body and tested for changes or disease.

Blood urea nitrogen (BUN) A substance in the body made by the breakdown of protein.

Chronic liver disease A disease of the liver that occurs over a long period of time.

Cirrhosis A disease that causes irreversible scarring of the liver.

CMV (cytomegalo virus) A common viral infection that can affect the lungs and other organs.

Coagulation Blood clotting.

Coagulopathy A problem in the body with blood clotting.

Deceased liver transplant The transplant of a healthy liver from a person who has just died.

Deceased donor A person who has just died. The cause of death does not affect the function of the organ to be transplanted.

Diabetes A disease marked by high levels of sugar in the blood. Too little insulin, resistance to insulin, or both, can cause it.

Diuretic A drug that helps the kidneys make and excrete more urine.

Edema Excess fluid in body tissues.

Electrolytes Minerals in your blood and other body fluids, such as sodium, potassium and chlorine.

Endoscopy A test to look at the inside of organs and cavities of the body. It uses an endoscope, which has a lighted mirror and camera on the end of it, so a doctor can see and take pictures of the area.

Enzyme A protein made in the body that can change a substance from one form to another.

Gall bladder A sac attached to the liver that stores bile.

Gastroenterologist A doctor who takes care of people with problems in the digestive (GI) tract.

Gingival hypertrophy Enlargement of the gums. It is a common side effect of cyclosporine therapy.

Glucose A type of sugar found in the blood.

Graft An organ or tissue that is transplanted.

Graft survival When a transplanted tissue or organ is accepted by the body and functions properly.

Hemochromatosis A rare disease of iron metabolism. It causes excess iron deposits in the body.

Hemolytic anemia A type of anemia that causes premature destruction of the red blood cells.

Hepatectomy(ies) Removal of part of the liver.

Hepatic Relating to the liver.

Hepatic encephalopathy A brain disorder caused by liver disease. The condition can cause lethargy, stupor and coma.

Hepatomegaly An enlarged liver.

Herpes A family of viruses that infect humans. Some types of herpes can cause chickenpox, shingles and cold sores.

HLA system Antigens that are present on human white blood cells (leukocytes) and tissues.

Hypertension High blood pressure.

Immune response Reaction of the immune system to a foreign material.

Immune system The system that protects the body from harmful substances, such as germs and cancer cells.

Immunity Being able to resist a disease or harmful substance.

Immunosuppressive agents Medicines given to prevent rejection of a transplanted organ.

I.V. or intravenous In the vein. It is a way to give medicines or fluids directly into a vein.

I.V. catheter A small needle with a hollow tube put into a vein. It is used to give medicines or fluids.

Jaundice Yellowing of the skin and eyes caused by excess bilirubin in the blood.

Kidney One of the two bean-shaped organs on both sides of the spine, just above the waist. They rid the body of waste and maintain fluid balance by producing urine.

LifeLink Foundation A nonprofit organization that recovers organs and tissues for transplants.

Liver A large, dark-red gland in the upper part of the abdomen on the right side, just beneath the diaphragm. It stores and filters blood, secretes bile, converts sugars into glycogen and many other metabolic activities.

Liver enzymes Chemicals made by the liver and released into the blood. They are measured to check liver function.

Living donor transplant When the diseased liver is removed from a patient and replaced with part of a living donor's healthy liver.

Living donor A person who donates a portion of their liver.

Malignant tumor A tumor made up of cancerous cells that have the ability to spread, invade and destroy tissue.

Match The compatibility between the person who receives an organ and the donor. In general, the better the match, the greater the chance for success with a transplant.

Native liver The original liver of a patient.

Neonatal hemochromatosis A rare disease of iron metabolism in newborns. It causes excess iron deposits in the body.

Neutrophil A type of white blood cell.

Noncompliance Failure to follow the instructions of one's healthcare providers, such as not taking medicine as prescribed or not showing up for clinic visits.

Orally By mouth.

Organ procurement organization (OPO) An OPO serves as the organ link between the donor and recipient. It retrieves, preserves and transports the organ for transplant. They are part of UNOS.

Percutaneous Transhepatic Cholangiogram (PTC) a closer look at the bile ducts

Perforated bowel Holes or cuts in the bowel (colon).

Platelet A blood cell needed for normal blood clotting.

Portal hypertension An increased pressure in portal circulation (veins carrying blood from the digestive organs and spleen to the liver.) It is often seen with cirrhosis.

Potassium A mineral needed for body function.

Prednisone A steroid medicine taken by most transplant recipients to help prevent rejection.

Prophylactic medicine A medicine that helps prevent disease.

Rejection An immune response against grafted tissue, such as a transplanted organ. If it is not successfully treated, the transplant can fail.

Renal Refers to the kidney.

Re-transplantation A second transplant. Due to organ rejection or transplant failure, some patients need another transplant. If this happens, they return to the waiting list for another organ.

Sclerosis A hardening of tissues that result from several causes, such as inflammation or disease.

Sensitized Being immunized, or able to have an immune response against an antigen. It often occurs from previous exposure to that antigen.

Sodium A mineral needed for body function. It is the main salt in blood and is also a part of table salt (sodium chloride).

Status The degree of medical urgency for patients waiting for a liver transplant.

Stricture or stenosis A narrowing of a passage in the body.

Survival rates Survival rates tell us how many patients or transplanted organs are alive or functioning after transplant. Survival rates are often given at one, three and five years.

T cells A type of white blood cell that is part of the immune system. T cells help the body fight disease and germs. They can also react against cells in a transplanted organ.

Tissue typing A blood test to check for human leukocyte antigens (HLA) It is also called genetic matching. Tissue typing is done for all donors and recipients before a transplant.

T-tube A tube placed in the bile duct that allows bile to drain into a bag outside the body. This helps the body to heal after surgery.

United Network for Organ Sharing (UNOS) An organization that helps advance organ availability and transplantation by uniting and supporting its communities. It helps patients through education, technology and policy development.

Varices (varix) Enlarged, dilated veins.

Viral hepatitis Inflammation (irritation and swelling) of the liver caused by a virus.

Virus A very small type of germ that causes infection.

Waiting list After evaluation, patients are added to the national waiting list by the transplant center. Lists are made based on area of the country and organ type. Each time a donor organ becomes available, the UNOS computer makes a list of potential recipients based on factors such as tissue typing, organ size and medical urgency. Through this process, a new list is made each time an organ becomes available.

White blood cells Cells in the blood that fight infection. They are part of the immune system.

Helpful abbreviations

BID	Twice daily
CC	Same as mL (1cc = 1mL)
GTT	Drop
MG	Milligrams (dosage amount)
ML	Milliliters (fluid amount)
NPO	Nothing by mouth
PO	By mouth
PRN	As needed
QDAY	Every day
QD	Every day
QID	Four times a day
QOD	Every other day
TID	Three times a day

My child's medical records

The liver transplant team at Children's would like to encourage you to keep a record of your child's lab results, imaging and surgical procedures with you at all times. This can be a quick reference for you or your child's caregiver in case of an emergency.

We encourage you to place your child's records in this notebook for easy access and quick reference.

You can obtain your child's records through Children's online service called MYchart. MYchart is a web-based tool that provides patient families with the ability to access their health information in the computer charting system used at Children's. MYchart also allows families to communicate with their ambulatory care teams from the convenience of an online portal or mobile device.

You can enroll in MYchart by visiting choa.org/MYchart and creating a profile for your child.

If you need assistance with enrolling in MYchart or in printing medical records, please contact your liver transplant coordinator at 404-785-1807.

My child's immunization record

It is important to keep a record of your child's most updated immunization record. You can get a copy of this from your child's primary physician or by requesting a copy at your child's clinic visit with the liver transplant team.

We encourage you to place your child's immunization records in this notebook for easy access and quick reference.

My child's current medication list

It is important to always keep a copy of your child's current medication list with the correct medication name, dosing and timing instructions.

There are many helpful websites designed to create a medication list. One example is www.mymedschedule.com.

Your liver transplant coordinator can also help you print a current medication list for your child.

We encourage you to place your child's current medication list in this notebook for easy access and quick reference.

Liver Transplant Evaluation