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Welcome

Welcome to the Children's Healthcare of Atlanta Center for Transplantation. We offer pre and post-transplant services for children that get a liver, heart or kidney transplant. Our focus is on the children we care for and their families. We want to create a friendly, family-centered experience for you and your child.

In addition to our clinical areas, our unit includes a:

- Playroom for patients.
- A kitchen with a stove and refrigerator.
- Laundry room with washer and dryer.
- Consult room to meet with medical teams.

The hospital family services include a:

- Family amenities area with sleep rooms, lounge areas and tables to work.
- Family library.
- Parent business center.
- Coffee shop.
- Gift shop.

The inpatient transplant unit is on the 12th floor of the West tower at Arthur M. Blank Hospital. The outpatient Transplant Clinic at Arthur M. Blank Hospital is in the South tower on the 5th floor.

Our promise to you

The Children's liver transplant team wants to provide you and your child with high quality, family-centered care. Our team can help support you during your child's treatment. Our goal is to have a nurturing and caring environment during each admission and visit.

Please call us if you have any questions or concerns about your admission or visit. We look forward to caring for you and your child.

About the handbook

This handbook helps you learn more about liver transplants. It also includes information about resources. Visit choa.org/transplant or call the Transplant Information Line at 800-605-6175 for more information about the Children's Liver Transplant Program.

This handbook should not replace instructions given to you by your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child's doctor is the best source of information about what is best for your child's treatment and care.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

Important contacts and phone numbers

Liver transplant team (Monday through Friday from 8 a.m. to 4 p.m.)	404-785-1807*
Nights, weekends and holidays (ask to page the liver transplant fellow	404-785-5437
Billing and finance	404-785-6478
Liver transplant social worker	404-785-1132
Clinic visits	404-785-1807
Family library	404-785-1611
Liver transplant team email	livertransplantemails@choa.org
MyChart	mychart.choa.org

PLEASE NOTE:

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

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

- Skin that itches more than normal.
- Skin or eyes are more yellow.
- A belly that is bigger than normal for them.
- Any blood in their vomit or stool, nosebleeds or other bleeding.
- More fatigue (tiredness) or acting confused.
- Weight loss or weight gain (1 to 2 pounds in 2 days).
- A fever of 101.5°F (38.5°C) or higher.
- Problems taking medicine.
- Problems getting medicine from your pharmacy.

Call 911 <u>right away</u> for any emergency that may be life threatening.

General information sheet

Child's name ____

Medical condition ____

Your child's transplant team

Please write down the name and phone number of each person you meet. Ask them how to spell their names and what they do.

- **Transplant surgeon:** The doctor that does the transplant surgery.
- **Liver doctor (hepatologist):** A doctor that takes care of patients with liver disease before and after a transplant. They work with the transplant surgeon to care for your child's digestive system (stomach, liver and intestines).
- **Fellow:** A doctor that is doing extra training in liver transplants, hepatology or gastrointestinal (GI). Fellows have already finished medical school and residency.
- **Anesthesiologist:** A doctor that monitors your child during surgery. They will give your child special medicine (anesthesia) that puts them in a deep sleep so they cannot see, hear or feel anything.
- **Physician assistant (PA) and nurse practitioner (NP):** Clinical staff that assist your child's doctor. They are supervised by doctors and help take care of your child before, during and after a transplant.
- **Transplant coordinator:** A nurse that helps you and your family plan your child's care and treatment before and after the transplant.
- **Intensive care unit (ICU) and patient floor nurses:** Nurses who care for your child while they are in the ICU and on the patient floor.
- **Respiratory therapists:** Clinical staff that check and treat any breathing issues. They can give breathing treatments, give oxygen and watch how your child breathes.

- **Registered dietitians (nutritionists):** Clinical staff that help check your child’s diet, food and nutrition needs.

- **Transplant pharmacist:** A pharmacist who has special training with transplant medicines. They check your child's medicines, teach you what you need to know about them and help with research studies.

- **Psychologist:** Clinical staff that 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 that teaches you, your child and your family about the hospital and procedures. They can help answer you and your child’s questions and provide medical play.

  Social workers: Clinical staff that help provide guidance, counseling and coping skills for you and your family. They help you get the services and resources you and your child need while in and out of the hospital.

- **Physical therapists:** Clinical staff that help your child with movement and exercises to make them stronger before and after transplant. Physical therapists can also teach you what you can do at home to help your child regain strength.

- **Chaplains:** Hospital staff that help meet your family's spiritual needs. A chaplain can work with your pastor or religious leader to provide spiritual support. Hospital chaplains also lead interfaith services in the hospital chapel.

- **School program teachers:** Certified teachers in the hospital that help your child keep up with their schoolwork so the transition between hospital, home and school will be easier. There is a school room at the hospital.

- **Transplant financial counselor:** Financial counselors help you learn about your insurance plan and how to reduce your expenses for your child's care. A financial counselor can help your family set up a long-term payment plan if needed.

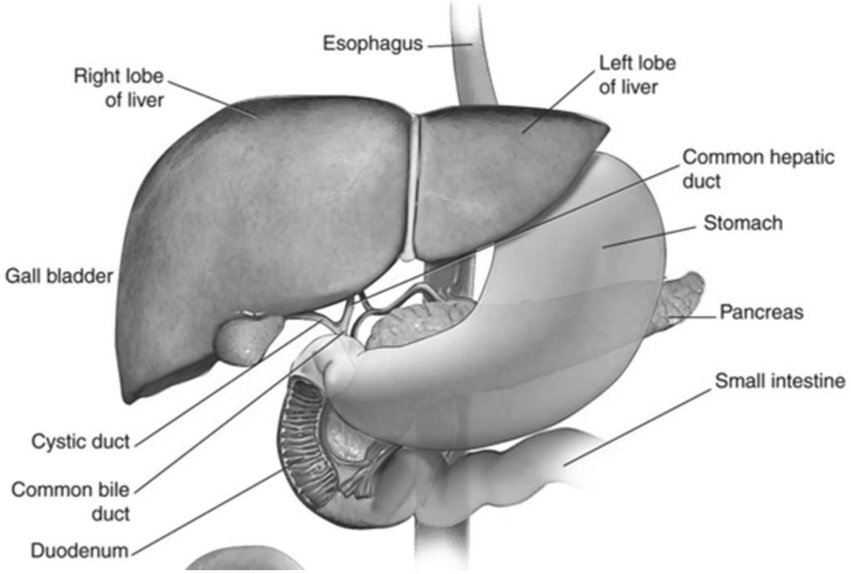
Why Your Child May Need a Transplant

What is the liver?

The liver is:

- The largest solid organ in the body.
- Divided into right and left sections called lobes.
- Found on the right side of the body. It is below the lungs and behind the lower ribs. It is 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 complex organ that has many jobs. It keeps our body healthy. You cannot live without a working liver. Some of the things the liver does are listed in the chart below.

What does the liver do?	
Helps the body digest, absorb and store food and nutrients	• The liver makes a liquid called bile. • Bile helps to digest food and absorb nutrients (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. • It cleans harmful chemicals from the blood.
Makes albumin	• Albumin is a blood protein. • It helps to carry some medicines and other things through the blood. • Your body needs it for tissue growth and healing. • When albumin levels drop, fluid may collect in the ankles, lungs or abdomen (belly).
Helps with clotting	• The liver makes proteins that help the blood clot. • Clotting happens when blood changes from a liquid into a solid (such as when a scab forms over a cut or wound).

What happens when the liver does not work?

It is called liver failure when the liver does not work. These things can happen:

- Your child may not grow and develop like normal.
- The liver does not absorb or store enough nutrients and vitamins from food.
- Blood does not clot as fast as it should. This can cause your child to bruise easily or bleed longer.
- Your child's eyes or skin may look yellow. This happens if their liver cannot filter out harmful waste. The yellow coloring is called jaundice.
- Your child's stomach may get larger because of extra fluid in their abdomen (the area between the chest and hips). This is called ascites.
- Fluid may collect in your child's feet and legs. This is called edema.
- Your child's skin may itch.

- Your child may be weak or tired.
- Your child may have a decreased appetite, upset stomach or lose weight.
- Your child may develop cirrhosis. This is from chronic liver disease. It can cause scars in the liver and liver failure.

Causes of liver failure

Medical name	**What this means**	**How this hurts the liver**
Alpha-1 antitrypsin deficiency (A1AD)	• This is a disease passed from parent to child. • It is caused by low levels of a protein called alpha-1 antitrypsin (A1AT). • A1AT is found in the blood.	• When the body has low A1AT, substances that break down protein attack other tissue in the body. • This causes liver damage.
Autoimmune hepatitis	• This happens when there is a problem with the immune system. • Immune cells attack healthy liver cells.	• Liver cells are damaged by the body's immune system.
Biliary atresia	• Tubes (bile ducts) that carry bile from the liver are not normal when a baby is born.	• Bile carries waste away from the liver and breaks down fats we eat. • Bile is not able to leave the liver. This causes liver damage.
Intrahepatic cholestasis	• Bile ducts in the liver are blocked. • This causes a build-up of bile in the liver.	• Bile is not able to leave the liver. This causes liver damage.
Cystic fibrosis (CF)	• CF is a disease that affects the lungs and digestive systems. • It causes the body to make too much thick mucus.	• Too much mucus causes the bile ducts to get blocked and swollen. • This causes liver damage.

Medical name	What this means	How this hurts the liver
Acute liver failure	• The liver stops working because of severe damage to liver cells. • We may not know what causes this.	• Acute liver failure causes the liver to not work well. • Symptoms include: - Jaundice - Poor blood clotting (as measured by blood tests) - Sleepiness or confusion
Gestational alloimmune liver disease	• Iron builds up in the liver before birth.	• The liver is damaged before the baby is born. • This can lead to end stage liver disease at birth.
Hemochromatosis	• The body cannot break down iron. • Iron builds up in the liver.	• Small amounts of iron are kept in the liver, kidneys and heart. • Too much iron can damage the organs.
Hepatitis A (viral hepatitis)	• A virus that is found in contaminated food or water.	• The liver becomes inflamed. • This causes short-term mild to severe symptoms.
Hepatitis B (viral hepatitis)	• A virus that is found in infected blood or body fluids.	• The liver becomes inflamed. • This causes severe or long-term symptoms.
Hepatitis C (viral hepatitis)	• A virus that is found in infected blood or body fluids.	• The liver becomes inflamed. • This causes severe or long-term symptoms.
Liver cancer	• When cells in the body start to grow out of control. • Normal cells grow, divide and die. Cancer cells grow and form new abnormal cells.	• The liver is made of different types of cells. Different types of tumors can form in the liver. • Some of these are cancers (malignant) and some are not cancer (benign).

Medical name	**What this means**	**How this hurts the liver**
Tyrosinemia	• The enzyme that breaks down amino acids is missing from the body. • An enzyme is a protein that helps the body break down important nutrients.	• A build-up of toxic chemicals can happen. • This leads to liver disease.
Wilson disease	• This is a rare illness passed from parent to child. • It causes extra copper in the body and causes some organs to not work well.	• Extra copper in the liver causes tissue damage, scarring and liver failure.

Please ask your child's nurse or doctor to write down the name of their liver problem here:

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Notes

Liver Transplant Evaluation and Surgery

Steps for a liver transplant

The liver transplant team talks with you and your child about each step of the process.

Step 1

Your child's doctor refers your child to Children's. Your child's doctor must:

- Include the medical need for a transplant.
- Send medical records.

Step 2

A Children's financial counselor works with you to get approval for your child's pre-transplant evaluation from your insurance company.

- A pre-transplant evaluation includes tests. These tests help the liver transplant team decide if a transplant is the best option for your child.
- The liver transplant team helps you through this process. Our financial counselor works with you to set up a payment plan if your child does not have insurance.

Step 3

The liver transplant team calls you to schedule your child's pre-transplant evaluation with the transplant coordinator.

Step 4

Your child has a pre-transplant evaluation at Children's. This is a 1 or 2 day outpatient visit. This may be an inpatient admission if needed.

Step 5

The liver transplant surgeon and team will decide if a transplant is the best option for your child after the evaluation.

- Your child is placed on the UNOS list if:
  - Their pre-transplant evaluation proves the need for a transplant.
  - Your insurance company approves a transplant.

- The liver transplant team will decide if there are living donors who might be a good match for your child.
- If your child knows a person wants to be a living donor, the donor should call the liver transplant coordinator. The liver transplant team will not reach out to a potential donor first. The potential donor needs to contact the liver transplant team first.

Step 6

Your child waits to be matched with a liver from the UNOS list if there is no living donor.

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 Children's.

Step 8

Your child has their transplant surgery. Your child will stay in the hospital for about 2 weeks after their transplant. Each child's transplant recovery is different. Their time in the hospital is based on their age and health needs.

Step 9

Your child will have follow-up care at Children's. This is based on your child's needs. Please read about clinic visits in the After the Transplant section of this handbook.

Pre-transplant evaluation

The pre-transplant evaluation (eval) is a group of tests that helps decide if a liver transplant is the best option for your child.

- The liver transplant coordinator will schedule the evaluation. It most often happens as a Children's outpatient visit. It can take up to 2 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 through the whole process.
- Plan to stay for the whole day (or days) of evaluation.
- Ask the coordinator or social worker if you need help with lodging. We can help reserve a room at a hotel or Ronald McDonald House.

How do we prepare for the eval?

To make sure that the eval goes smooth:

- Make sure your insurance company approved the evaluation. Bring a copy of your insurance benefits and insurance ID card with your deductible and co-payment. See the financial resources sections for questions.
- Please arrive on time. Give yourself time to park and walk to the clinic. We may need to reschedule your visit if you are late.
- Please leave young siblings at home. Your focus should be learning about the transplant. We do want your family to be part of follow-up clinic visits.
- Call your pediatrician to make sure your child's immunization (shot) records are up to date. Please bring your child's records to the evaluation.
- Write a list of questions to ask the team. Share your concerns and fears with them.

What happens during the eval?

Transplant evaluation takes 2 full days in the outpatient center. Your child meets with different transplant team members. Your child may need 1 or more of these:

- Physical exam
- Blood tests
- Radiology tests
- Other imaging tests
- Breathing and heart function tests
- Liver biopsy

Please bring these things with you to the evaluation visit:

- A copy of your child's medical records.
- A copy of your child's immunization records.

Physical exam

A member of your child's care team will do a physical exam. This may include:

- Your child's height and weight.
- Family history of long-term diseases.
- Your child's health history (this includes any past surgeries).

Blood tests

Your child may have one or more of these blood tests:

- Blood type. This test checks your child's blood to see if it is type A, B, AB or O.

- Blood chemistry. This includes sodium and potassium.
- Blood counts. This includes red and white blood cell counts.
- Liver enzymes. Liver enzymes are proteins that help the body.
- Check for viruses. This includes EBV and CMV. Read the After the Transplant: Viral infections section of this book for more information.

Radiology tests

Your child may have one or more of these tests:

- Chest X-ray. This test checks your child's lungs and heart size.
- 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 test checks the size and shape of your child's liver and major blood vessels.
- MRI (magnetic resonance imaging). Your child may have this test instead of a CT scan or ultrasound. This test checks the liver and major blood vessels.

Other imaging tests

Your child may have 1 or more of these tests:

- Total body bone scan. Your child may need this test if they have a liver tumor.
- Upper GI series. GI stands for gastrointestinal. This test checks your child's esophagus (the tube between the mouth and stomach) and stomach.
- Lower GI series. This test checks your child's intestines, the tubes that absorb nutrients from the food we eat.
- Angiogram. This test checks the size of the blood vessels outside of the liver or if there are any blockages.
  - A special dye is injected into an artery so the blood vessels who up on X-ray.
- Cholangiogram (co-lan-gee-o-gram). Your child may need this test to check for any blockages or growths in their bile ducts.

Breathing and heart function tests

Your child may have 1 or more of these:

- Pulmonary function test (PFT). This test checks your child's lungs.
- Electrocardiogram (EKG). This test checks your child's heart rhythm.
- Echocardiogram (echo). This test checks your child's heart muscles.

Liver biopsy

Your child may need surgery for a liver biopsy.

- This test checks the liver tissue.

- A needle is put between 2 of the right lower ribs to take a sample of the liver.
- The tissue sample goes to a lab for testing.
- Your child is put to sleep with sedation medicine for this procedure.

Other

Your child may meet with other members of the liver transplant team. This is based on your child's needs. Your child may:

- Meet other specialists who will help coordinate care. This may include a cardiologist (heart doctor).
- Have a psychosocial eval. This helps teach you about the emotional parts of a liver transplant. Your family may speak with a:
  - Social worker
  - Child life specialist
  - Psychologist
- Meet with a dietitian (nutritionist). The dietitian will help you choose the best foods for your child to eat.

What happens next?

Your child's care team decides if your child should be added to the transplant waiting list. We will contact you through this process so that you know what to expect.

Write down questions you have for the liver transplant team and bring them with you:

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Blood tests

Below is a list of the most common blood tests (labs) that your child may need.

- Liver tests include the ALT, AST, GGT, albumin and bilirubin.
- Your child's care team will use the results to check how well your child's liver works.
- Your child's care team will check these blood tests:
  - At your child's pre-transplant evaluation.
  - During the transplant.
  - After the transplant.
- Call 404-785-1807 if you have any questions about your child's lab results.

Test name	**Description**
Albumin	• Albumin is a protein in the blood. • It is made by the liver.
Ammonia	• Ammonia is made when proteins break down. • A healthy liver removes ammonia from the blood and turns the ammonia into waste (urea). • Urea leaves the body through the urine.
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 damaged, it puts AST in the bloodstream.
Aminotransferase (ALT)	• ALT is an enzyme found in the liver. • When the liver is damaged, it puts ALT in the bloodstream.
Bilirubin	• Bilirubin is made when red blood cells die. • The liver takes the waste to remove it from the body. • It is removed from the body as bile.
Glutamyltransferase (GGT)	• GGT is an enzyme in the bile ducts of the liver.
Hemoglobin	• Hemoglobin is part of the red blood cell. • It carries oxygen to the body. • Hemoglobin is low when iron in the blood is low. • Low red blood cells is called anemia.

Test name	**Description**
Hematocrit	- Hematocrit measures the number of red blood cells in the blood. - A low hematocrit level can show anemia or blood loss.
Prothrombin time (PT)	- PT measures how long it takes your child's blood to clot. - The liver makes proteins (factors) that help blood to clot. - Blood takes longer to clot when the liver does not work well.
International ratio (INR)	- INR is the difference between the PT and the number the lab team uses to check the machine.

Learning about liver transplant

A liver transplant gives your child a healthy liver from a donor. The donor is the person who gives your child a liver.

The 2 most common types of liver transplants:

- Deceased donor (also known as cadaveric donor).
- Living donor.

Deceased donor

A deceased donor transplant gives your child 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 could be across the country.
  - You may visit unos.org to learn more about UNOS.

Living donor

A living donor is a person who gives your child part of their 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 surgeons remove part of a donor's liver, the liver grows back.
  - Even when more than half of the liver is removed, the donor can recover well.
- Your child is placed on the UNOS list even if there is a potential living donor. This increases your child's chances of getting a liver as soon as possible.

Other types of liver transplants

- **Reduced graft.** This is when a donor's liver is "cut down" to a smaller size and then given to your child.
- **Split liver transplant.** This is when a deceased donor liver is cut into 2 parts. The larger part is given to an adult or larger child. The smaller part is given to a small child or infant.
- These are both deceased donor transplants.

Deceased donor transplant

What are the steps for a deceased donor transplant?

There are many 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 get a liver from someone who recently died.
    - Right after your child is added to the list, you will get a:
        - Phone call from your liver transplant coordinator.
        - Letter in the mail.
    - Your child's name is placed on the UNOS list before a living donor has their eval.
2. Your child may get a deceased donor liver before a living donor is found.
    - UNOS works with an agency to get organs from deceased donors.
    - They keep a national list of people waiting for transplants.
    - Your child will stay on the list until they get a liver.
3. UNOS gives your child a score based on their age, weight and lab results. The scores are called:
    - Pediatric End Stage Liver Disease (PELD).
    - Model for End Stage Liver Disease (MELD).
4. Your child is matched with a liver based on their score and blood type.
    - Talk with a member of your child's care team about the average wait time.
    - You may visit srtr.org for more details.

How does the UNOS matching process work?

1. A liver is donated from a person who has recently died.
2. The donor's medical information is put into the UNOS database.
3. Your child will show as a match to the donor's information.
4. UNOS notifies Children's that a liver is available.
5. The transplant surgeon and team review the information to decide if it is a good fit for your child. The team accepts or declines the liver.

6. The Emory Call Center calls you when a liver is available. This phone call may come from a number you do not recognize or a blocked number.
7. 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 matched to the child with the highest PELD or MELD score and with the same blood type and size.

Other matching factors include:

- Your child’s current medical status.
- The location of the liver and your child.
- How long your child has been on the waiting list.
- Your child’s blood type. Your child can get a liver from a person with the same or with a compatible blood type. The 4 blood types are O, A, B and AB.
  - Liver transplants are most often done with the same blood type.
  - If your child has an urgent need, their liver transplant may be done with a different blood type.

Blood type compatibility

If your child’s blood type is:	**The donor’s blood type can be:**
O	O
A	A or O
B	B or O
AB	AB, A, B or O

About the deceased donor

Families often want to know the age of the donor and how the donor died. Details about the donor cannot be shared. Likewise, details about you and your family are not shared with the donor’s family.

- You may write a letter to the donor’s family.
- The liver transplant coordinator will send a letter to the donor agency. The agency will send it to the donor’s family.
- If you have any questions about how to write this letter, your transplant coordinators will be happy to help you.

Living donor transplant

A living donor transplant means doctors take a lobe or part of the liver from a living person to replace your child's unhealthy liver. The liver transplant doctor will decide which lobe your child will need.

How does a living donor liver transplant work?

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

- The left lobe makes up about 40% (a little less than half) of the liver.
- The right lobe makes up about 60% (a little more than half) of the liver.
- The surgeon decides how much liver tissue to remove from the donor during surgery.

Who can be a living donor?

A living donor can be a parent, family member or friend.

- A donor must meet health standards and have a donor eval.
- The donor's liver transplant team will decide if the donor is a good match for your child.

A living donor must be:

- Older than 18 years of age.
- In good health. Some health 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 that can be passed from one person to another). This includes HIV, hepatitis or tuberculosis (TB)
  - Obesity (very overweight)
- Willing to donate part of their liver. The decision to donate must be made freely and without pressure from anyone.
- Admitted to Emory University Hospital for the eval and surgery.
- Able to take time away from work or school. Stay in the hospital for an average of 7 to 10 days. The donor may not be able to work for up to 2 months.

What are the steps to be a living donor?

A living donor must have a series of tests to make sure they are the best match for your child.

1. A person who wants to be a donor for your child's transplant should tell your child's liver transplant team.
2. The financial counselor asks your insurance company to approve the donor evaluation.
    - Your child's insurance may pay for the donor's tests.
    - If you do not have insurance, talk with your financial counselor to set up a payment plan. See the section called Resources: Financial resources.
3. Your insurance company approves the donor eval. The Emory liver transplant coordinator and living donor advocate set up the donor eval at Emory University Hospital.
4. The eval happens if the donor's blood type is a good match with your child's.
5. The donor has a 2-day outpatient evaluation at Emory University Hospital. The donor's test results may take 6 weeks.
6. The transplant team reviews the donor test results and decides if the donor is a good match. If the donor is not a good match, the process will start over with the insurance company (Step 2).

What if I want to become a living donor?

A person must clearly state their interest to be a living donor.

- Before a donor evaluation is scheduled your child must be placed on the UNOS list.
- Set up a visit with the transplant surgeon. Schedule a donor evaluation. This can be done as an outpatient.
- Your insurance company must approve a donor eval. You may need to pay for the eval if the insurance company does not pre-approve these tests.
- Only 1 person at a time can do a donor eval. If that person is not accepted, the process will start over with the insurance company.
- Exercise often. Activities such as walking, swimming or biking are strongly advised for donors. This helps the donor recover better after surgery.
- Follow a healthy diet.
- Stop drinking alcohol or smoking. This helps your liver work better.
- You may need to stop some medicines (this includes herbs, vitamins and supplements). Talk with your doctor and the liver transplant team before you stop any medicine.

The living donor evaluation

The living donor eval may include these tests:

- Screening tests before the evaluation.
    - Female donors must have a pap smear and mammogram.

  - Men donors must have a prostate specific antigen (PSA test).
  - These tests are not included in the regular evaluation.
- A routine physical exam. This includes the donor's:
  - Height and weight
  - Blood pressure
  - Family history of heart, kidney or other chronic diseases
  - History of obesity or smoking
  - Alcohol or drug use
  - Surgery history
- Lab tests. The transplant surgeon decides which lab tests the donor needs. These may include:
  - Complete blood count (CBC)
  - Drug tests
  - Tests for hepatitis and HIV
  - Pregnancy tests
- Tests to check the donor's heart and lungs. These may include:
  - Chest X-ray
  - Electrocardiogram (EKG)
- Liver biopsy. This test checks the health of the liver.
  - A needle is placed between 2 of the right lower ribs to take a sample of liver tissue.
  - The tissue sample goes to a lab for testing.
- CT scan. This test checks the size and shape of the donor's liver and the amount of liver tissue in each lobe.
- Angiogram. This checks the size of the donor's blood vessels around 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 they understand the emotional parts of a living donation. The psychosocial exam makes sure that the donor wants to donate their liver without any outside pressures from family or friends.

A donor may need more tests if their medical history is complex. The next step is to schedule the donor surgery. The entire process from referring to surgery can take 6 months.

Questions to ask the transplant team

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

1. Why does my child need a transplant?

2. What are the risks of a transplant?

3. How long is the transplant process from beginning to end?

4. What are options for my child if they do not get a transplant?

5. Questions that have not been answered yet:

Preparing for your child's transplant

While you wait for a donor

Here are some steps you and your family can take while your child waits.

- Stay in touch and be ready at all times.
    - Make sure the liver transplant coordinator can reach you at all times. Make sure we have your current:
        - Phone numbers (this includes home, cell, school, work, family and vacation numbers).
        - Email addresses.
        - Any other contact information you have. This allows the transplant team to contact you quickly.
    - Tell us right away if your phone number, address or other information changes. A liver may go to another person waiting for a transplant if we cannot reach you quickly.
    - Call the liver transplant coordinator before you leave for vacation. Make sure your cell phone is working so we can contact you at all times.
    - Call or message the liver transplant financial counselor if your family has a change in work status or insurance coverage.
- Have a plan for transportation the hospital the day of the transplant.
    - The liver transplant coordinator will tell you when your child must arrive at Children's.
    - Make sure your car is working well and is ready for your trip at all times.
    - Have a plan for siblings to be taken care of during the transplant.
- Make sure your child is ready.
    - Call the liver transplant coordinator if your child has any illness or infection. This includes the common cold or sore throat.
    - Get treatment right away if your child gets sick. This helps to make sure that your child will be ready for transplant when a donor liver is ready.
    - Tell the liver transplant team about any changes in your child's health.
- Help your child get in good physical shape for the transplant.
    - Help your child to eat healthy foods (follow their diet guidelines).
    - Help your child to be as active as possible.
- Spend time with your child. Talk with your child about their transplant.
    - Let your child express their feelings, fears or concerns.
    - Let your child ask questions. Be truthful with your answers.
    - The liver transplant team will be happy to help you with any questions or concerns.
- Keep your child in school and involved in activities, if possible. Try to keep your child's routines normal and balanced.
    - Tell your child's school that your child has been placed on the transplant list.

  - Ask school to tell you right away if there is even 1 case of a contagious infection (such as chickenpox, shingles, measles or others). Call your liver transplant coordinator at 404-785-1807 if this happens.
  - Your child may need an Individualized Education Program (IEP). The IEP can help your child reach their education goals. It will be custom to your child's unique needs.

When the call comes

The Emory Call Center will call you when UNOS finds a donor liver. You may not recognize this phone number. When you get the call, you must bring your child to Children's right away in a safe manner.

- Your child should stop eating and drinking as soon as they get a call Their stomach should be empty when we start surgery.
- Please give your child all of their medicines as prescribed to prevent problems. It is OK for your child to swallow small sips of water with their medicine.

Bring these with you:

- Your child's favorite blanket or stuffed animal
- A list of your child's medicines
- A list of your child's allergies
- Your child's health information
- Your health insurance card

Transportation

You need to get to the hospital as fast and as safe as you can. If you live far from Atlanta, you and your family should be ready to fly here for the transplant if needed. If you plan to fly to Atlanta:

- Talk with your child's care team about your insurance company.
- They may pay for flights.

Transplant surgery

A deceased donor transplant

1. The Emory Call Center will call you at home when a donor liver is ready.
2. You will go to the main entrance of Arthur M. Blank Hospital. Then go to the registration desk on the 1st floor to check in.
3. Your child will be admitted to the hospital.
   - A staff member will show you to your child's room.
   - A member of your child's care team will prepare your child for surgery.

4. The liver transplant team will check your child. Your child may need 1 or more of these:
   - A complete health history and physical exam.
   - Blood tests.
   - A review of your child’s current medicines. Please bring a complete list of all of your child’s medicines.
   - A review of your child’s recent health. Please let your child’s care team know right away if your child has had any of these:
     - Sore throat
     - Cough or cold symptoms
     - Peritonitis (infection of the fluid in the abdomen)
     - Ear infection
     - Rashes
     - Cold sores
     - Contact with any person who has had an infection
   - A chest X-ray.
   - Urine tests.

Note: Your child’s surgery may be cancelled if your child is sick or if there is an emergency.

5. The anesthesiologist will come to your child’s room to go over your child’s allergies and anesthesia medicines.
   - An anesthesiologist is a doctor who gives anesthesia medicine and watches your child closely during surgery.
   - Anesthesia is medicine that puts your child in a deep sleep. Your child will not see, hear or feel anything (not even pain).
6. The liver transplant surgeon will come and talk with you about your child’s surgery. The surgeon will explain the surgery and its possible risks. You need to sign consent for surgery after the doctor explains it.
7. The transplant surgery will take place.
   - The surgery may take 4 to 12 hours.
   - There is a room for you and your family to wait during surgery.
   - You will get updates about your child from 1 or more of these care team members:
     - Liver transplant coordinator
     - Operating room (OR) nurse
     - Child life specialist
   - The surgeon will talk with you after your child’s surgery.
   - Please tell your coordinator if you leave the hospital. Be sure to leave a number where you can be reached.
8. Your child will go to the Children’s pediatric intensive care unit (PICU) for close monitoring after surgery.
   - Visitors are limited.

  - 1 or 2 caregivers are allowed to stay.
9. Your child will go to the Children's transplant stepdown unit (TSU) when they are ready. Talk with your child's care team for more details.

A living donor transplant

The living donor's surgery

- The donor's surgery is scheduled at Emory University Hospital when the donor evaluation is done. Scheduling starts for your child's surgery at the same time.
- The Emory transplant coordinator will give the donor more details about:
  - Preregistration
  - When to stop eating and drinking the day before surgery
- The donor will be admitted to Emory University Hospital.
- The surgery may take 3 to 8 hours.
- The donor will recover at Emory University Hospital after surgery.

Your child's living donor transplant surgery

1. The transplant surgery is scheduled.
   - Your child may be admitted to Children's the afternoon before surgery.
   - The transplant surgery will be cancelled if your child is sick.
   - If there is an emergency, your child's surgery may be postponed. This includes if the donor is sick.
2. The anesthesiologist will come to your child's room to go over your child's allergies and anesthesia medicines.
   - An anesthesiologist is a doctor who gives anesthesia medicines and watches your child closely during surgery.
   - Anesthesia is medicine that puts your child in a deep sleep. Your child will not see, hear or feel anything (not even pain).
3. The liver transplant surgeon will talk with you about your child's surgery. The surgeon will explain the surgery and its possible risks. You need to sign consent for surgery after the doctor explains it.
4. The transplant surgery will take place.
   - The surgery may take 4 to 12 hours.
   - There is a room for you and your family to wait during surgery.
   - You will get updates about your child from 1 or more of these care team members:
     - ▪ Transplant coordinator
     - ▪ Operating room (OR) nurse
     - ▪ Child life specialist
   - The surgeon will talk with you after your child's surgery.

- Please tell your coordinator if you need to leave the hospital. Leave your phone number where you can be reached.

5. Your child will go to the Children's pediatric care unit (PICU) for close monitoring after surgery.
6. Your child will go to the Children's transplant stepdown unit (TSU) when they are ready. Talk with your child's care team for more details.

Notes

After the Transplant

In the hospital

PICU

After surgery, your child will go to the Pediatric Intensive Care Unit (PICU). Most children are there for about 2 to 3 days.

- There is a kitchenette, child life activity room, laundry and family lounge.
- Talk with a member of your child's care team for more details about amenities.

The liver transplant team and the PICU team will work together to take care of your child after surgery.

- Your child could be sleepy from the anesthesia for several days after surgery.
- Your child can hear you and knows you are with them even when they are asleep.

TSU (transplant stepdown unit)

Your child will go to the TSU after the PICU.

- The nurses and staff will help your child recover and prepare all of you to go home.
- Most children go home about 10 to 14 days after surgery.
- Your child's care team will teach you how to care for your child at home.

Visitor guidelines

- Wash your hands each time you enter and leave your child's room.
- Your child should not have visitors who are sick. This includes fever, cough, sore throat, runny nose or vomiting and diarrhea.
- Visitors are limited in the PICU and TSU. Talk with your child's nurse about how many visitors can come at a time.
- Please be aware that there are visitor age restrictions.

Daily rounds

- Please be in your child's room for the care team's daily rounds.
- Each day your child's care team meets with you to talk about the plan of care for your child.
    - The doctors, nurses and liver transplant team will ask about your child's symptoms.
    - Your child's nurse will tell you when the team will round.

  - We value your input in decision-making. We will ask for your suggestions and if you have questions. Write them down before rounds so we can talk about them with you.
- The team will talk with you about your child's:
  - Current symptoms.
  - Blood tests and imaging results.
  - Fluid intake and output.
  - Response to treatment.
  - Plan of care.

Devices

Your child may be attached to monitors and pumps after their transplant. The nurses will remove them as your child recovers.

Your child may have 1 or more of these:

- An **NG tube** is a soft, thin tube that is placed into your child's nose and goes down to their stomach. It can be used to:
  - Remove extra fluid from their stomach.
  - Give your child nutrition.
- A **CVAD** (central venous access device) is a soft tube that is placed into a large vein that leads into the heart. It can be used to:
  - Give your child nutrition.
  - Give your child fluids and medicine.
  - Collect blood for lab work.
- A **Foley catheter** is a small flexible tube that is placed into your child's urethra (where urine comes out) and goes into the bladder. It drains and measures your child's urine.
- A **biliary tube** is a tube that is placed in the bile duct. Bile drains into a bag outside of your child's body.
- An **intubation tube** is a tube that is placed into your child's mouth and down into their airway. This tube helps your child breathe after surgery.
- **Oxygen** through a mask or nasal cannula (short tubes that go in your child's nose).
- **IV (intravenous) lines** are tubes placed into your child's veins. They are used to give fluids and medicines.

Taking care of yourself and your family

We know that you have a great need to be near your child during their hospital stay. We also know that it is easy to become tired from worry or lack of restful sleep.

- We encourage you to take regular breaks, eat well and get plenty of rest.
- You are better able to make care decisions for your child when you are rested.
- Please let us know if there is anything we can do to help you.

Going home

Taking your child home with a new liver can be very stressful. The liver transplant team helps you get ready.

- Your child's care team will give you information to help care for your child at home.
- Most often, you will meet with these team members for discharge teaching:
    - Liver transplant coordinator
    - Liver transplant APP (advanced practice provider)
    - Liver transplant pharmacist
- You may be able to stay overnight at the Ronald McDonald House if your family lives far from the hospital. Talk with a member of your child's care team for more details.

Complications

Some children have complications or problems after their liver transplant. The most common complications are **infection and rejection**. Talk with your child's transplant team about:

- Early signs of complications.
- Your child's care.
- If your child needs treatment.

Rejection

Rejection is a natural response of your child's immune system.

- The immune system is the body's defense against "unknown" things such as:
    - Viruses
    - Bacteria
    - Some types of cancers
- Your child's body treats a transplanted organ as an unknown thing. It tries to reject the new liver.

Immunosuppressants

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

- These medicines can lower the risk of severe rejection that damages the liver.
- They also decrease how well your child's immune system works. This increases your child's risk for infections.
- Give these medicines on time and as ordered by your child's doctor.

- Most children take these for the rest of their life.

Tacrolimus and Cellcept

Tacrolimus and Cellcept are immunosuppressants. Give these medicines on time every day as ordered by your child's doctor.

- Tacrolimus (Prograf) levels are drawn every time your child gets bloodwork.
- Blood levels should be drawn right before your child takes the medicine.
    - If your child takes tacrolimus at 9 a.m. and 9 p.m., the labs (bloodwork) should be drawn at 8:30 a.m.
    - This is called a 12-hour trough level.
- We can change your child's medicine schedule to fit your needs.
- Call the liver transplant coordinator right away if you have questions about your child's medicine.

Liver biopsy

Rejection can still happen even when your child takes their medicine the right way. The only way to detect rejection is with a lab test or biopsy. Many children need a liver biopsy at some point after having a liver transplant.

A liver biopsy is a test to check the liver tissue.

- Your child will get anesthesia. Your child will not feel the procedure.
- A needle is used to take a sample of the liver tissue.
- The sample is checked under a microscope to look for rejection.
- Your child may need to stay in the hospital for a few days.

Infection

Your child is more likely to get an infection when taking immunosuppressants. The risk of infection is greatest in the first 6 months after transplant. Some ways to help prevent infection include:

- Handwashing. Wash you and your child's hands often.
    - Teach your child to wash their hands BEFORE they:
        - Eat and drink.
        - Take medicine.
    - Teach your child to wash their hands AFTER they:
        - Go to the bathroom.
        - Take medicine.
        - Handle uncooked food.
        - Touch trash or anything that might have germs.
        - Blow their nose, cough or sneeze.

    - Wipe their nose.
    - Care for someone who is sick
    - Play with or touch pets.
    - Leave a public place.
- Avoid large crowds and other unknown children.
  - Avoid people who are sick. This includes colds, stomach viruses, measles, mumps, chickenpox and the flu.
  - Use common sense.
- Clean your child's cuts and scrapes with soap and water.
- Cover cuts with antibiotic ointment and a clean, dry dressing.

Infection warning signs

Call the liver transplant coordinator **right away** at 404-785-1807 if your child has any of these symptoms.

- Fever over 101.5° F
- Hands, fingers or toes are cold
- Sleepy and does not want to wake up (lethargy)
- Wound that:
  - Has redness.
  - Has swelling.
  - Feels warm or tender to touch.
  - Has yellow drainage.

If it is after hours, call 404-785-KIDS (5437).

Other infection warning signs to call about include:

- Cold or flu symptoms.
- Tiredness.
- Nausea, vomiting or diarrhea that lasts more than 24 hours.
- Abdominal pain 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 when urinating.
- Rash.
- Snoring or mouth breathing when sleeping.

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away. We can help transfer your child to Children's if needed after your child is stabilized in the nearest emergency department (ED).

Viral infections

Epstein-Barr virus (EBV) and cytomegalovirus (CMV) are common viral infections that affect many people. These viruses are in the community. They can be serious for your child because their immune system is weak.

- Your child may show no signs or symptoms if they get EBV or CMV.
- Your child may show signs of tiredness, muscle aches or fever. Young children may complain of stomach pain, cramping and diarrhea. Call the liver transplant team right away if your child shows any of these signs.
- Your child may need to come to the hospital. Talk with your child's care team about treatment. This may include antiviral medicine or changing immunosuppressant medicines.
- Tests for EBV and CMV are done often after transplant to check for these viruses.

Clinic visits

Follow-up clinic visits and lab tests are important for your child's care when they are well and sick. Infection and rejection can happen even when your child is well. There are not always signs or symptoms to show a problem.

Each child is different. Talk with your child's care team about your child's treatment plan and any problems that may arise. Blood work helps the team to know how well the liver is working and if any medicines need to be adjusted.

The liver transplant team will follow your child closely after their transplant. You will see your child's liver transplant doctor and team each week during the first few months. Your visits will be less frequent as your child recovers and their health improves.

- Your child will follow up in the clinic 1 time each week.
- Please call the clinic at 404-785-1807 to schedule your visits.
- Your child's care team will review your child's medicines at each visit.
  - Please bring your child's medicines with you to each visit.
  - Bring a dose of all medicines for your child to take after lab work is drawn.
- Your child may have a telemedicine visit.

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

- Time with each member of the care team.

- Vital signs (blood pressure, heart rate and breathing)
- A review of your child's energy level, appetite, weight and activity level.
- A physical exam.
- Lab work.
- A chance for you to ask questions.

Your child's care team is available at clinic visits and at other times. Call 404-785-1807 if you need to speak with the liver transplant team. Your child will continue to see a liver transplant team as they grow older.

Routine lab work (blood tests)

- Lab work is one way to make sure your child is on the right amount of medicine.
- Your child will need lab work often. The lab schedule will vary based on how your child is doing.
- Get your child's labs checked when your liver transplant team instructs.
- Call the transplant clinic if you forget to have lab tests done or need to have them done at a time other than scheduled.
- Most often, your child will have a CVAD right after transplant. We may use it to take blood for lab work.
- Always let our team know when labs will be drawn at a different location. This is so that we can request lab results.

Teen clinic

The teen years can be challenging after a transplant. The Children's Teen Liver Transplant Clinic helps make the transition to adulthood as smooth as possible. We give you and your teen:

- Guidance and support.
- Education.
- Resources.

Teens will learn:

- 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 teens between the ages of 14 and 21. Call 404-785-1807 for more details.

Notes

Caring for Your Child

Vital signs

Many children have high blood pressure after their transplant. Medicines may increase blood pressure. It is important for your child to take blood pressure medicines as ordered by their transplant team.

- You may need to check your child's vital signs at home. These include blood pressure, weight and temperature.
- Tell the liver transplant coordinator if you need a scale, thermometer or other supplies to help care for your child at home.
- Ask your child's coordinator when you should call about vital sign changes. Call 404-785-1807.

Immunizations (vaccines)

- Your child should get all their vaccines before their transplant surgery.
- Talk with your child's transplant team about the vaccines your child needs. Most often, your child should get these vaccines before transplant:
    - Diphtheria, pertussis and typhoid (DPT)
    - Polio
    - Measles, mumps and rubella (MMR)
    - Influenza type B (inactivated)
    - Haemophilus flu type B
    - Chickenpox
    - Hepatitis B
- Often after transplant, children cannot have live vaccines because their immune system will be weak. Live vaccines include:
    - Measles, mumps and rubella (MMR)
    - Smallpox
    - Rotavirus
    - Chickenpox
- Your child should only get inactivated immunizations unless the transplant team tells you otherwise.
- You, your child and family members older than 6 months old should get a flu shot each year.
- If your child is exposed to (around someone with) chickenpox or shingles, call the transplant doctor or coordinator right away.
    - Your child might need intravenous (I.V.) medicine.

  - Your child may need a special shot if they are exposed to chickenpox and have not had either chickenpox or the chickenpox vaccine. Your child will need a varicella zoster immunoglobulin (VZIG) shot within 72 hours of exposure.

Pediatrician

Schedule a visit with your child's pediatrician or family doctor after your child's transplant. This gives your child's doctor a chance to check your child and update the chart with your child's new medicines.

- Keep your child's vaccines up to date and give them a flu shot each year.
- Your child's pediatrician can treat your child for routine problems such as ear infections, colds or rashes.
- Your child's pediatrician will get a copy of your child's hospital notes. Please let the liver transplant team know any time your child starts a new medicine.
- Your child's pediatrician should call us with any questions or concerns.

Car seats

All states have laws that require babies and toddlers to be in a car safety seat. The right car seat is based on your child's age and weight. Your child should:

- Always wear a seatbelt.
- Ride in the back seat.

Medical alert identification

Your child can wear a medical identification (ID) bracelet or necklace. In case of a car accident or other emergency, health workers will know details about your child such as:

- Your child has had a liver transplant.
- Allergies.
- Emergency contact.
- Blood type.
- Other important details.

Nutrition

Eating healthy food helps your child's body grow and heal. Your child's 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 their appetite.

Your child's dietitian will:

- Check your child's nutrition needs.
- Teach your family about the right foods or formulas for your child.
- Check your child's diet and growth after transplant.

Most often, your child will need a special diet before their liver transplant. The amount of these things your child can have may change. Your child may need to limit:

- Sodium (salt).
- Potassium.
- Protein.
- Phosphorus.

It is important for your child to avoid these things after their transplant:

- Pomegranate and grapefruit juice. These can interact with your child's medicine (tacrolimus).
- Uncooked or raw foods such as clams, oysters or sushi.
- Snack foods such as chips, sodas and excess fruit juice. They are empty calories and do not provide good nutrition.

Your child should:

- Drink plenty of fluids for kidney health.
- Eat a balanced diet that includes fruits and vegetables.
- Follow a no added salt rule.

Other nutrition information:

- You should eat the healthy foods you are encouraging your child to eat.
- Your child's care team will check your child's weight at each clinic visit. This is to make sure your child is growing well. Our goal is for your child to reach the ideal body weight for their age and height.
- Your child may dislike foods they used to enjoy. Your child may start to like new foods. Be sure to support your child during this time of change.
- If your child is bottle-fed, give your baby formula or milk in their bottle. Do not give your baby soda or juice.

Tube feedings

Your child needs many calories to grow and heal. Some children cannot eat enough during the day and need tube feedings. Tube feedings:

- Give your child extra calories and nutrients they need to heal and recover.

- Are given through a thin, flexible tube that passes into the stomach.
- Can help with weight gain.
- Can be given at night when your child sleeps.

Many parents say that their child has more energy with tube feedings. Your child's care team may recommend tube feedings before or after your child's transplant. Talk with your child's nurse for more details.

Exercise

Your child's activity level will increase as they feel better. Your child should avoid contact sports until their doctor says it is OK. Talk with your child's care team for more details about your child's activities and energy level.

Sunscreen

Your child must use sunscreen because some of their medicines cause sunburns. Choose a sunscreen that is SPF 30 or higher. Use sunscreen even if your child will only be in the sun for a short time.

To help prevent sunburn, your child should:

- Wear clothes that protect their skin (such as a hat, long pants and long sleeves).
- Put sunscreen on exposed skin 30 minutes before going outside. Put it on again as the package directs. Most sunscreens state you need to put it on every 2 hours and after playing in the water.
- Use sunscreen for children of all ethnic backgrounds, regardless of skin color.
- Wear sunscreen all year. 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 care

It is important to tell your child's dentist that your child had a transplant. Cyclosporine can cause overgrowth of the gums. Keep your child's teeth, mouth and gums clean. This helps reduce the chance of an infection.

- Make sure your child brushes and flosses their teeth 2 times a day.
- Use a soft toothbrush and gently brush up and down. This may help keep your child's gums from overgrowing.
- Your child should see their dentist beginning 6 months after their transplant surgery. Most children do not need prophylaxis (preventative antibiotics) before dental procedures. Talk with your child's doctor for more details.
- Your child's dentist should call us at 404-785-1807 or email us at livertransplantemails@choa.org for more details or dental clearance forms.

Ear and body piercings and tattoos

Your child should not get piercings or tattoos until you talk with the liver transplant team. We recommend no piercings and tattoos as they can cause infection. Call your child's care team at 404-785-1807 if you have questions.

School and daycare

Talk with your child's liver transplant team about when your child can return to school, preschool or daycare. The goal for all transplant children is to attend school. This helps your child's learning, socializing and physical activities. Children's offers a hospital school program to help your child with their schoolwork.

Most children go back to school 3 months after their immunosuppression medicines are lower. Ask your child's care team about letters, guidelines and options. Your child may:

- Need to return to school part-time.
- Not be able to get certain vaccines that are needed to enroll in school.
- Have limited physical activity such as no contact sports.
- Need home-care school options for when they are sick or cannot go to school full-time.

Travel tips

Most families want to travel or take a vacation when their child feels better. Please call your liver transplant coordinator before you travel.

- Take your child's medicines in a purse or carry-on bag. This is helpful in case your checked luggage gets lost.
- Bring extra medicine in case of travel delays.
- Carry an up-to-date list of all your child's medicine in case of an emergency.
- Always have a copy of your child's health insurance card.
- Your child should wear a medical alert bracelet and carry an identification (ID) card.
- Include the phone number of the liver transplant team (404-785-1807).
- Your transplant team can provide a travel letter with details of your child's transplant.

When to call the transplant coordinator

During office hours, call: 404-785-1808 (Monday through Friday from 8 a.m. to 4 p.m.)

After hours, call: 404-785-KIDS (outside of office hours, holidays and weekends)

Call the liver transplant clinic 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, CVAD site or other sites.
- 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 2 to 3 hours.
- Headaches or dizziness.
- Exposure to chickenpox or shingles.
- A rash.
- Stomach pain.
- Decrease urine or darker urine.
- Poor appetite or fluid intake.
- Cold hands, fingers or toes.
- Weight gain or swelling.

Also call if your child:

- Is not able to take their medicine.
- Is sleepy and does not 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

Your child will take many medicines after their transplant. These medicines are very important. They will help keep your child from rejecting their new liver and keep them in the best possible health.

It is important to keep a chart or list to make sure you give your child's medicines as instructed. You may visit mymedschedule.com for help making a medicine chart.

Give your child all of their medicines on a regular schedule.

- Do not skip doses, even if they are several hours late.
- Do not double doses. Call the liver transplant coordinator right away if you accidentally give the wrong dose of medicine or skipped a dose. Your child may need care to help prevent a bad reaction.
- Call the liver transplant financial counselor if you have any problems paying for your child's medicines.
- It is important to always have a supply of medicines and to never run out.
- Your child's care team may change or stop some of their medicines. You should update charts and family members when these changes happen.

Medicines your child may take

Name of medicine	What does the medicine do?
Immunosuppressants • Tacrolimus (Prograf) • Everolimus • Cyclosporine • Prednisone • Cellcept	Helps prevent rejection
Blood pressure medicines (antihypertensives) • Amlodipine • Nifedipine	Helps control blood pressure
Antivirals • Acyclovir • Famciclovir • Ganciclovir • Valganciclovir	Helps the body fight viruses such as chickenpox
Antifungal • Nystatin • Fluconazole	Helps prevent fungal infections
Antacids, proton pump inhibitors (PPI) • Pepcid • Omeprazole (Prilosec)	Helps prevent gastrointestinal (GI) pain from some medicines
Antibiotics • Ciprofloxacin • Sulfamethoxazole (Bactrim) • Trimethoprim • Penicillin • Mepron	Helps to fight and prevent infections caused by bacteria
Anticoagulation • Lovenox • Aspirin	Helps prevent blood clots
Antipyretics • Acetaminophen	Helps lower fevers

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

Immunosuppressants

Name of medicine	Reason for taking	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 (trouble sleeping) • High blood glucose (steroid induced diabetes)
Mychophenolate mofetil (Cellcept)	• Suppresses immune system • Prevents organ rejection	• Nausea • Diarrhea • Weakness • Tremors (hand shaking)

Medicine tips

When to give medicine

- Ask your child’s care team or pharmacist for the best time to give each medicine.
- Call the transplant coordinator or your child’s doctor if your child vomits the medicine within 30 minutes of taking it. You may need to give it again.

Ways to give medicine

- Ask your child’s care team if medicines can be crushed or opened.
- Some medicine can be crushed and put in a small amount of food (such as applesauce, ice cream, juice or syrup). Use a small amount in case your child does finish all of it.

- Some medicine can be crushed and put in a gel cap for older children who can swallow a capsule.

Other medicines

- Some over-the-counter medicine can change how prescription medicines work. Keep track of all the medicines you give your child.
- Ask the liver transplant coordinator before you give your child any medicine for coughs or colds.
- Call the coordinator if your child starts any new medicine. This includes medicine from the pediatrician or other doctors. The liver transplant team keeps a complete record of all your child's medicines and illnesses.
- Ask other medical teams to call the liver transplant coordinator if you take your child to a local doctor or emergency center. This will help them provide the best care for your child.
- Check with your child's transplant team before you give your child any herbs or supplements. This includes:
    - Herbal medicine
    - Teas
    - Nutrition supplements
    - Vitamins
- Please call the liver transplant clinic if you have questions about your child's medicines or treatments.

Keep an updated medicine list

- You must give transplant medicines on a regular basis and at the right times. This is to help prevent rejection or other complications.
- It is important to keep a chart to help make sure your child gets their medicines correctly.
- You may visit mymedschedule.com for help making a chart.

Refills

- Call the coordinator before you need a refill. Call when you have 1 refill left so you do not run out.
- Some medicines need a prior approval (PA) from the insurance company before they can be filled at the pharmacy.
    - A member of your child's care team can submit the PA to your insurance company.
    - Please know that this process may take several days or weeks.
- Call your pharmacy a few days ahead of time to refill your prescriptions. This makes sure the pharmacy has enough medicine in stock for your child. Bad weather and holidays can cause delays with medicine refills.
- Check the bottle for the right dose and strength each time you get a refill. **The dose may change if the prescription is filled with a different strength tablet or a more concentrated liquid.** The dose on the bottle may not be correct.

- Your child needs their blood work checked often after the transplant. Their medicine may need to be changed based on blood work results. The liver transplant coordinator or healthcare team 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. Call the liver transplant clinic or have your pharmacist contact the clinic if you have questions about the dose of a medicine.

Helping your child cope

A transplant changes the life of your child and family. Many parents ask:

- What does my child know or understand about their 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 they cope with their transplant. It is normal for behaviors to change when there is stress. Your child may become more dependent on adults and act younger than their age. Your child may not know how to handle their feelings.

You know your child best. Work with the care team to find new ways to help your child cope. Child life specialists can also help.

Guidelines to support your child

Babies (birth to 12 months)

Your child expects you to meet their needs. They do not understand liver transplants. A baby will:

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

Common issues and fears	**How you can support your baby**
Separation from their parents	• Be with your baby as much as possible. • Leave something of yours when you go such as a picture or shirt. • Rock or hold your baby. Keep familiar blankets and toys in the room.
Fear of strangers	• Have the same people take care of your child. • Limit the number of people and voices in the room.
Development	• Allow your baby to explore toys with their hands and mouth. This is normal development. Be sure toys are clean and do not have small pieces they could choke on. • Use gentle touch and massage to comfort them. • Play games with your baby like you would at home.
Sense of safety	• Keep your baby's crib as a safe place. Ask if staff can use the treatment room for painful procedures. • Make sure your baby is awake before a painful procedure. • Continue or develop familiar feeding, bedtime and bathing routines.

Guidelines to support your child

Toddlers (12 months to 3 years)

Children begin to do more on their own as toddlers.

- Your child may say no and want to do things on their own.
- Let them do things that are safe for them to do.
- Their actions may reflect their feelings.
- Help them understand how their body works.
- Explain the transplant in their words.
- Toddlers think they make things happen. This creates the wrong idea about how they got sick.

Common issues and fears	**How you can support your toddler**
Separation from their parents and fear of strangers	• Be with your toddler as much as possible. • Have the same people care for your child. • Leave security things such as a blanket or stuffed animal. • Tell your child where you are going and when you will be back. • Leave something of yours when you go such as a picture or shirt.
Loss of control	• Allow your child to make choices when it is appropriate. • Give your child a job to do. • Allow them to play and choose the game or activity.
Loss of normal routine	• Keep normal eating, sleeping and bathing routines as much as possible • Let them play with their favorite toys.
Behavior changes	• Give them safe ways to express anger and other feelings such as painting or building blocks. • Tell your child it is OK to feel mad or sad. • Spend time with them and support them. • Set limits with your child and give discipline when needed. Boundaries and limits help them feel safe. • Praise them whenever possible.
Fear of treatment	• Tell your child that they did not do anything wrong. • Keep security things nearby such as a blanket, pacifier or stuffed animal. • Use simple words, pictures or books to tell them what is going to happen. • Tell them what will happen just before the treatment or procedure.

Guidelines to support your child

Preschoolers (3 years to 5 years)

Preschoolers like to do things for themselves. They may:

- Have more words to say what they think and feel.
- Use play to express themselves.
- Think the hospital is punishment for something they did wrong.
- Get confused by adult words and make up reasons for what happens.

Common issues and fears	**How you can support your preschooler**
Fear of treatment	• Use simple words, pictures or books to tell them 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	• Allow your child to make choices when it is appropriate. • Give them a job to do.
Loss of normal routine or behavior changes	• Praise your child for doing things for themselves. • Give them time to adjust to change. • Use play to help them share their feelings.

Guidelines to support your child

School age children (6 years to 12 years)

School age children like to do things themselves.

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

Common issues and fears	**How you can support your school age child**
Loss of control	• Allow them to make choices when appropriate. • Give your child a job to do. • Let them practice new things. • Let them go to school or do schoolwork. • Provide games and activities.
Being away from friends and school	• Schedule friends to visit at the hospital. • Write letters to friends and family with your child.
Fear of harm to body and fear of unknown	• Use simple words, pictures or books to tell your child what will happen. • Tell them what will happen a few days before a treatment or procedure. • Let your child play with safe medical supplies.

Guidelines to support your child

Teens (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 their friends and cares about what others think of them.
- Illness and treatment cause teens to be different.
- Teens can see things from many points of view.

Common issues and fears	**How you can support your teen**
Loss of control or independence	• Allow your teen to make choices when appropriate. • Let them be active in school and social activities. • Involve them in the treatment plans and discussions. • Have them do their own self-care as much as possible.
Body image or self-esteem	• Give your teen chances to talk about physical and emotional changes. • Talk with them about their feelings. • Talk with them about things they are doing well. • Allow your teen to do things that make them feel good about themselves.
Loss of privacy	• Respect their need to do things by themselves. • Knock before entering their room. • Offer them alone time.
Separation from friends	• Provide time with friends. • Allow friends to visit and call.
Concern for the future	• Answer their questions openly and honestly. • Help your teen plan for the future. • Allow your teen to do their normal activities.
Behavior changes	• Give your teen safe ways to express feelings, especially anger. • Tell your teen that their feelings are normal.

Talking with 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 they do not know what is happening. Talking with your child can:

- Build trust in you and hospital staff.
- Help them know what to expect.
- Correct false ideas about transplants.
- Help them cooperate during treatment.
- Help give them a sense of control.
- Help them learn how to get through hard situations.

It may be hard to tell your child about the 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 the 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 again.

How to talk with your child about a transplant

The items below may help you talk with your child and answer their questions. Be sure to tell the truth when answering questions.

- A transplant is no one's fault. Many children believe a transplant is caused by something they thought, said or did. Explain what your child thinks, says and does will not cause their 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 them in a deep sleep so they cannot see, hear or feel anything, not even pain.
- Tell your child how healthy bodies work. Avoid using words like bad and good; instead use sick and healthy.
- Talk with your child about their feelings. Let them know that any feeling is normal. Children feel angry, guilty, sad, lonely, scared and sometimes, even happy. Be honest with your child about your feelings.

Disciplining your child

From the time you find out that your child needs a transplant, your family’s routine and the way your family reacts to each other may change.

- Your child may become the center of attention and receive gifts. Although they may feel sick, gifts and attention are fun. It is easy for them to feel special and want special treatment to last.
- Once your child feels better, discipline problems may happen. This happens because special attention stops as normal routines begin again.

Your child's illness can also slow discipline. Pain and side effects of treatment can put any child in a bad mood. Your child may act more helpless when they feel sick. This can make it hard to know what to expect from your child. Medicines may also cause them to feel bad.

You may feel helpless when you see your child suffer. You may want to help your child by giving special rewards. These feelings are normal. Children need adults to provide rules and limits. Structure helps children feel safe.

If you do not expect your child to follow the same rules that are in place for your other children, you can:

- Set clear limits that your child can understand.
- Know that the limits may need to change when your child does not feel well.
- Praise them and reward good behavior.

Notes

Caring for the Whole Family

Coping with your feelings

Caring for a child with health issues can be a lot for anyone to cope with. A transplant brings changes to your home life. It brings new stress. Every family is unique.

- Your family may feel fear, anger, depression and guilt.
- You may find it easier to cope with change when you share these feelings.
- Your child's care team is here to listen to your concerns and help you in any way that they can.
- Talk with the transplant psychologist for more resources.

Fear

The time that you find out about your child's illness is often the hardest. Most say the fear of the unknown is overwhelming. This may be the first time your child has been in the hospital. You may also have fears about treatment, cost or how to help your child cope. 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 process your anger such as taking a walk or talking with someone.

Guilt

Parents may feel guilty because they did not know their child was sick. Some families think 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. Tell your family they did not cause your child's liver failure.

Depression or grief

Depression is used to explain emotions and behaviors like feeling sad and tired. These are normal reactions. They may cause changes in family routine. Feelings of loneliness and change can cause grief and depression.

Common symptoms are:

- Crying spells
- Decreased or increased eating
- Not being interested in things

- Not having energy
- Tightness in the chest
- Headaches

All of these feelings are common human emotions. You are not alone. Most families are able to work through these emotions with support from family, friends and your child's care team.

Here are some tips to help you cope with your child's illness:

- Find private time to talk with your partner or a close friend. Try not to talk only about your sick child.
- Avoid talking about your child in their presence (unless they are included).
- Find ways to reduce stress. You know what works best for you. Some people reduce stress through 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 care 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 find balance. This is very true when there were stresses before your child's illness.

- Talk with your child's care team about counseling or medicine. These may be helpful if there have been other family stressors such as:
    - Strains or losses
    - Mental health problems
    - Substance abuse
- Talk with your child's care team about your feelings. They can help you get the help that you need.

Impact on marriage or relationship

An illness can turn a family's life upside down. You may feel emotionally and physically tired. Most parents keep working and try to keep a normal home routine. Many parents feel the strain on their marriage or relationship. They feel angry and upset about what has happened to their child. They often say that they do not have time for their partners.

Ideas that may help prevent marriage or relationship problems

- **Knowing your partner's coping style.** It is important to know how your partner deals with stress. Each person shows feelings in different ways. Some people pull away, cry or get angry. Some people try to learn as much as possible. Be aware of how your partner deals with their feelings.
- **Talk with each other**. The key to a good relationship is talking. It is important to talk about feelings, fears and information during times of stress. Silence can make you feel distant from your partner. Sharing feelings and facts can help you know what your partner is thinking. Sharing and talking may help you make decisions.
- **Change roles when needed.** The stress of an illness can change the roles of family members. One parent who took care of the home may now be too busy. The other parent may have made most decisions in the past. If 1 parent is with the sick child more than the other, they may now make many decisions. Changing roles can cause stress in a relationship. Some ways parents can work together include:
  - Show your partner kindness and understanding. Do not blame or criticize.
  - Make your sick child a priority. Both parents need to learn about the diagnosis and treatment.
  - Share in caring for your other children.
  - Share your feelings of anger, sadness and hope with each other.
  - Accept the help of family, friends and neighbors.
  - Be loyal to each other if family members criticize or blame 1 of you for decisions that are made.

Divorced parents

Divorce is hard on most families. Problems may get worse when a child is sick. Sometimes children try to use their illness to bring together divorced parents. Other times, they may try to play 1 parent against the other to gain some feeling of control. Try not to let the stress of divorce affect your child's care. Good communication can help you both provide the best care for your child.

Tips to help avoid problems

- Talk with the transplant team if your child is having behavior problems.
- Provide copies of divorce paperwork, custody agreements and visitation rights for your child's medical record.
- Meet together with your child's transplant team to help avoid confusion about the plan of care.
- Ask for 2 copies of all teaching materials so both parents have the same information.

Siblings

Most brothers and sisters are also stressed by this process. They may have some of the same needs as their sick brother or sister. They may feel upset, scared and unsure of the future. They may worry about death. Children of any age will see a change in their family life.

Siblings may:

- Feel sad and worried about their sick brother or sister. They may cry easily.
- Feel angry or jealous. Their parents may spend a lot of their time with or talking about the sick child.
- Have trouble sleeping, physical complaints or problems in school.
- Feel they are being left out of what is going on and the latest updates.

Some tips to help siblings include:

- Try to spend time alone with your other children, doing things that they like.
- Let them know that you love them and they are special.
- Talk with them about the transplant in a way they can understand. Help them understand their brother or sister's illness and treatment.
- Let them know that the illness is not contagious and they did not cause their brother or sister to get sick. Ask your child life specialist for helpful tips.
- Take them to the hospital. Help them feel involved in the care of their sibling. This may help decrease fears and help them feel closer to their brother or sister.
- Ask a friend or family member to stay in your home. Try to avoid sending your children somewhere else to stay.
- Ask your children to help with chores at home. Including your other children makes them feel needed.
- Talk with their teachers. Teachers can support your children and tell you if there are any problems at school.
- Ask for help from the transplant team. Talk with a child life specialist, social worker or child psychologist.

Grandparents

Grandparents have many responses when they hear their grandchild has liver disease. They may feel:

- Shock and disbelief.
- Guilt for living a long life.
- Blame. They may think they passed liver disease through the family.
- Sadness for their grandchild and also their son or daughter.

Include grandparents in meetings with the care team. This can help them understand the treatment plan.

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

- Gives you breaks at the hospital or home.
- Spend time with your other children.
- Help update others so you do not have to spend as much time on the phone.

Programs and events

The Children's liver transplant team knows there is more to treating your child than just taking care of their health. Our goal is to treat your whole child. This includes improving your child's quality of life. We also understand your child's life is focused on their family. We offer programs that involve the entire family, including:

Teen program

- This program is open to transplant recipients between ages 14 to 21.
- Teens participate in 2 outings in the spring and fall. The program lets teens socialize with peers in a fun and relaxing environment.

Parent support groups

- Groups are for parents to get 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 patients, 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 get pictures with Atlanta Braves players before the game.

Family camp

- This is a weekend camp for the whole family. They get to experience camp, build friendships and make memories.
- Camp is at Camp Twin Lakes in Rutledge, Georgia.
- Families go to educational seminars about transplant topics.
- Activities are family-friendly and include:
  - 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, Georgia.

Family gatherings

- There may be other family gatherings during the year.
- Families can meet and mingle with family and friends and enjoy other activities.

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

Notes

Resources

Financial resources

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 about your child's benefits.
- Get approval for the evaluation and transplant.
- Help you understand your insurance benefits.
- Answer questions about your benefits.
- Help assess your financial needs.
- Talk about 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 that you may qualify for.
- 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 about Medicare, Medicaid, Georgia's Peach Care program and hospital and doctor payment plans.
- Forms and paperwork for government assistance your child can receive.
  - There may be a lot of paperwork to complete.
  - Fill out the forms as soon as you can.
  - The sooner the papers are sent, the sooner you may receive benefits.
  - This process may take weeks, or even months.

Call our financial coordinator or registration office if your insurance coverage changes. Medical bills can be confusing. Please tell the financial coordinator if you are having any financial trouble with your child's medical costs.

Insurance companies

It is important that you understand your insurance coverage.

- Talk to your human resources department where you work to explain your benefits.
- If the Children's doctor or hospital is not in network, please call your insurance company to discuss your co-insurance rates and out-of-pocket costs. The transplant financial coordinator can help you.
  Please call 404-785-6478 or 404-785-0924.
- Your insurance company may ask for a letter of medical necessity to treat your child at Children's. Contact the hospital financial coordinator for this information from your transplant surgeon.
- Bring a copy of your insurance card to each visit. It lists your benefits, deductible and copay amounts.
- Tell the liver transplant clinic right away of changes to your address, phone number or insurance coverage.

Helpful hints about the billing process

You will get bills from several places. These include hospital bills (called technical or facility fees) and provider bills (called professional fees).

- If you have a question about a bill, please call the phone numbers on your billing statement.
- Make a folder for hospital bills and insurance forms. This can help you 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 from Children's hospital or satellite location)
- Children's Cardiology (for some radiology imaging)
- Other staff or doctors who care for your child

Read bills closely. You may get statements that are pending payment. These statements are for your records and are not bills. If a billing office or your insurance company contacts you, please respond quickly.

Medicaid

Medicaid is a state medical assistance program. It covers most costs for hospital stays, clinic visits and medicines.

- Some procedures or exams are not covered by Medicaid. They have to be pre-approved.
- Some Medicaid programs are based on family income. Others are based on medical needs.
- You may be able to get coverage for medical services that happen 3 months before the month your child becomes eligible for Medicaid.

Medicaid may be able to pay for:

- Provider and hospital bills.
- Up to 5 prescriptions a month.
- Physical, occupational and speech therapy.
- Home health equipment.

Your child may get to keep their Medicaid coverage until the end of the month of their 19th birthday. These programs include:

- Peachcare
- Peachstate
- Wellcare
- Amerigroup
- Any other Georgia Medicaid CMO

It is important that you keep your child's Medicaid coverage after they turn 18. If it is cancelled after they turn 18 it will not be reinstated between their 18th and 19th birthday.

If your child was approved for SSI Medicaid before they turned 18, your child has to apply for adult SSI benefits before their 18th birthday.

- You can appeal the denial if it was denied.
- Request that SSI Medicaid stays active during the appeals process (which can take up to 4 months).

Please call your social worker for more details about the programs offered through Georgia Medicaid. Children's has an onsite Medicaid office where you can talk with a case manager from DeKalb or Fulton county.

Resources at Children's

Sleep rooms

Please know that details may change.

- Only 2 legal guardians or parents who are 18 years or older 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.
- For more details, please contact the front desk in the Family Center or a Family Experience Liaison.

Showers and restrooms

- Private showers and restrooms are available for parents and guardians.
- If you need toiletries, talk with a family experience liaison, the liver transplant social worker or your child's nurse.

Washers and dryers

- You may use the washers and dryers found on the unit where your child is admitted.
- You may do laundry at any time.

Family kitchen and lounge

Each unit has a family kitchen or lounge. This includes:

- Vending machines
- Ice machine
- Family refrigerator
- Stove and microwave

Lactation and feeding rooms

- You may use a hospital breast pump if your child is admitted to the hospital.
- These rooms are available on the first floor and on every unit.
- Ask your child's nurse if you would like to speak with a lactation consultant.

Food services

- The Eatery (1st floor)
  - 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.
- Coffee shop (2nd floor)
  - Open every day 8 a.m. to 11 p.m.
- Room service
  - Dial extension 56262 from your child's room.
  - Available every day from 7 a.m. to 8 p.m.

Seacrest Studios (1st floor)

- Open Monday through Thursday from 10 a.m. to 8 p.m.

- Open Friday from 10 a.m. to 5 p.m.
- Open Saturday and Sunday from 2 p.m. to 6 p.m.

The Zone and The Zone Garden (1st floor)

- Open Monday through Thursday from 10 a.m. to 12 p.m. and from 1 p.m. to 7 p.m.
- Open Friday through Saturday from 10 a.m. to 12 p.m. and from 1 p.m. to 5 p.m.
- Open on Sunday from 1 p.m. to 5 p.m.

Gift shop (1st floor)

- Open Monday through Friday from 7 a.m. to 7 p.m.
- Open Saturday and Sunday from 9 a.m. to 5 p.m.

Family library (2nd floor)

- Open every day from 10 a.m. to 4 p.m. (closed from 12 to 12:30 p.m. for lunch)
- Consumer health collection
- Fun books and movies for all ages
- 1-hour digital camera checkout
- Laptop checkout for patients
- Computers with internet access
- Library staff to help

Chapel and prayer room (2nd floor)

- Open every day, at all times

Business center (2nd floor)

- Open every day from 8 a.m. to 10 p.m.
- 4 computers that have internet access and printing

Family resource center (2nd floor)

- Open every day

Family respite (2nd floor)

- Open every day from 8:30 a.m. to 5 p.m.

Area lodging

The social work office keeps a list of hotels that offer reduced rates to families. The transplant social worker can help you make reservations.

Ronald McDonald House

795 Gatewood Road NE
Atlanta, Georgia 30329-4200
404-315-1133

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

Other transplant resources

There are many family resources that can help with costs. Each has its own rules. Make sure to choose the resources that fit your needs. For example:

- Some groups require families to include 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 successful fundraising is often done before a transplant.

Some of the more common resources are listed here.

American Liver Foundation (Southeast)

2250 North Druid Hills Road NE #285
Atlanta, Georgia 30329
888-443-7872
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, Indiana 47403-4204
800-366-2682

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, Georgia 30328
770-457-3796 or 866-428-9411
gatransplant.org

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

Make a Wish Foundation of Georgia

1775 The Exchange SE, Suite 200
Atlanta, Georgia 30339
770-916-9474
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 details.

National Organization for Rare Disorders (NORD)

P.O. Box 1968
Danbury, Connecticut 06813-1968
800-999-6673 or 203-744-0100
rarediseases.org

Organization that manages drug cost share program for people who cannot afford cyclosporine.

Pharmaceutical Research and Manufacturers of America (PhRMA)

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

PhRMA has a Directory of Prescription Drug Indigent Programs. You may write to the company to get a copy.

United Network for Organ Sharing (UNOS)

P.O. Box 2484

Richmond, Virginia 23218-2484

888-894-6361 or 804-782-4800

unos.org

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

Websites

Liver related websites

- American Liver Foundation: liverfoundation.org
- CDC Vaccines and Immunizations: cdc.gov/vaccines
- Children's Organ Transplant Association: cota.org
- American Liver Foundation - Georgia: liverfoundation.org/chapters/georgia
- Hepatitis Foundation: hepatitisfoundation.org
- Immunizations contraindication: cdc.gov/vaccines/hcp/imz-best-practices/contraindications-precautions.html
- LifeLink of Georgia: lifelinkfoundation.org
- DonateLife Georgia: donatelifegeorgia.org
- United Network for Organ Sharing (UNOS): unos.org
- Scientific Registry of Transplant Recipients: srtr.org

Local Georgia resources

- Atlanta Chamber of Commerce: metroatlantachamber.com
- Children's Healthcare of Atlanta: choa.org
- Georgia Department of Human Resources: dhs.georgia.gov/community-resources-0
- Medicaid: medicaid.georgia.gov
- Medicare: medicare.gov
- PeachCare for Kids: dfcs.georgia.gov/programs/peachcare-kids

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Notes

Glossary

Helpful definitions

Absorption: The amount and time it takes for a medicine to get into the bloodstream.

Alkaline phosphatase: Enzyme made by the liver and other cells. High blood levels may mean problems with the liver or other organs.

Allograft (allogenetic graft or homograft): Transplant between 2 people.

Anesthesiologist: A doctor who gives anesthesia medicines to put your child to sleep.

Anesthetic (anesthesia): Medicine that reduces pain. Some of these are used to put people into a deep sleep for procedures or surgery.

Antibiotics: Medicine used to fight infections from bacteria.

Antibody: A protein the body makes to fight things in the body, like germs.

Antigen: Something in the body that causes the immune system to make antibodies. Antibodies try to destroy the antigen. A transplanted organ is an antigen, and the body makes antibodies to the organ.

Arteriogram: X-ray of the arteries or tubes that carry blood throughout the body. A dye is used to help the arteries show up on the X-ray.

Ascites: Extra fluid in the stomach area.

Atherosclerosis: Collection of fats in the lining of the arteries that can slow blood flow.

Autoantibody (ies): Type of antibody that fights a person's own organs.

B cell: Type of white blood cell that helps the immune system make antibodies.

Bacteria: Germs that can cause infection.

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

Bile ducts: Tubes that carry bile.

Bile leak: Hole in the bile-duct system that causes bile to spill into the abdominal space.

Biliary stenosis: When the bile duct narrows or gets thin and bile cannot flow easily.

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

Biliary tree: The paths inside and outside the liver that carry bile to the intestines.

Bilirubin: Orange substance in bile from the breakdown of red blood cells. Bilirubin levels are often high with liver disease.

Bioavailability: The amount of a medicine that the body can use. This tells doctors how much of the medicine gets to the organ.

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

Blood urea nitrogen (BUN): A blood test that measures the amount of urea in the blood. Urea is formed when protein breaks down in the body. It is carried in the blood to the kidneys and removed through the urine. BUN is high when the kidneys do not work well.

Cirrhosis: Disease that causes scarring in the liver that cannot be reversed.

CMV (cytomegalovirus): A common virus that affects most adults.

Coagulation: Blood clotting.

Coagulopathy: 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: High levels of sugar in the blood. It can be caused by too little insulin, resistance to insulin, or both.

Diuretic: A medicine that helps the kidneys make and remove more urine.

Edema: Extra fluid in body tissues.

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

Endoscopy: Test that includes a tube with a light and camera to look at the inside of organs and spaces in the body.

Enzyme: Proteins the body makes to change a substance from one form to another.

Epstein-Barr virus (EBV): Common virus that affects most adults.

Gallbladder: A small sac attached to the liver that stores bile.

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

Gingival hypertrophy: Large gums. It is a common side effect of cyclosporine therapy.

Glucose: How we measure sugar 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 works.

Hemochromatosis: A rare disease of extra iron in the body.

Hemolytic anemia: A type of anemia that causes red blood cells to be destroyed too soon.

Hepatectomy (ies): Removal of part of the liver.

Hepatic: Relating to the liver.

Hepatic encephalopathy: Brain disorder caused by liver disease. Symptoms include lethargy and coma.

Hepatologist: A doctor that takes care of people with problems in the liver.

Hepatomegaly: Large liver.

Herpes: Viruses that infect humans. Some types of herpes can cause chickenpox, shingles and cold sores.

HLA system: Antigens on the white blood cells (leukocytes) and tissues**.**

Hypertension: High blood pressure.

Immune response: Reaction from the immune system to a foreign material like a transplanted organ.

Immune system: The system that protects the body from harmful substances like germs and cancer cells.

Immunity: The body's ability to fight a disease or harmful substance.

Immunosuppressants: Medicines that help prevent rejection of a transplanted organ.

I.V. or intravenous: A way to give medicines or fluids into a vein.

I.V. catheter: A small hollow tube put into a vein. It is used to give medicines or fluids. It is put in with a needle and then the needle is removed.

Jaundice: When the skin and eyes look yellow. It is caused by too much bilirubin in the blood.

Kidney: An organ that is on both sides of the spine, just above the waist. They remove waste and maintain fluid balance in the body. They make urine.

LifeLink Foundation: A nonprofit organization that helps receive organs and tissues for transplants.

Liver: A large organ in the body that is also a gland. It is found in the upper right side of the abdomen. It is just below the diaphragm. The liver filters blood, releases bile, changes sugars and helps with metabolic activities.

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

Living donor transplant: A healthy liver from a living person that is given to someone that needs a new liver.

Living donor: Person who donates a part of their liver.

Malignant tumor: A tumor made of cancer cells that can spread and destroy tissues.

Match: The ability for an organ from one person to be given to another person. The better the match the greater the chance for success with a transplant.

Native liver: A person’s original liver.

Neonatal hemochromatosis: Rare disease of iron processing in newborns. It causes extra iron in the body.

Neutrophil: Type of white blood cell that fights bacteria and fungus.

Noncompliance: When patients and families do not follow doctors’ instructions. This often means a child does not take their medicine or come to clinic visits.

Oral (PO): By mouth or to be swallowed.

Organ procurement organization (OPO): This is the organization that matches donors and recipients. It picks up, preserves and transports the organs. OPO is part of the United Network for Organ Sharing (UNOS).

Percutaneous transhepatic cholangiogram (PTC): X-ray of the bile ducts.

Perforated bowel: When the intestine gets a hole or cut in it. This can cause bacteria and fluid to leak out and cause an infection in the abdomen.

Platelet: Type of blood cell that helps form clots.

Portal hypertension: When there is high pressure in the liver circulation. This includes veins that carry blood from the digestive organs and spleen to the liver. This often happens with cirrhosis.

Potassium: Mineral needed for cells and muscles to work.

Prednisone: A steroid medicine that most transplant patients take to help prevent rejection.

Prophylactic medicine: Medicines that helps prevent disease.

Rejection: An immune response that fights the transplanted organ. The transplant can fail if rejection is not treated.

Renal: It means kidney.

Re-transplantation: A second transplant. Some people need another transplant. This could be due to organ rejection or transplant failure. If this happens, they return to the wait list for another organ.

Sclerosis: When tissue or organs get hard. It can be caused by inflammation (irritation and swelling) or disease.

Sensitized: When the body already has an immune response against an antigen. It happens when the body has made antibodies to something it has been exposed to before.

Sodium: A mineral needed for the body to work. It is the main salt in blood.

Status: The level of medical need for patients waiting for a liver transplant.

Stricture or stenosis: Narrowing of a path or tube in the body.

Survival rates: The number of patients or transplanted organs that are alive or working after transplant. Survival rates are often given at 1, 3 and 5 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: Blood tests to check for human leukocyte antigens (HLA). It is also called genetic matching. Tissue typing is done for donors and recipients before a transplant.

T-tube: Tube placed in the bile duct to let bile drain into a bag outside the body. This helps the body heal after surgery.

Trough levels: When the medicine level is lowest in the blood.

United Network for Organ Sharing (UNOS): An organization that teaches people in the community about organ donation. It supports donors and recipients. It helps recipients through education, technology and policy development.

Varices (varix): Large, dilated veins.

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

Virus: A very small germ that causes infection.

Waiting list: The list of people who are waiting for an organ. Patients are added to the national UNOS waiting list after evaluation. Lists are based on area of the country and organ type. The UNOS computer makes a list of possible recipients based tissue typing, organ size and medical need.

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

Helpful abbreviations

BID	2 times a day
CC	Same as milliliter (mL). 1cc = 1mL
MG	Milligrams (used for medicine doses)
ML	Milliliters (used to measure fluid amount)
NPO	Nothing by mouth
PO	By mouth, to be swallowed
PRN	As needed

QDAY	Every day
QD	Every day
QHS	Every day at bedtime
QID	4 times a day
QOD	Every other day
TID	3 times a day

Health-related information changes frequently, and therefore information contained in this handbook may be outdated, incomplete or incorrect. This handbook may contain printed material that has been updated by Children's Healthcare of Atlanta. Please talk with a member of your child's healthcare team if you need an up-to-date copy.

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Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.