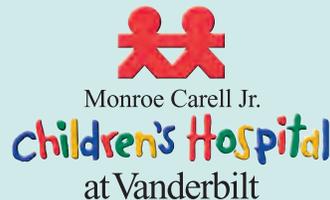


Liver Transplant Patient and Family Handbook



Liver Transplant Team
(615) 343-BILI (2454)

www.ChildrensHospital.vanderbilt.org/LiverTransplant

Dear Family,

At Monroe Carell Jr. Children's Hospital at Vanderbilt, we understand that your family will have many questions about your child's transplant. We hope this booklet will help you understand the transplant process and give you basic information about:

- liver transplant evaluation
- transplant surgery
- recovery period
- other issues involving your child's transplant and recovery.

While reading this booklet, write down notes or questions for your child's health care providers. We will review the information covered in this booklet with you.

If you do not find the information you need in this booklet, we will be happy to help you. We will take the best care of you and your child during your time here.

Sincerely,

The Liver Transplant Team



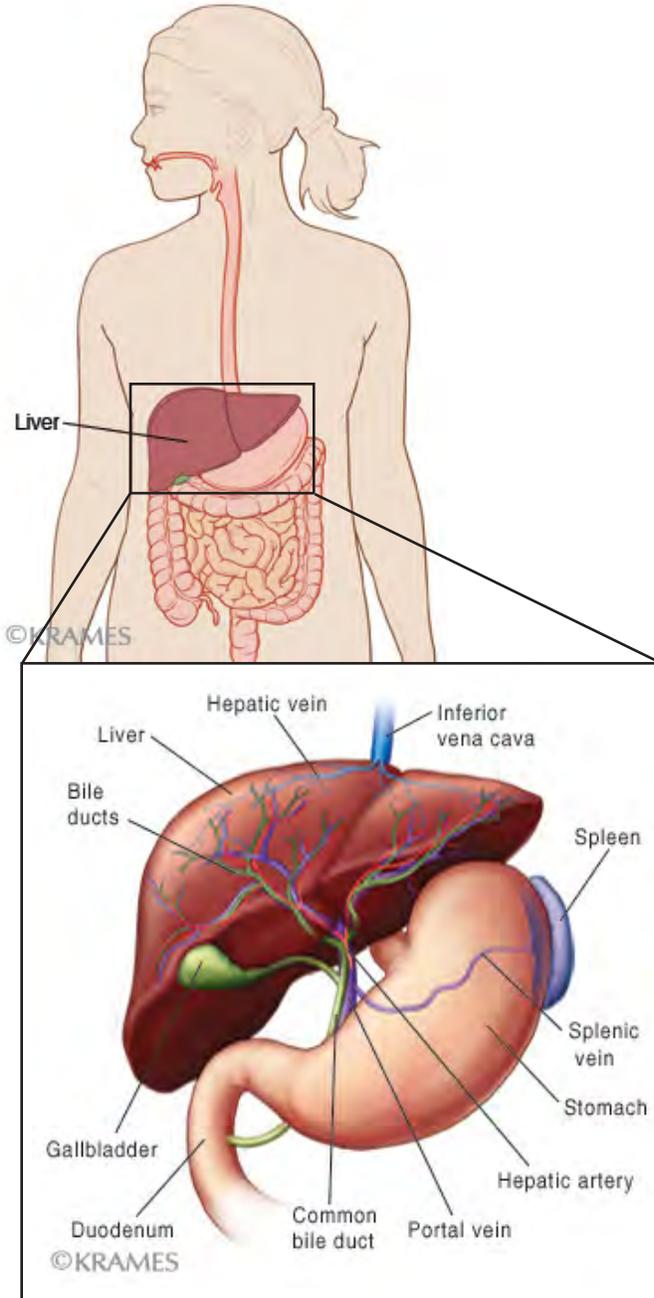
Table of Contents

Section 1: Introduction to Liver Transplant...	1–4	Section 5: Home Care and Lifestyle Changes	27–40
What a Liver Does for Your Body	1	Follow-Up Care	27
Types of Liver Transplant	2	Wound Care	28
Transplant Team and Support Staff	3	Activity	29
Section 2: Transplant Evaluation and Getting Listed	5–7	Food and Food Safety	30
Transplant Evaluation	5	Organ Rejection	33
Getting Listed	6	Illnesses and Long-term Risks	34
Immunizations	7	Coping After Transplant	37
Section 3: Transplant and Hospital Stay	9–16	Dental Care	40
When a Liver Becomes Available	9	Section 6: References	41–51
The Surgery	12	Over-the-counter Medicines after Transplant	41
After Surgery	14	Food and Drinks to Avoid after Transplant	42
Risks of surgery	15	Champ teaches how to wash your hands	43
Recovery	16	Taking Your Child’s Temperature	44
Section 4: Transplant Medicines	17–26	Glossary*	46
Guidelines and Helpful Tips	17	Lab Tests	48
Transplant Rejection Medicines	22	Resources	49
Infection Prevention Medicines: Bacterial	24	Websites	49
Infection Prevention Medicines: Fungal	25	When to Call the Liver Transplant Team	51
Infection Prevention Medicines: Viral	25		
Other Medicines	26		
Over-the-counter Medicines	26		

* Throughout the book, words in **bold** type are defined in the Glossary on page 46.



Section 1: Introduction to Liver Transplant



What a Liver Does for Your Body

The **liver** is the largest organ in the body. It is located on the right side of the abdomen, underneath the ribs. The liver has many important jobs, which include:

- changing food into chemicals needed for life and growth
- making proteins, such as albumin or blood-clotting factors
- changing medicines so that the body can use them
- cleaning poisons and drugs from the blood
- helping keep blood sugar levels steady
- making **bile**, which helps the body digest and absorb medicines, and vitamins A, D, E, and K.
- filtering blood and removing many unnecessary chemicals, drugs, and waste products from the blood.

A normal liver is the only organ in the human body that can repair itself if it is damaged.

All the blood that flows from the intestines, stomach, and spleen is filtered through the liver. The blood flows into the liver mainly through the portal vein and some through the hepatic artery. It filters through the liver in a system of smaller and smaller veins. As blood passes over liver cells, these cells process nutrients in the blood. This processing makes products like proteins and sugars that your body can use. Blood is carried out of the liver through the hepatic vein to the heart.

Signs of liver disease

Signs and symptoms of liver disease in children include:

- **jaundice** (yellowing of eyes or skin) from too much bilirubin in the blood
- excessive itching from too much bilirubin in the blood
- delayed growth and development related to malnutrition
- weakness and fatigue related to malnutrition or shortness of breath
- malnutrition from the liver not taking in or storing nutrients and vitamins from food like it should
- loss of appetite, nausea, and weight loss
- fluid collection in the abdomen (ascites)
- bruising and prolonged bleeding due to blood not clotting as quickly as it should
- cirrhosis (scarring of the liver) from chronic liver disease
- repeat infections of the bile ducts (cholangitis)
- high blood pressure in the portal system which can cause blood in stool or cause the child to cough up blood
- enlarged spleen from high blood pressure in the portal vein (Having a large spleen can lower the body's ability to fight infection and lowers the platelet count.)
- decline in brain function and confusion from too much ammonia in the blood
- shortness of breath from ascites or end-stage liver disease.

Types of Liver Transplant

Whole-organ transplant

With a whole-organ **transplant**, a liver from a donor who has died (deceased donor) replaces the liver in the recipient.

Split liver transplants

Split liver (splitting a liver into 2 parts) donations can come from a deceased or living donor.

Split liver, deceased donor

From a deceased donor, the liver is split into 2 parts for 2 transplant recipients. The portion of the liver used for each recipient is based on the size and shape of the donor organ and the weight of each recipient.

Split liver, living donor

Surgeons are able to safely take part of a living donor's liver and transplant it into a recipient. The donor could be a family member, or could be a donor that is not related to the recipient. The advantage of a living donor transplant is that we can schedule a liver transplant from a matched donor. There is a chance that the donor may have some problems, but there is personal satisfaction of giving a life-saving organ to another person. The recovery time for the donor is about 8 weeks.

Transplant Team and Support Staff

You will get to know many health care professionals during the transplant process. They are here to help answer your questions and help you make decisions about your child's care. They are also here to support you and your child during a difficult time. Some of the people you will meet include:

Administrative assistant

The department administrative assistant coordinates multiple specialty appointments to organize your child's care.

Case manager/discharge planner

The case manager contacts your insurance company and arranges for any equipment or services your child needs after transplant.

Child life specialist

The child life specialist works with your child to help him or her cope with being in the hospital, through play and age-appropriate activities.

Doctors

There will be a doctor who specializes in diseases of the liver (hepatologist) and a transplant surgeon who will do the operation. Both the hepatologist and surgeon manage your child's care, including the anti-rejection medicines.

Financial advisor

The financial advisor will talk with you about the hospital bill and insurance for the transplant, hospital stay, medicines, and other medical expenses for your child.



Vanderbilt's Liver Transplant Team pictured with liver transplant recipient Antwane "AJ" Cole (on left), his mother Monjineh Singer, and brother Braylen "BJ" Singer.

❁ The liver transplant coordinator is your main contact before, during and after transplant.

Liver transplant coordinator

The liver transplant coordinator is your main contact. The coordinator organizes the transplant process from pre-transplant evaluation to post-transplant care. The coordinator serves as a link between the transplant team and other health care professionals involved in your child's care.

Nursing staff

The nursing staff cares for your child while he or she is in the hospital. Nurses give you and your child information about tests so you know what to expect. They also teach you how to care for your child after transplant.

Nutritionist

The nutritionist works with you to come up with the best eating plan for your child. Many children with liver disease do not feel like eating and have problems growing. The nutritionist will work with your child to build healthy eating behaviors.

School teacher

The teacher can help you by sharing information with your child's school about his or her absence, tutoring your child while in the hospital, and helping with the transition back to school.

Social worker

The social worker gives emotional support and help to you, your child and your family. He or she may help you with funding, housing, transportation, and community resources.

Pharmacist

The transplant pharmacist teaches you about your child's medicines, before and after transplant.

Rehab staff

A rehab specialist can be a physical, speech, or occupational therapist. They work to help your child get back strength and movement, and the skills needed for play, learning, and self-care after surgery.



Section 2: Transplant Evaluation and Getting Listed

Transplant Evaluation

Your child will need to go through a transplant evaluation process before being placed on the transplant waiting list. During this time, you and your child will learn more about liver transplant and meet members of the liver transplant team. The evaluation helps you and the liver transplant team decide if a liver transplant is the best option for your child.

The evaluation includes meeting the entire transplant team, clinic visits, blood work, and other diagnostic testing.

Tests include:

- blood tests (we will test your child's blood a few times)
- urine tests
- an EKG (**electrocardiogram**), which checks the electric rhythms of the heart
- an echo (**echocardiogram**), which are pictures of the heart and blood vessels made by an **ultrasound** [Sometimes an intravenous (IV) line needs to be placed.]
- CT (**computed tomography**) scan, which is a special **X-ray** of the liver that looks at the blood vessels and the size and shape of the liver (Your child may need an IV for this test if sleep medicine is needed.)
- abdominal ultrasound
- breathing tests.

Your child may not need all of these tests.

After your child is evaluated, which may take a few weeks if done as an outpatient, the selection committee at Monroe Carell Jr. Children's Hospital at Vanderbilt will decide if liver transplant is the best option for your child.

The selection committee is made up of the transplant team and any specialty doctors that were consulted. We will submit your entire transplant evaluation to your insurance company. Insurance approval typically takes a few days, but can take up to a month.

We will talk to you and your child's referring doctor about the test results and the selection committee's recommendations.

Getting Listed

When your insurance company approves the transplant, your child will be placed on the transplant list.

The national agency that manages the list of people waiting for transplant is the United Network for Organ Sharing (UNOS).

When your child has been added to the UNOS transplant list, we will give you a “Golden Ticket,” which will help check your child into the hospital quickly and easily, if you are called for a transplant after business office hours.

Who gets an available organ?

UNOS matches donated organs to children and adults by size, blood type, and need. Deciding who gets a liver is based on a score from lab values (test results), height, and weight.

Children 11 years old and younger

The score for children ages 11 years and younger is called a Pediatric End-Stage Liver Disease (PELD) score. It ranges from numbers less than zero (children who are not as sick) to 40 (children who are very sick).

The score is based on:

- **bilirubin** levels
- INR (clotting factor)
- albumin (protein made by the liver)
- sodium
- creatinine
- age of younger than a year old
- height
- weight.

Children 12 years old and older

The score for children ages 12 years and older is called a Model for End-Stage Liver Disease (MELD). It ranges from 6 (children who are not as sick) to 40 (children who are very sick). The score is based on:

- creatinine (kidney function)
- bilirubin levels
- INR (clotting factor).

Once a donor is identified, the PELD/ MELD score and blood type are compared to those of other people awaiting liver transplants. Children with the highest score are transplanted as soon as possible.

Waiting for a liver

Waiting for an organ will probably be one of the hardest times for you and your family. It is impossible to know when an organ will become available. A liver may become available quickly, or the wait may be weeks, months, or years. You may worry about your child’s medical condition, and you may feel helpless. Waiting can become very stressful and frustrating.

One of the most important things you can do to help the time pass is to focus on taking good care of your child. This way you can help him or her be in the best health possible when an organ becomes available. You should continue to take your child to the pediatrician for regular check-ups and you will need to come to the transplant clinic at least once a month during the time you are waiting for a liver.

It is important that you stay in contact with the transplant coordinator. He or she will need to know about changes in your child’s health. Contact the transplant coordinator if your child is hospitalized.

Other ways to ease the stress of waiting:

- keep as normal a daily routine as possible
- talk to your family or supportive friends about your concerns
- contact a member of your child's transplant team. The transplant team is available to help you through this stressful time.

While waiting for an available organ, it is important that the transplant center be able to reach you if an organ becomes available. You will be asked to leave phone numbers of people who can easily locate and contact you.

Your child may travel while waiting for a liver transplant, but, before your child leaves on a trip, let the transplant coordinator know where your child is going, the travel schedule, and phone numbers where you can be reached during the trip.

Immunizations

Your child should continue to get immunizations while on the organ waiting list. Our transplant coordinator will contact your child's pediatrician about continuing scheduled immunizations.

Live-virus vaccines should be given before transplant. They are not safe to give after transplant. Live-virus vaccines include flu nasal spray, rotavirus, varicella (chicken pox), and MMR (measles, mumps and rubella) vaccines. Occasionally, vaccine schedules will be changed so that all or most of these vaccines can be given before transplant. **Your child should not get any live vaccines before transplant without first talking to your transplant coordinator.**

If your child is exposed to any childhood diseases, such as chicken pox, measles, mumps, rubella, or any others, before he or she has been vaccinated against them, contact the transplant office or the liver transplant coordinator. There are ways to treat these childhood diseases.

For the latest schedule of immunizations, go to the Centers for Disease Control and Prevention website at www.cdc.gov/vaccines.

❁ Your child should not get any live vaccines before transplant without first talking to your transplant coordinator.



Section 3: Transplant and Hospital Stay

When a Liver Becomes Available

It is important that we have all your telephone numbers and that you keep all cell phones charged, turned on, and with the sound turned up. If the transplant coordinator cannot reach you, the available liver may go to the next person on the list. We can work with you for the best way to consistently reach you.

When we contact you to tell you that an organ is available, we will ask about your child's health. We need to know if your child has or has just gotten over a cold, flu, or fever, or if your child has been recently exposed to chicken pox or other infectious diseases. It is very important that your child be in the best possible health for the transplant. If there are any concerns about your child's health, the transplant coordinator will talk about them with the transplant doctors.

If your child is in the best possible health for transplant, we will ask you to bring your child to the hospital as soon as possible. Your child should not eat or drink anything after this time to be ready for surgery. The transplant coordinator will give you an estimated time for the transplant surgery.

It is very important to be prepared to travel to the hospital. Travel arrangements should be planned before it is time to go. Whether you are traveling by car, plane, or train, make your arrangements in advance.

Be ready

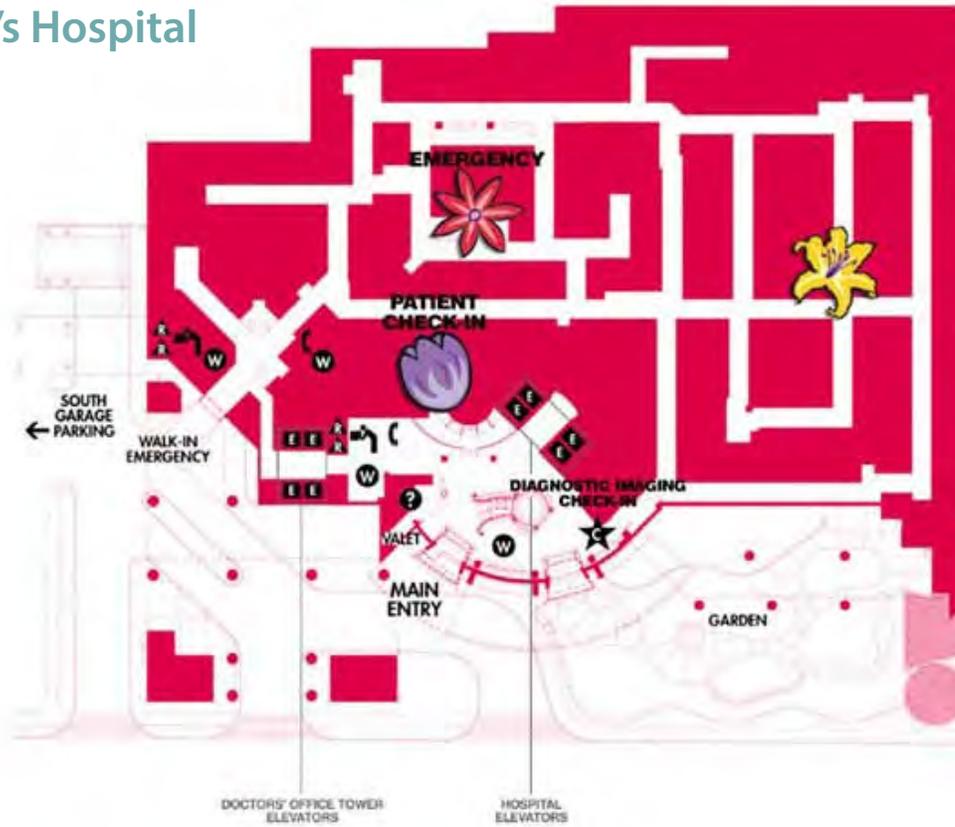
- Make a list of things you want to bring with you to the hospital.
- Keep a bag of your belongings packed.
- Bring a comfort item for your child, such as a special toy or blanket to help your child cope.
- If it is after Business Office hours, bring the "Golden Ticket" that we gave you to help your child be admitted to the hospital fast.

Occasionally, patients and their families are called into the hospital for transplant and the donor organ is found to not be a good match for the patient. Though this is very disappointing, we will do the transplant only if the surgeons are confident the organ is perfect for your child.

Arriving to Children's Hospital

If you are called for a transplant and arrive to the hospital **between 7 a.m. and 7 p.m.:**

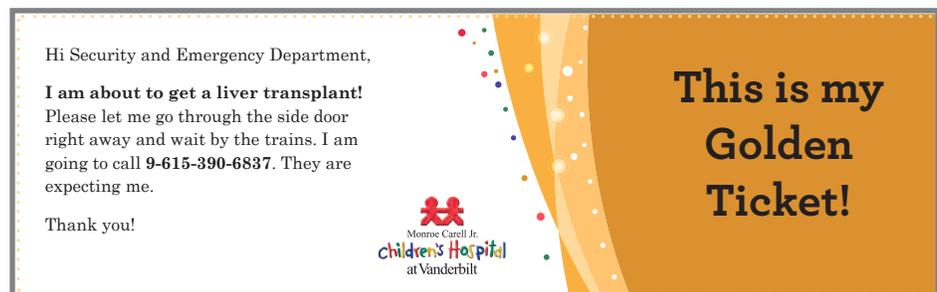
- go to Patient Check-in (Business Office) on the first floor of Children's Hospital. This is located to the left of the big blue staircase.
- staff members in this office will check your child into the hospital.



If you arrive to the hospital between **7 p.m. and 7 a.m.:**

- go to the Emergency Room entrance of Children's Hospital
- show the security guard your Golden Ticket. The guard will let you go through the side door that leads to the first floor of the hospital
- use the lobby phones on the wall (across from the trains) to call the number on your Golden Ticket to check in. (Do not call the number until you are waiting by the trains on the first floor of Children's Hospital.)

When you are checked in, a nurse will walk you to the Pediatric Intensive Care Unit.



In the Pediatric Intensive Care Unit

- Your child will change into hospital clothes
- You and your child will meet with your child's anesthesiologist, transplant surgeon, hepatologist, and nurses.

We will:

- draw blood from your child's IV
- do some tests, including X-rays and getting a urine sample
- check your child's blood pressure, heart rate, breathing rate, and temperature
- give your child antibiotics through the IV
- do a physical examination of your child to check his or her health
- review the consent forms for anesthesia (sleep medicine for surgery) and surgery with you and ask you to sign them.

Waiting for the surgery to begin can be a long time. Please bring items such as books, a digital tablet, or other quiet entertainment with you to help pass the time.



This is what a room inside PICU looks like.

The Surgery

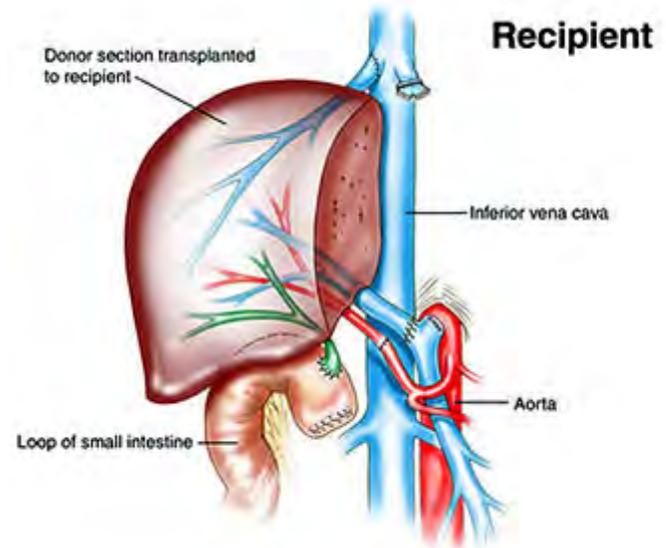
There is a team of health care professionals in the operating room who work together to care for your child and do the transplant. The team includes anesthesiologists, surgeons, nurses, and technicians.

The surgery takes 4 to 8 hours. Your child will be taken to the operating room an hour or more before surgery, so that the anesthesiologist and nurses can get your child ready for the operation.

In the operating room

There are several actions that take place as soon as your child gets to the operating room before the operation itself can start. These actions include:

- The anesthesiologist will give your child sleep medicine through the IV.
- When your child is asleep, 2 more IV lines and an **arterial line** will be put in. The arterial line looks like an IV but is placed in an artery instead of a vein. It is used to monitor blood pressure and to draw blood.
- A **central line** may also be put in. This is a **catheter** that is put in a large vein. Blood can be drawn from the central line and it may stay in place even after your child is discharged from the hospital.
- A **Foley** catheter will be put in your child's **urethra** and bladder to keep track of urine output.
- A blood pressure cuff, EKG stickers, a temperature probe, and a **pulse oximeter** will be used to track your child's vital signs.



- An **endotracheal** tube, or ET tube, will be placed in your child's nose or mouth. This tube connects to the windpipe (trachea) and a **ventilator** to help your child breathe.
- A **nasogastric tube** (NG tube) will be put in your child's nose through the esophagus and into the stomach. This tube helps drain stomach contents.

The surgeon will begin by cleaning your child's skin. Drapes will be placed around the area to be operated on. Next, an incision is made in the upper part of the abdomen, sometimes extending up to the breast bone. If your child has had a previous procedure, the Kasai procedure for example, the same incision is usually used.

The diseased liver will be removed and sent to the laboratory for examination, and the surgeons will sew the healthy liver in place.

Three major groups of blood vessels are connected:

- hepatic veins
- hepatic artery
- portal vein.

Once these steps are done, the new liver will look pink and feel firm.

Next, a drain is made to drain bile into the intestines. If your child has had a Kasai procedure, the biliary connection will be similar, and is called a Roux-en-Y. A Roux-tube may be placed to keep the biliary connection open. It drains to outside the body.

Everything is checked carefully before closing the abdomen.

Two or 3 Jackson-Pratt drains, which look like soft hand grenades, are placed around the liver to remove extra fluid that happens after surgery. You will be able to see these drains coming out of the incision site.

The wound is then closed with stitches in the abdominal wall and sometimes staples in the skin. If stitches are used, they do not need to be removed later because they will dissolve on their own.

Most children need a blood transfusion during surgery. Sometimes families ask if they should donate blood before the surgery, but because the surgery is not scheduled, it is better to wait until after surgery.



This small drain on top of the gauze square is called a Roux-tube.



This is a Jackson-Pratt drain (JP drain).

After Surgery

After surgery, your child will be moved to the Pediatric Intensive Care Unit (PICU).

There will be a wait before you can see your child while the doctors and nursing staff get your child settled.

What will be on my child's body after surgery?

- There will be monitors on your child that check heart rate, breathing, blood pressure, and oxygen level. Sometimes the monitors' alarms go off. If this happens, the nurses will check your child and the equipment.
- Your child will still have the IV lines and arterial line that were put in for surgery. IV pumps will be used to give IV fluids and medicines. The arterial line will be removed before your child is transferred from the PICU to a surgical recovery unit.
- If a central line was put in for surgery, it will still be in place. If your child still has the central line when he or she goes home, we will teach you how to use it and take care of it.
- The ET tube will still be in place. Your child will not be able to talk, eat, or drink with the ET tube in place. Many children communicate by using hand signals or by writing on a pad. The ET tube is removed when your child no longer needs help breathing. Once the tube is removed, your child must do deep breathing and coughing exercises to keep his or her lungs clear and to prevent pneumonia.
- The NG tube and JP drains will stay in place for several days.

- The Foley catheter will stay in place, also. It is used to measure urine output and to keep track of how well your child's kidneys are working.
- A Roux-tube may be placed to keep the bile duct open. This tube may stay in place up to 4 months.

Your child will have many routine tests after surgery. These will include ultrasounds, X-rays and blood tests. Chest x-rays are done to assess your child's lungs. Blood tests are done daily throughout the hospital stay.

When medically stable, your child will be transferred to a room on the 8th floor. The surroundings will be more relaxed because patients in the surgery recovery unit no longer need the continuous monitoring that they needed in the PICU.

The time in the PICU is usually a few days to a few weeks. Smaller children tend to stay in the PICU for a longer time.

The time on the 8th floor is usually an additional 1 to 2 weeks, after leaving the PICU.

Risks of surgery

- **Biliary leaks and biliary strictures.** The new bile duct connection may leak or become blocked. This happens in about 5 to 15 patients out of 100 pediatric liver transplants. Most biliary leaks do not need surgery, but some do.
- **Bleeding.** It is very common for there to be bleeding after transplant, and your child may need blood or other blood-product transfusions. Sometimes this means another trip to the operating room, but not always. Bleeding becomes less of a problem as the liver begins to recover, which is soon after the operation.
- **Hepatic artery thrombosis.** This is a serious complication that happens in 2 to 10 patients out of 100 pediatric liver transplants. The **hepatic** artery, which is attached to the new liver's artery, narrows from a blood clot. This causes the liver to fail and it must be corrected, either by surgery or another transplant.
- **Infection.** Your child has a higher chance of getting infections because of the medicines he or she must take to help keep the transplanted liver from being rejected. Infections may be in the blood (sepsis), surgical wound, or in other parts of your child's body. We give your child antibiotics and other medicines to try to prevent infections.
- **Primary non-graft function.** Sometimes the transplanted liver may not work at all and another transplant may be needed. This does not happen very often.
- **Rejection.** This is when an organ recipient's **immune system** attacks the transplanted organ. Almost all transplant patients have rejection at least once. Rejection usually happens within the first month after transplant, but can happen anytime. Rejection does not necessarily mean that your child needs another transplant, but it does need to be treated right away. Sometimes the only symptom of rejection is increased liver numbers on blood tests, which is why getting blood drawn a few times a week after transplant is important. Your child will need fewer blood draws over time.
- **Vascular complications** (problems with blood vessels). Two to 10 patients out of every 100 pediatric liver transplants have problems with the connections between veins and arteries of the new liver, such as narrowing (stenosis) or clotting. Sometimes this means removing a clot (thrombectomy) in the operating room. This can happen later after transplant, too.

Recovery

Parents and caregivers can help during recovery by participating in your child's care. There are many things you can do, including:

Walking

Take your child for walks around the room and hallway. Your child will become more active every day. This helps build your child's strength.

Coughing and deep-breathing exercises

Your nurse will show you and your child how to do these exercises. Your child will use an **incentive spirometer**, which is a plastic tube connected to a container, to help him or her take deeper breaths.

Eating

When your child is able to eat after surgery, he or she will start with clear liquids and advance to solid foods. The body needs many calories to heal and grow. It is important that your child eat well-balanced meals. If your child cannot get enough calories, he or she may be fed through the NG tube or the IV. Nutritionists will meet with you and your child to help make a good eating plan.



Relaxation and play

Play is an important part of your child's physical and emotional recovery. The child life specialist will help your child find toys and games to play with during the recovery.

Daily care

Your child should continue bathing, brushing teeth, and putting on fresh clothes while in the hospital. Your child's nurses will be glad to help you.



Section 4: Transplant Medicines

Guidelines and Helpful Tips

Your child's immune system is programmed to react to foreign objects, like germs, by attacking them and getting rid of them. Unfortunately, the immune system will react to the new liver as a foreign object, too, and will try to reject it. For the rest of his or her life, your child will need to take medicines to prevent rejection. These medicines are referred to as anti-rejection or immunosuppressive medicines.

We will start giving your child medicines at the time of the transplant operation to prevent organ rejection including tacrolimus, prednisone, and mycophenolate.

Your child will also need to take medicines to prevent infections that can happen because the immune system is not working like normal. Many of these medicines may be stopped by one year after transplant.

Other medicines, including aspirin, will be needed. Medicines to lower high blood pressure and stronger anti-rejection medicines may be prescribed over time.

Generally, transplant patients will take 10 to 12 medicines every day. A consistent caregiver is recommended so medicine mistakes are less likely. Parents and caregivers should try to understand why and how each medicine is given.

We will work with you to make a medicine plan and daily schedule to help you

keep track of your child's medicines. It is important that you mention any special situations at home or school that may affect the medicine schedule. School nurses may be available to give your child medicine during school hours, but we try to avoid the need to give medicines during school hours, because it can lead to medicines being given at the wrong time or missed completely.

Don't run out of medicine

It is your responsibility as parent/guardian to be sure your child does not run out of medicines. Call your pharmacy to refill prescriptions at least 1 week before the medicine supply will run out. Pay attention to the number of refills to avoid running out of refills. To order a refill, tell the transplant coordinator while you are at a clinic visit or call the Liver Transplant office, Monday through Friday at (615) 343-BILI (343-2454).

It is difficult to fill prescriptions on weekends and holidays because it is outside of regular office hours, limited pharmacy hours, and problems getting medicines compounded (made from pills into a liquid). If you need prescriptions called in on the weekend, call the Liver Transplant Office at (615) 343-BILI (343-2454). You will need to provide the name(s) of the medicine(s), if it is in pill or liquid form, the strength, the dose, and the phone number of the pharmacy.

Do not assume that because you have no refills that it is okay to stop giving that medicine to your child.

Tips to help your child take medicine

Getting children to cooperate in taking medicine can sometimes be difficult. Parents and nurses often need to be firm with children about taking medicine. It is important that your child take his or her medicine as prescribed and on time.

Here are some tips to help both you and your child:

- **Try giving your child some control by offering choices**, such as which medicine to take first, what to drink with the medicine, and how to take the medicine. Our child life specialist, transplant coordinator, and transplant pharmacists can help.
- **Help your child learn to swallow pills.** Pills travel better and the prescriptions are easier to refill than liquids. Pills can help prevent struggles with liquid medicines that may taste bitter.
- **Use simple, honest language about the medicines and why your child needs them.**
For example: "This medicine helps fight the germs that can make you sick."
- **Prepare your child in advance about taking the medicine.** This will help your child feel more in control.
For example: "After breakfast, it is time to take your medicine."
- **Make medicine time part of a daily schedule or routine.** This helps children be ready for the medicine.

- **Use incentives that can help your child work toward a goal.** This can also be a visual reminder of success.

For example: Post a sticker chart and let your child place bright-colored stickers on the chart after taking each medicine.

- **Be easy-going and upbeat when talking about medicines.** Children are tuned into your emotions and can sense if you are expecting a lack of cooperation or resistance.
- **Use play to explain and understand the importance of the medicine.**
For example: Pretend to give medicine to a stuffed animal or doll. This can help your child practice taking medicine and let him or her explain to the stuffed animal why it is important.
- **Give praise.** Remember to praise and hug your child when he or she has taken medicine. When needed, you may need to apologize to your child for the difficulty of taking medicine. Talk about ways to make the process better next time.
- **Ask your doctor or pharmacist if the medicine can be mixed or taken with food or liquid.**

Positioning for babies and toddlers

- If your child is a baby, toddler, or preschooler, let him or her sit in your lap to take the medicine. Sitting close to you can give your child a sense of comfort and control.
- Let your child hold a comfort item, like a blanket or toy.

Liquid medicines

Medicines with bitter tastes are difficult for children to take. Here are some things you can try to help make taking liquid medicines easier:

- Use a syringe to give young children medicine. You can get a syringe from your doctor or pharmacist.
- Let your child suck on an iced pop or ice before taking the medicine. The cold will numb the taste buds.
- Mix medicine with a strong-flavored liquid, such as chocolate syrup, cherry syrup, pancake syrup, or flavored coffee syrups.
- Let your child eat some peanut butter or maple syrup before taking the medicine. This will coat the tongue and make the taste less bitter.
- Ask your pharmacist if flavoring can be added to the medicine.

Pills

Swallowing pills can be difficult for children. To help your child learn to swallow pills, try some of these tips:

- Ask for pills in gel caps. The gel coating hides the bitter taste of the pill.
- Place the pill in gelatin or pudding and let the pill slide down the throat. Practice swallowing the food first, so it is easier when the pill is placed inside.
- Practice by swallowing candy first. Start with something small like candy cupcake decorations, mini chocolate dots, candy-coated hard mints, fruit-flavored dots, and jelly beans. Start with a size your child is comfortable with and move up to larger candy after swallowing successfully 5 times with one size.

Note: Teaching your child to swallow pills using candy can be helpful. However, be sure to teach your child that medicine is not candy, even though sometimes it may look like it.

- Try a pill-swallowing cup. Ask your pharmacist or stop by Champ's Corner Store on the 2nd floor of Children's Hospital to find a pill-swallowing cup.
- Try coating the pill in a fast-hardening chocolate syrup. You will need to put the pill in your freezer at least 30 minutes before trying the coating, however, as the chocolate syrup only works if the pill is very cold.
- Use a piece of a rolled fruit snack to wrap around the pill.
- Chop pills up into smaller pieces if your pharmacist says it is okay to chop the pills. Give your child the pieces one at a time to build up confidence.
- Crush pills into a powder and mix with foods or liquids. Before mixing medicines in foods or liquids, check with your pharmacist, in case the medicine cannot be crushed or mixed with foods or certain kinds of foods, like dairy. Use only a small amount, such as a teaspoonful, of food or liquid to be sure all the medicine is taken. Ask your child what food or liquids sound good for mixing, be creative, and try different foods and juices to make medicine taste better. You might try:
 - applesauce, yogurt, sherbet, pudding, or ice cream
 - fruit-flavored syrup or juice
 - frozen raspberry juice .

Preventing errors with medicine

- **Give the right dose.** The dose of medicine will change often and the instructions on most medicine bottles will not match the dose your child actually needs to take. It is important to keep new dosing instructions written down.
- **Use a syringe to measure and give liquid medicines.** Do not use a kitchen teaspoon or tablespoon. They are not a correct way to measure and may cause an overdose or underdose. Ask your pharmacy for measuring syringes.
- **Shake liquid medicine.** Mixing up liquid medicine before giving it allows a more accurate dose because most medicine will settle to the bottom if it is not shaken.
- **Measure liquid medicine in milliliters** (abbreviated “mLs” or “mL”). Using a teaspoon or tablespoon to measure with is not safe, because they are not exact.

- **Do not confuse milligrams (mg) with a milliliter (mL).** These are 2 different measurements, but are close in spelling. The milligram tells how much medicine is being given, **not** how much liquid to measure out of the medicine bottle.
For example: you are told that your child needs to take 2 mg of a medicine. You are told to measure 4 mL out of the bottle in order to give the 2 mg of medicine. This is because the example medicine mentioned is 0.5 mg of medicine for every 1 mL of liquid. Be very careful, and only give your child the amount of mLs we ask you to measure out of the bottle.
- **Remove the cap from syringes** before giving your child medicine from a syringe. Children can choke on a syringe cap if it gets squirted into the mouth by mistake. Children can also find the caps on the floor or in bedding and try to swallow them. Throw caps away or keep them away from children.

Sample prescription label

Pharmacy name, address, and phone number

Doctor's name

Prescription number
(used by pharmacy
for refills)

Name and address
of person who gets
the medicine

Instruction on
amount to take and
how often
(**may not match
the dose your child
needs to take**)

Name of medicine
and strength

VANDERBILT CHILDREN'S HOSPITAL
OUTPATIENT PHARMACY RM 2106
NASHVILLE, TN 37232-9650
DEA# CH123456 (615) 936-6337

RX#000000

PATIENT'S FULL NAME
Patient's Address, City, State, Zip

Prescribing Dr. Name here
DATE 00/00/00

Dose, *example:* **TAKE 1 ML DAILY**

Medicine name and strength, *example:* **100 mL Tacrolimus 0.5 mg/mL**

Number of refills: 6 **Use by: 9/9/09**

CAUTION: Federal law prohibits the transfer of this drug to any persons other than patient whom prescribed.

Number of refills

Do not use the medicine
after this date

Date prescription
was filled

- **Use the same pharmacy for every refill.** Children’s liquid medicine is usually made from crushed pills combined with liquid (compounded). Different pharmacies use different recipes to make these compounded medicines, which can effect the dose. The recipe difference may actually change your child’s blood level of certain medicines.

Also, many immunosuppressant or anti-rejection medicines for children are not easily available at a neighborhood pharmacy that doesn’t fill these types of medicines on a regular basis. Your child’s transplant coordinator will help you find a pharmacy that you like and you will need to continue using that one pharmacy.

- **Use mail order prescriptions when possible.** Many pharmacies ship medicines to your home and some insurance companies give a discount for filling a 90-day supply of a prescription.

About 6 months after transplant, many of the medicine dosing changes stop, so it will be easier to use mail order, even with liquid prescriptions. This is a good way to avoid running out of medicine.

Dealing with resistance to taking medicine

There may be times that your child will not want to take medicine. There will likely be times that the ideas and tips we have described will just not work. Your child may need a break for a few minutes. Wait for a few minutes, then ask if he or she is ready to take the medicine. If more than 15 minutes pass, explain to your child that the medicine is not a choice and that you have to give the medicine. At times you will have to be firm.



If needed, try these suggestions:

- **Get a helper.** Place your child in your lap and hug him or her. Ask your helper to give the medicine.
- **Hold your child’s mouth closed until medicine is swallowed.** Have your child sit up straight to help with swallowing.
- **Praise your child after he or she takes the medicine.** Tell your child you are sorry for how hard it is to take the medicine. Ask your child how you both can try to make it better next time.

Transplant Rejection Medicines

Your child will take a combination of some of these transplant rejection medicines.

Tacrolimus (FK506, Prograf)

Tacrolimus is an immunosuppressive medicine that is used to prevent rejection of transplanted organs. It is important to give this drug exactly as directed. Tacrolimus is taken for the rest of your child's life.

Tacrolimus comes in 0.5 mg, 1 mg, and 5 mg capsules; and as a liquid of 0.5 mg per mL.

- Tacrolimus is taken in the morning and at night, with 12 hours between each dose.
- The dose is adjusted based on blood levels. It is important to take tacrolimus exactly as directed and at the same time every day.
- Your child may take tacrolimus on an empty stomach or with a meal, but it is important to keep taking it the same way with regard to meals once you start it.

Special directions

- On a morning when your child is coming in for a blood draw, we want to draw the blood 30 to 60 minutes before the tacrolimus dose is due to be given. So, arrive to clinic in time for this blood draw, bring the tacrolimus dose with you, and give it to your child **after** the blood draw.
- See “**Food and Drinks to Avoid after Transplant**” on page 42 for details on what food and drinks your child should avoid while taking tacrolimus.

Possible side effects

Possible side effects of tacrolimus are high blood pressure, headache, infection, high blood sugar, tremors, high creatinine levels, high potassium, low magnesium level, diarrhea, higher risk of infection, and hair loss.

Cyclosporine (Gengraf, Neoral, sandimmune)

Cyclosporine is an immunosuppressive medicine that is used to prevent rejection of transplanted organs. Cyclosporine comes in 25 mg, 50 mg, and 100 mg capsules; and as a liquid of 100 mg per mL.

- Cyclosporine is taken in the morning and at night, with 12 hours between each dose.
- The dose is adjusted based on blood levels. It is important to take cyclosporine exactly as directed and at the same time every day.
- Your child may take cyclosporine on an empty stomach or with a meal, but it is important to keep taking it the same way with regard to meals once you start it.

Special directions

- On a morning when your child is coming in for a blood draw, we want to draw the blood 30 to 60 minutes before the cyclosporine dose is due to be given. So, arrive to clinic in time for this blood draw, bring the cyclosporine dose with you, and give it to your child **after** the blood draw.
- See “**Food and Drinks to Avoid after Transplant**” on page 42 for details on what food and drinks your child should avoid while taking cyclosporine.

Possible side effects

Possible side effects of cyclosporine are tremors, especially in your hands; kidney damage; high blood pressure; increased gum growth; and increased hair growth.

Sirolimus (Rapamune)

Sirolimus is an immunosuppressive medicine that is used to prevent rejection of transplanted organs. Sirolimus comes in 0.5 mg, 1 mg, 2 mg tablets; and as a liquid of 1 mg per mL.

- Sirolimus is taken once a day.
- The dose is adjusted based on blood levels. It is important to take sirolimus exactly as directed and at the same time every day.
- Your child may take sirolimus on an empty stomach or with a meal, but it is important to keep taking it the same way with regard to meals once you start it.

Special directions

- On a morning when your child is coming in for a blood draw, we want to draw the blood 30 to 60 minutes before the sirolimus dose is due to be given. So, arrive to clinic in time for this blood draw, bring the sirolimus dose with you, and give it to your child **after** the blood draw.
- See “**Food and Drinks to Avoid after Transplant**” on page 42 for details on what food and drinks your child should avoid while taking sirolimus.

Possible side effects

Possible side effects of sirolimus are high blood pressure, headache, infection, high blood sugar, tremors, high creatinine levels, high potassium, low magnesium level, diarrhea, higher risk of infection, hair loss, high cholesterol levels, swelling of feet and ankles, constipation, and rash.

Mycophenolate mofetil (Cellcept, MMF)

Mycophenolate mofetil (Cellcept, MMF): is an immunosuppressive medicine that is sometimes used in addition to tacrolimus and prednisone to treat or prevent rejection of transplanted organs in some patients. Mycophenolate mofetil comes in 250 mg capsules, 500 mg tablets, and as a liquid of 200 mg per 5 mL.

- Mycophenolate mofetil is taken in the morning and at night, with 12 hours between each dose. It should be given at the same time every day.

Special directions

Mycophenolate mofetil should be taken with food or after a meal to prevent upset stomach. It is not greatly affected by foods or when taken in combination with tacrolimus as was previously thought.

Possible side effects

Possible side effects of mycophenolate mofetil are upset stomach, diarrhea, infections, and low white blood cell count. This medicine may cause birth defects if your child becomes pregnant while taking it or becomes pregnant within 6 weeks of stopping the medicine.

❖ See page 42 for details on foods and drinks to avoid after transplant when taking tacrolimus, sirolimus, and cyclosporine.

Prednisone or prednisolone (Solu-Medrol, Orapred, Pediapred, Prelone)

Prednisone and prednisolone are steroids that decrease the body's ability to reject transplanted organs. We prescribe prednisone in 1 mg, 5, mg, or 10 mg tablets.

- It is given once a day in the morning or may be divided. The dose will be decreased over a period of 3 months and may eventually be stopped, unless your child has autoimmune disease.
- Do not stop prednisone if you run out of refills and if you have not been specifically told to do so.

Special instructions

- Take prednisone with milk or food to prevent an upset stomach.
- Do not stop suddenly or change doses without direction from your child's doctor.

Possible side effects

- Side effects from prednisone are high blood pressure, upset stomach and stomach ulcer, increased appetite, weight gain, puffy face, acne, high blood sugar, emotional changes, insomnia, fluid retention.
- The side effects from these medicines usually happen when taking high doses and will lessen when the drug is lowered or stopped.

Infection Prevention Medicines: Bacterial

Co-trimoxazole (trimethoprim and sulfamethoxazole) (Bactrim, Septra)

Co-trimoxazole is an antibiotic to prevent pneumocystis pneumonia. It comes in a pill of 80 mg and 160 mg, and as a liquid of 40 mg per 5 mL.

Possible side effects

Side effects are skin rash, low white blood cell count, and sun sensitivity.

Infection Prevention Medicines: Fungal

Nystatin

Nystatin is an antifungal medicine to prevent thrush. Nystatin comes as a liquid of 100,000 units per mL.

- It is taken 3 times a day.
- Your child should swish the liquid in his or her mouth and swallow it. If your child is unable to swish the medicine, use an oral swab to coat your child's mouth.

Special instructions

- Your child should not eat or drink for 30 minutes after taking nystatin.

Possible side effects

- Side effects are nausea, vomiting, and diarrhea.

Fluconazole

Fluconazole is an antifungal medicine used to prevent fungal infections like thrush or fungal bloodstream infections like candida. Your child may take this medicine for about 30 days after transplant. Fluconazole comes in 50 mg, 100 mg, 150 mg, and 200 mg tablets; and as a liquid of 10 mg per mL and 40 mg per mL.

- It is taken by pill or liquid once a day for 30 days for some patients.

Possible side effects

- Side effects of fluconazole are nausea, vomiting, diarrhea, and increased tacrolimus levels.

Infection Prevention Medicines: Viral

Ganciclovir

Ganciclovir is an antiviral medicine that is given through an IV to prevent and treat cytomegalovirus (CMV). Your child may receive this once a day while in the hospital.

Possible side effects

- Side effects of ganciclovir are low platelet count, low white blood cell count, rash, and elevated creatinine.
- Ganciclovir is a medicine that can cause birth defects in both sperm and eggs (**teratogen**).

Valganciclovir

Valganciclovir is an antiviral medicine taken by mouth and used to prevent CMV. Your child may have to take this medicine after they leave the hospital. Valganciclovir comes in a 450 mg tablet or as a liquid of 45 mg per mL.

- It is taken daily for 3 to 6 months after transplant.

Possible side effects

- Side effects from valganciclovir are low platelet count, low white blood cell count, rash, and elevated creatinine.
- Valganciclovir is a medicine that can cause birth defects in both sperm and eggs (**teratogen**).

Acyclovir (Zovirax)

Acyclovir is an antiviral medicine that prevents herpes simplex virus (HSV). It comes in a pill or liquid. Acyclovir comes in 200 mg, 400 mg, and 800 mg tablets; and as a liquid of 200 mg per 5 mL.

- May take on an empty stomach or with a meal.

Possible side effects

- Acyclovir may cause nausea, vomiting, and headache.

Other Medicines

Aspirin is given to prevent blood clots from forming in the liver blood vessels. It is taken once a day in the morning.

Magnesium supplements may be prescribed for your child because tacrolimus can cause low magnesium. These are usually taken 2 to 4 times a day.

Calcium supplements may be prescribed if your child has low bone density because of liver disease or anti-rejection medicines, such as prolonged use of steroids or tacrolimus.

Famotidine, omeprazole, lansoprazole, or esomeprazole are antacid medicines prescribed when taking prednisone to protect the stomach. These are also used to treat other stomach-acid problems.

Take antacids on an empty stomach 30 minutes before first meal of the day; do not chew or crush. Capsules can be opened and the contents sprinkled on applesauce or yogurt, given with fruit juices, or swallowed right away with water. Do not crush or mix contents into food.

May cause headache, nausea, vomiting, and diarrhea.

Over-the-counter Medicines

Contact the liver transplant coordinator if your child is taking medicine prescribed by another doctor and any herbals, over-the-counter medicines, or home health remedies. All of these may affect the blood levels of the anti-rejection medicines, raise blood pressure, or cause other side effects.

Age- and weight-appropriate doses of acetaminophen (Tylenol) can be given to treat cold and fever symptoms, as long as the liver is working normally. **Do not give your child ibuprofen (Motrin or Advil) after liver transplant because it can affect kidney function and blood clotting.**

Please use caution when giving over-the-counter medicines for relief of cold symptoms. Those medicines may hide important signs and symptoms of problems. See “**Over-the-Counter Medicines after Transplant**” in the References tab on page 41 for more information on what medicines your child can and cannot take.

Call the transplant clinic before giving over-the-counter medicines to your child.

❖ Do not give your child ibuprofen (Motrin or Advil) after transplant.

❖ Use caution when giving your child over-the-counter medicines for cold symptoms. See page 41 for details.



Section 5: Home Care and Lifestyle Changes

Follow-Up Care

If all goes well, you can expect a hospital stay of 1 to 4 weeks after your child's liver transplant. When your child is discharged from the hospital, you will need to come to the Liver Transplant Clinic for regular visits and lab tests. These visits also give you a chance to ask questions about your child's health and medicines.

The Liver Transplant Clinic is located on the 10th floor of Doctors' Office Tower inside Monroe Carell Jr. Children's Hospital at Vanderbilt. Your child will be seen 1 to 2 times a week for the first 1 to 2 months after transplant, then every other week for 1 to 2 months after that. Over time and as your child's recovery is going well, your child will not have to come to the clinic as often. Sometimes lab tests may need to be done in between clinic visits. These can be done either at the hospital or at a lab close to your home through your pediatrician's office.

When you bring your child to clinic, please bring referral paperwork that your insurance company needs, if any.

After your child is checked in on the 10th floor, we will send you to the lab so your child can have his or her blood drawn.

Important: We want to draw the blood 30 to 60 minutes before the tacrolimus (Prograf), sirolimus (Rapamune), or cyclosporine (Neoral) dose is due to be given. So, arrive to clinic in time for this blood draw and bring the medicines with you and give to your child **after** the blood draw.

The transplant team will review your child's lab results the day of the clinic visit, but sometimes the drug level is not back until the following day. The Transplant Coordinator will contact you to let you know if any medicine changes need to be made or if more lab tests need to be done.

If your child has any medical problems or if you have questions, call to leave a message for the liver transplant team at (615) 343-2454 (615-343-BILI) anytime day or night. The liver transplant coordinators check messages Monday through Friday, 8 a.m. to 5 p.m. and will return your call. After these normal business hours, doctors will be paged for urgent issues.

Wound Care

After liver transplant, there will be a large surgical line across the belly. At first, the wound will be covered in gauze dressings, and later it will be open to the air. No medicines or ointments are put on the wound, unless the surgeon thinks it is needed.

Incision healing

It is common to see light-yellow drainage from the incision during the first few days after surgery, but the skin will begin to heal quickly. The surgical drains usually will be taken out the first week after surgery.

The incision is usually closed with stitches, but sometimes staples are used. If stitches were used, they dissolve on their own and do not need to be removed. If staples were used, they are typically removed about 10 days to 3 weeks after surgery.

Small white strips of tape (Steri-strips) might be across the incision to help support the wound. These fall off on their own about in 10 days.



Cleaning the incision

The wound must be kept dry and clean. This can be a challenge, especially if your child is young. It is best to have your child shower, instead of taking a bath. Use clean running water and mild soap to wash the incision. If a shower isn't possible, give your child a bath and use a clean washcloth and fresh bath water to clean the incision area first, before bathing the rest of the body. The incision can be patted dry with a clean towel or cloth; do not rub it dry.

A snug T-shirt or onesie may be worn after bathing. The staples may itch a little, so it is important to keep your child's fingernails clipped short and try to keep your child from scratching the incision.

Clean the incision right away if clothing or diapers soil the area around the incision.

Key points about wound care

- ✓ Keep the incision clean and dry
- ✓ Do not use ointments or creams
- ✓ Do not let your child soak in a tub or swim until all scabs are gone and the wound is completely healed
- ✓ Showers or clean running water over the incision is preferred over baths
- ✓ **Check for signs of infection at the incision site and call the Liver Transplant Clinic at (615) 343-BILI (343-2454) right away if:**
 - the incision is red or hot to the touch
 - there is swelling around the incision
 - there is pus coming from the wound
 - the incision comes apart
 - there is any tissue that pushes out or feels different around the incision
 - your child's temperature is 100.5°F (38°C) or higher.

Activity

There will be some limits to your child's activities at first to give the incision time to heal. However, after the incision has healed, your child can be as active as other children—participating in physical education classes, riding a bike, skateboarding, and other activities.

Start your child with slow, easy exercises to gradually build up strength. Walking is a great exercise to get your child moving after surgery. Your child may get tired easily at first and will need to take many rest breaks.

Most parents of children with transplanted livers say that the child has more energy after transplant than before transplant. This is because the child now has a healthy liver that works the way it should to use nutrients and process the body's waste.

We do suggest that your child wear a medical identification bracelet (or other style of medical jewelry) at all times. In case of an emergency, the bracelet explains that your child has had a liver transplant and how to contact your transplant team. You can order a medical identification bracelet online by searching “medical ID bracelets” or visit a local medical supply store.

Key points about activity

Your child should not:

- ✓ participate in any contact sports for 3 months after surgery
- ✓ drive while still taking prescription pain medicine (narcotics)
- ✓ drive until your child's surgeon says it is okay
- ✓ swim for at least 3 months after surgery. Before your child can swim, his or her incisions must be completely closed and healed. Swimming in chlorinated pools is best.
- ✓ swim in a public “kiddy pool”.
- ✓ do sit-ups or abdominal exercises for 3 months after surgery.

Your child should:

- ✓ know how to wash his or her hands well. Good hand hygiene is very important to keep from getting sick from germs.
- ✓ return to school and normal social activities 2 months after transplant.

✱ Wash hands with soap and warm water for at least 20 seconds—if your child is old enough, remind him or her to say the “A, B, C’s” twice while washing hands. See page 43 for details.

Food and Food Safety

It is very important for your child to eat healthy foods and drinks after transplant. Usually, a well-balanced diet of fruits, vegetables, and low-fat proteins, and a multi-vitamin are all your child needs.

However, if your child had a difficult time eating enough calories and nutrients before transplant because of liver disease, he or she may need extra time after surgery before feeling well. Sometimes children are not able to take in enough calories even after transplant and need other kinds of nutrition. Dietary supplements, such as high-calorie drinks or nasogastric tube feeds, may be needed for your child to get enough calories, vitamins, and minerals.

Sometimes vitamin and mineral supplements may be prescribed, such as vitamin D, calcium, magnesium, and iron.

Some foods your child might normally eat should not be eaten after transplant because of the medicines your child takes. Grapefruit and grapefruit products may increase the amount of these medicines in your child's body. This can be dangerous and possibly life threatening. See "**Food and Drinks to Avoid after Transplant**" on page 42 for details on what food and drinks your child should avoid.

Your child's eating habits may change after the transplant. His or her appetite may be better or worse. This happens for many reasons. It is important to know that every child's appetite is different.



Follow safe food guidelines

- Your child should always wash his or her hands before eating
- If your child takes lunch to school, be sure to use a cooler (insulated) lunch box to keep deli meat and other **perishable** foods at a safe temperature.
- Be sure that fruits and vegetables have been thoroughly washed under running water, or eat them cooked.
- When dining out, ask your server to explain how foods are prepared, if needed.
- Your child **should not** eat:
 - raw or undercooked seafood
 - raw sprouts, including alfalfa sprouts
 - soft cheeses like Brie, unless it is baked
 - cold, smoked fish
 - foods containing raw eggs, such as hollandaise or Caesar dressing.

Cook foods correctly

- Use a food thermometer to measure that food is cooked to the correct internal temperature. This is the only way to know for sure if the food is done and safe to eat. Food thermometers are available at most grocery stores. Wash the thermometer in hot soapy water after each use.
- Cook eggs until the whites and yolks are completely hard cooked and not runny.
- Make sure milk, dairy products, and juices are **pasteurized**.

Keep different foods apart

Preparing meat and fish using the same cutting board and utensils as other foods, such as fruits and vegetables, can spread germs from the raw meat. This is called “cross contamination.” To keep foods from being cross contaminated:

- wash knives, cutting boards, and food preparation areas with hot, soapy water after touching meat and fish
- wash your hands with soap and warm water after handling foods
- rinse fresh fruits and vegetables well with running water before eating.

Keep foods at safe temperatures

- Store all perishable foods in the refrigerator.
- Thaw frozen meat and fish only in the refrigerator (1 to 2 days) away from raw fruits and vegetables. **Do not thaw meat or fish on the counter or in the sink.** Cook defrosted meat right away; do not re-freeze. If you are in a hurry, you can thaw in the microwave, but you must cook the meat right away.
- Pay attention to expiration dates of foods and do not give them to your child if the food is out of date.

Type of Food	Safe Temperature When Cooked
Beef, veal, lamb	At least 145°F (74°C), which is considered medium rare
Fish	Usually 140°F (60°C) or until fish flakes easily with a fork
Ground beef, ham, pork, and sausage	160°F (71°C)
Ground turkey and chicken, hot dogs, and lunch meat	165°F (74°C)
Egg casseroles and custards	160°F (71°C)
Leftovers	165°F (74°C)
Poultry white meat (chicken, turkey, and duck breast)	170°F (77°C)
Poultry dark meat (chicken, turkey, duck wings, legs, and thighs) and whole bird	180°F (82°C)

❁ See page 42 for details on foods and drinks to avoid after transplant.

Safe drinking water

- Well water must be boiled to a rolling boil for at least 10 seconds, then cooled to room temperature before drinking
- City water is safe out of the faucet and a filter is not required.
- Young children usually swallow water when swimming, which is why swimming in lakes is not recommended.

Keep foods safe at a picnic

- Take only foods that can be kept at a safe temperature on picnics.
- Carry cold foods in an ice chest. Keep cold food at or below 40°F (4°C)
- Be sure that grilled meat is cooked to a safe temperature (see chart).
- Throw away any leftovers that were left out of the ice chest more than one hour.



Organ Rejection

The immune system is the body's natural defense mechanism against infection. It protects the body from foreign substances, such as bacteria and viruses, by destroying them. The body's immune system considers the transplanted liver to be a foreign body and tries to attack and destroy it. This is called rejection.

As described in the medicines section on page 17, your child will take medicines called immunosuppressants, or anti-rejection medicines to lower the activity level of the immune system. Your child will have to take immunosuppressive medicine for the rest of his or her life. Rejection, however, can happen even while your child is taking immunosuppressive medicine. Stopping medicine may not cause a rejection right away, but rejection will eventually happen if your child stops taking immunosuppressive medicines without being instructed to do so.

Early signs of rejection

- Temperature of more than 100.5°F (38°C) under the arm
- Increase in liver enzymes (blood work)
- Abdominal or stomach pain.

Later signs of rejection

- Yellow color of the skin and eyes (jaundice)
- Urine color changes to what looks like tea or cola
- Stool color changes to white or beige.

Some or none of these symptoms may happen during rejection. Often, changes in blood levels found with a blood test are the only sign of rejection. It is important to keep your child's transplant clinic appointments and get lab work done to keep the liver healthy. A **liver biopsy** will be done if the doctors think your child has rejection. Rejection can only be diagnosed by a liver biopsy, and the biopsy also helps your child's doctors know how much of your child's liver has been affected by rejection and what medicines will work best to treat it.

Your child may be admitted to the hospital depending on the severity of the rejection. **Intravenous** steroids and adjustments to the immunosuppressive medicines are the usual treatments for rejection.

Causes of rejection

It is important to know that most rejection is preventable, especially as more time passes after transplant.

One of the number one causes of rejection is not giving the right dose of medicines at home or simply not taking the medicines at all. Since rejection can happen at any time and sometimes without any symptoms, it is important to give the medicines exactly as prescribed and follow the schedule of getting blood work done.

Illnesses and Long-term Risks

After a liver transplant, your child will be able to do things like most other children: go to school, play sports, and grow. He or she will always need to take medicines, have blood work done regularly, and see a hepatologist or liver transplant surgeon at least once a year, after the first 2 years, to be screened for certain health problems.

Your child may catch a cold or have a fever, runny nose, or cough, as most children do. For this reason, it is very important to continue to see your child's primary care doctor for these common illnesses and contact the transplant office when your child gets sick.

We recommend that you send a letter to your child's school asking that they let you know right away if your child has been exposed to chicken pox, measles, or any contagious illness.

Tips to avoid illness and find problems early

- Teach your child how to wash his or her hands the right way and often (See *"Champ teaches how to wash your hands"* in the References tab on page 43)
- Keep hand sanitizer and tissues handy.
- Take your child's temperature nightly for the first few months after transplant (see *"Taking Your Child's Temperature"* in the References tab on pages 44–45).
- Teach your child to cough and sneeze into his or her sleeve.
- Keep your child away from sick children, when possible.
- Keep your child out of day care, if possible.
- Continue to see your child's primary care provider at least once a year.

Common childhood diseases

Chicken pox

Chicken pox is spread through the air or by close contact with someone who has the virus. It often begins with a fever. The rash may begin on the head and spread downward, or it may begin on your child's trunk (belly and back) and spread outward. The rash consists of small, watery blisters with red rings around them.

A person with chicken pox is contagious 2 days before the rash appears and until the entire rash has been covered by scabs. If your child is around someone during the contagious time, he or she may get the virus 10 to 21 days after exposure (the incubation period). As soon as you know your child has been exposed, your child may need medicines to lessen the effects of the chicken pox. Should your child actually get the rash, he or she will need to be admitted to the hospital. Chicken pox can be a serious illness for a child who has received a liver transplant.

Thrush

Thrush is a white growth on the inside of the mouth and throat caused by a fungus. It is very common when taking steroids, and it can be treated with medicines.

Your child will be taking medicines to prevent this type of infection early after liver transplant, and the medicines will be stopped once the other anti-rejection medicines are at lower doses.

Cold sores

Cold sores are little blisters that occur around the mouth and are actually caused by a virus. Children with transplant can develop more severe cases that cause blistering down the throat and the inside of the mouth.

Vomiting and diarrhea

Vomiting and diarrhea can raise or lower the drug levels like tacrolimus. If diarrhea or vomiting persists more than half the day, causes your child to look dehydrated or not to drink the usual amounts, or your child vomits up medicines we ask that you please call the transplant office.

High-risk illnesses

Increased infections

Anti-rejection medicines make it easier to get infections that other people do not get, or make common infections last longer and cause more problems. It is important that your child not be around crowds or people who may be sick especially for the first month after transplant.

Your child's transplant coordinator will teach you what to do to avoid infection and how to watch for certain infections that are common in transplant patients. The best protection against infection for you, your child, family members, and visitors is for everyone to wash their hands often and have immunizations as recommended by the transplant team.

Your child will need to take an infection prevention medicine after transplant to help prevent an infection called pneumocystis pneumonia for the rest of his or her life.

Cytomegalovirus infection

Cytomegalovirus infection (CMV) is a common infection in liver transplant patients. Symptoms range from no symptoms at all to very bad diarrhea, high fever, cough, inflamed liver (hepatitis), and liver rejection.

Your child can be exposed to CMV from the transplanted liver or from the general public. Usually, CMV is a problem in the first 6 months after transplant, but can happen anytime after transplant.

Your child will be taking medicines to prevent this type of infection early after liver transplant, and the medicines will be stopped once the other anti-rejection medicines are at lower doses. We can watch for this virus in your child's regular blood tests and treat it with medicines if needed.

Epstein-Barr Virus

Epstein-Barr virus (EBV) is a common infection in liver transplant patients. EBV is the same virus that can cause mononucleosis, also called 'mono' or the kissing disease. Symptoms range from no symptoms at all to sore throat, fever, and swollen lymph nodes. Your child can be exposed to EBV from the transplanted liver or from the general public. Usually, EBV is a problem in the first 6 months after transplant, but can happen anytime after transplant. We will watch for this virus in your child's regular blood tests and treat it with medicines if needed.

Post-transplant lymphoproliferative disease

Some children who take anti-rejection medicines may get post-transplant lymphoproliferative disease (PTLD), which is a disorder that causes lymphocytes (a type of white blood cell) to start growing rapidly and abnormally. This is usually triggered by EBV. This virus infects B-cells, which are cells that help your body fight off illnesses. B-cells are in the blood and lymph glands.

Transplant patients can be exposed to the virus from the transplanted liver or from the general public. PTLD can happen at anytime after transplant. Lowering the amount of anti-rejection medicines can help if PTLD is found early, but sometimes chemotherapy is needed if PTLD progresses into cancer of the lymph cells (lymphoma).

Cancer

One of the important things a normal immune system does is watch for abnormal cell growth (cancer) and eliminate those cells from the body. Taking anti-rejection medicines lowers the body's ability to do this. The type of cancer that transplant patients get most often is skin cancer. For this reason, any change in a mole or freckle should be reported right away. Your child should wear sunscreen and a hat when outside, even on cloudy days. This is for all patients, even those with dark skin. Yearly skin surveys by your child's primary care provider or a skin doctor (dermatologist) are recommended.

Bone disease

Many anti-rejection medicines cause bones to weaken over time. Your child will have special X-rays called bone density studies throughout his or her life to watch for bone loss. Sometimes extra medicines are needed to prevent broken bones. Most patients must take calcium and vitamin D supplements to support bone health.

High blood pressure

Many anti-rejection medicines and over-the-counter medicines cause high blood pressure (hypertension). This can happen at any time after transplant. Your child's blood pressure is watched closely and medicines may be needed to help lower his or her blood pressure.

Poor kidney function

Long-term risks of being on anti-rejection medicines is poor kidney function. This can happen anytime after transplant. Your child's blood and urine will be checked to watch for this. Your child will take fewer and fewer anti-rejection medicines over time to keep his or her transplanted liver working as best as possible and lower risk of poor long-term kidney problems. It is important for your child to not take ibuprofen (Motrin and Advil) and naproxen (Aleve) to protect the kidneys.

Coping After Transplant

Your child's liver illness and transplant not only changed his or her life, but the lives of everyone in your family. You, your child, and your family members may feel scared, worried, guilty, sad, and many other emotions. And, while it is exciting and a celebration to finally get the transplanted liver, it may also feel strange that someone else was needed to give part or all of their liver for your child to live a normal life.

Whatever feelings you and your child have, it is important for you to know that the feelings are normal and there is no right or wrong way for anybody to feel. It is also important to talk about these feelings because sharing how you feel can help you cope.

Emotions

Worry or fear

Not knowing what your child's life will be like after transplant, including how your child's recovery will go, can be stressful. You may also have fears about the costs, medicines, or organ rejection. Talk about these fears and get them out in the open.

Excitement

Your child can run, jump, and play with more energy than he or she may ever have before. It may be an exciting time for everyone in the family.

Guilt

You or other family members may feel guilty if you think you caused your child's illness, because you are healthy, or because someone else needed to give the donated liver. You and your family members need to know you did not cause the liver illness.



Depression or grief

Depression is used to describe many emotions and it can cause different reactions in different people. Some people may cry a lot, not feel like eating, have little interest in regular activities, not have any energy, or have physical symptoms like headaches or feel sick to their stomach.

Feelings of depression or grief can change family routines and make family members feel lonely or apart from each other. Some days everything may seem to be going great and the next day brings troubled feelings. This up-and-down range of emotions is very normal after transplant. You, your child, and your family members need to know you are not alone. With support from family, friends, and your child's transplant team, most families can work through the emotions.

Suggestions to help you cope

Here are some suggestions to help you, your child, and your family members cope:

- Set aside some time to talk to your spouse or a friend. Talk about topics other than your recovering child.
- Don't talk about your recovering child if he or she is in the room, unless you include your child in the conversation.
- Try to do some activities to reduce stress like reading, watching a funny movie with your family, or playing a game.
- Get out and walk. Walking is good exercise for you and your child, and it helps your body handle stress.
- Take breaks from full-time care of your child by asking your spouse, a close friend, or one of your older children to help. This gives you time to de-stress and lets other caregivers feel needed and involved. Having your spouse, partner, and older children involved can also reduce feelings of separation between family members that sometimes happens when one person is more involved in the care and treatment of the recovering child.
- Talk to other parents of children who have had transplants or join a transplant support group.
- Talk with your spiritual leader.
- Talk to one of the people on your child's transplant team: transplant coordinators, social workers, doctors, nurses, and child life specialists.

Impact on your marriage

Your child's illness, surgery, and recovery have a big impact on your relationships with friends, co-workers, your other children, and certainly your spouse. Spouses often take out their frustrations out on each other and don't take time for themselves.

You may both feel the pressure of trying to keep as normal a family routine as possible, keeping your jobs, and caring for your other children. This can be very upsetting to your family life and sometimes parents find themselves growing apart because they are stressed and tired.

Here are some tips to help you work together:

- **Talk to each other** about how you each cope with stress. Some people get angry, some withdraw, and some cry. Talking with each other about your reactions to stress may help prepare you and keep you working together.
- **Share your feelings.** Don't keep your feelings bottled up.
- **Talk about discipline for your recovering child.** Parents often make allowances for a sick child that can have long-term negative effects without proper planning.
- **Make plans for changing roles in the family, if needed.** Sometimes moms and dads take on different responsibilities when there is a child in the hospital or recovering at home. You might usually do all the household chores like cooking, cleaning, and taking care of the children. However, if you now have the primary role of caring for your recovering child, you may not have time. Your spouse will need to know he or she will need to step in to help.

Suggestions for divorced parents

Divorce is hard on any family, but when a child is ill, problems and miscommunication can increase. Sometimes a sick child can play parents against each other to make problems worse. Try to communicate with your ex-spouse. Remember, you are both still your child's parent.

Some things that can help keep you working together to care for your child:

- **Meet together with your child's health care team.** This can help avoid confusion about the plan of care.
- **If parents share joint custody, both parents must participate in transplant education before the child can return home.**
- **Ask for two copies** of patient education materials, medicine plans, etc.
- **Talk with a member of the transplant team** or ask to speak with a child life specialist if your child is having behavior problems.

✿ If parents share joint custody both parents must participate in transplant education before the child can return home.

Dental Care

All children should visit the dentist regularly. This is especially important for your child after liver transplant. Your child should brush his or her teeth at least twice a day, and most importantly before bedtime, because cavity-causing bacteria can do a lot of damage to teeth overnight.

Your child's dentist may put fluoride on the teeth, which helps prevent tooth decay. Applying fluoride will definitely be needed if the water supply in your home does not contain fluoride.

For 6 months after transplant and any time your child is on high doses of steroids, your child should not have any dental work or cleaning done.

For a year after transplant, your child will take prescription antibiotics 30 minutes to one hour before getting his or her teeth cleaned and before dental procedures. After a year, antibiotics will not be needed unless your child has artificial shunts in place.

If your child is taking cyclosporine, he or she can develop gum overgrowth. To prevent gum disease from this overgrowth, your child should visit the dentist at least 3 times a year for a checkup.

✿ For 6 months after transplant and any time your child is on high doses of steroids, your child should not have any dental work or cleaning done.



Section 6: References

Over-the-counter Medicines after Transplant

Some medicines should not be taken after transplant. Refer to the list below for medicines your child can and cannot take when for cold and allergy symptoms. Contact your child's transplant team to ask about any medicines not listed.

For cold, congestion, cough:

Medicines your child can take	Medicines your child cannot take
Dextromethorphan <i>Name brands:</i> Delsym, Robitussin DM	Pseudoephedrine (-D) <i>Name brand:</i> Sudafed D
Diphenhydramine <i>Name brand:</i> Benadryl	Phenylephrine (PE) <i>Name brand:</i> Sudafed PE
Guaifenesin <i>Name brands:</i> Robitussin, Mucinex	Ibuprofen <i>Name brands:</i> Motrin, Advil
Acetaminophen <i>Name brand:</i> Tylenol	Naproxen <i>Name brand:</i> Aleve
Saline nasal spray <i>Name brand:</i> Ocean Nasal Spray	

For seasonal and environmental allergies:

Medicines your child can take
Diphenhydramine <i>Name brand:</i> Benadryl
Loratidine <i>Name brand:</i> Claritin
Cetirizine <i>Name brand:</i> Zyrtec

Food and Drinks to Avoid after Transplant

Some foods your child might normally eat should not be eaten after transplant because of the medicines your child takes. Grapefruit and grapefruit products may increase the amount of these medicines in your child's body. This can be dangerous and possibly life threatening.

You should not let your child eat these foods or drink these drinks:



Grapefruit



Pomegranate



Star fruit



Grapefruit-flavored candy



Pomelo



Tangelos (also called Honeybell)



Grapefruit-flavored drinks, including Sun Drop, Fresca, Sunny D, Izze, Mountain Dew, and grapefruit juice.



Seville oranges and marmalade



Champ teaches how to wash your hands:

1. Wet your hands and squeeze on liquid soap or make suds with bar soap. If using bar soap, put the bar soap on a rack to dry.
2. Rub your hands together and scrub all parts of your fingers, palms, and backs of your hands. Remember to get between your fingers, too!
3. Keep scrubbing for 20 seconds. It helps to say the A, B, C's so you know how long to wash.
4. Rinse off the bubbles and dry your hands on a clean towel.

It's especially important to wash your hands:

- before, during, and after preparing food
- when someone at home is sick
- before you eat
- after you use the bathroom
- when your hands are dirty!

Taking Your Child's Temperature

There are many ways to check your child's temperature. You should use a digital thermometer, which shows the temperature as numbers printed in a window. Do not use glass thermometers with mercury in them. They are dangerous.

If your child is	Take temperature
Newborn to 3 months old	in child's bottom
3 months to 3 years old	in child's bottom or armpit
4 to 5 years old	in child's mouth, bottom, or armpit
Older than 5 years	in child's mouth, bottom, or armpit

Tips

- Be sure to wash the thermometer before and after using it—every time. Use warm, soapy water and rinse with clear water.
- If you take your child's temperature in the bottom (rectally), label it as a rectal thermometer. Do not use a rectal thermometer in your child's mouth.
- If your child has had a cold or hot drink or cold or hot food, wait 15 minutes before taking a temperature by mouth.
- Talk to your child's health care provider if you want information about ear or forehead (temporal) thermometers.

In your child's bottom (rectal)

A rectal temperature is taken by placing a thermometer in baby's bottom. This method gives the most accurate reading, but it should be done only when by your child's doctor says it is okay.

Get the thermometer ready

- Be sure to use a thermometer that is for rectal use.
- Wash the thermometer with warm, soapy water, then rinse with clear water. Wipe dry or let the thermometer air-dry.
- Put some water-based lubricant on the tip of the thermometer.

Position your child

- Use the position that works best for you.
- Lay your baby on his or her back on a firm surface. Hold your baby's ankles and lift both legs, as if changing a diaper.
- Or place baby face down across your lap. Use one hand to part baby's buttocks.



Take the temperature

- Gently slip the tip of the thermometer into the rectum (the opening where bowel movements come out), no more than $\frac{1}{4}$ inch to $\frac{1}{2}$ inch.
- Hold the thermometer in place until it beeps that it is ready. Slide the thermometer out. Read the temperature on the digital display.
- Before putting the thermometer away, clean it with soap and warm water.

In your child's armpit (axillary)

An axillary temperature is taken by holding the thermometer under baby's arm. To provide a correct reading, this must be done with care.

Get the thermometer ready

- Be sure to use a thermometer that is for underarm use.
- Wash the thermometer with warm, soapy water, then rinse with clear water. Wipe dry or let the thermometer air-dry.
- Be sure the thermometer is at room temperature.

Position your child

- Hold your baby on your lap or lay him or her on a firm surface; an older child can sit comfortably.



- Place the tip of the thermometer in the armpit. To get a true reading, the thermometer must rest directly against baby's skin on all sides.
- Hold your child's arm tightly against his or her side and hold the thermometer in place.

Take the temperature

- When the thermometer beeps that it is ready, release your hold and gently lift baby's arm. Remove the thermometer.
- Read the temperature on the digital display.
- Before putting the thermometer away, clean it with soap and warm water.

In your child's mouth (orally)

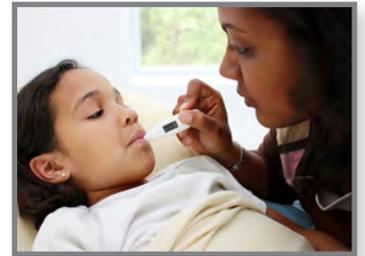
An oral temperature is taken by holding the thermometer under child's tongue. To provide a correct reading, this must be done with care.

Get the thermometer ready

- Be sure to use a thermometer that is for oral use.
- Wash the thermometer with warm, soapy water, then rinse with clear water. Wipe dry or let the thermometer air-dry.
- Be sure the thermometer is at room temperature.

Position your child

- Your child can sit or lay comfortably.



- Place the thermometer under your child's tongue as far as it can go comfortably. Do not push it in so far that it hurts your child.
- Your child should close his or her lips around the thermometer to help hold it in place. You may hold on to it as well.

Take the temperature

- When the thermometer beeps that it is ready, remove the thermometer.
- Read the temperature on the digital display.
- Before putting the thermometer away, clean it with soap and warm water.

Glossary

Alpha-1 antitrypsin deficiency – Alpha-1 is a protein made by the liver. If the liver does not make enough or make any alpha-1, a person may have liver disease.

Arterial blood gas (ABG) – A blood test that measures how well the body is using oxygen.

Arterial line (A-Line) – A catheter placed in an artery. It is used to check blood pressure without using a blood pressure cuff, and to draw blood for tests without having to use a needle each time.

Ascites – Too much fluid in the abdominal cavity.

Atelectasis – Collapsed air sacs in the lungs.

Atresia – A closing up of a normal opening or having no opening where there should be one.

Biliary tree – A series of ducts that provide transport of bile from the liver where it is made to the duodenum or small intestine where the bile is used to digest foods.

Bile – A thick, yellow fluid made in the liver that help your body digest fats.

Bilirubin – A brownish yellow material found in bile that comes from the liver breaking down old red blood cells. If the liver is working right, bilirubin leaves the body through stool. If the liver is not working right, bilirubin builds up in the blood and causes jaundice.

Cardiac respiratory monitor (CR Monitor) – A machine that measures heart and breathing rates. Three small, round stickers are put on the chest and thin wires called “leads” are connected from the stickers to the machine.

Catheter – A thin, flexible tube that can be guided into body organs.

Central line – A small, soft tube called a catheter that is put in a vein that leads to the heart. This lets the health care team give fluid, medicines, and nutrition to the patient and get blood samples for lab tests over a long period of time. The central line is put in during surgery and may stay in place when the patient goes home from the hospital.

Cholangitis – Swelling of the bile ducts.

Cirrhosis – A liver disease that slowly gets worse in which healthy liver cells are replaced by scar tissue. Over time the liver stops working right.

CT scan (computed tomography) – A test that combines X-rays and computer scans. The result is a detailed picture that can show problems with soft tissues like organs and blood vessels.

Echocardiogram – Also called an “echo,” this is a test that uses sound waves to produce images of the heart.

Electrocardiogram – Often referred to as ECG or EKG, it is a printout of the electric rhythms traveling through the heart. Small stickers or bands are put on several parts of the body, including the hands and feet.

Endoscopy – A long, flexible tube with a light and a camera on the end is guided down your child’s throat to look at the esophagus, stomach, and duodenum (first part of the small intestine). The tube does not affect your child’s breathing.

Endotracheal tube (ET tube or artificial airway) – A long, narrow plastic tube placed through the mouth or nose into the windpipe to provide an airway. It is taped in place.

Fibrosis – Abnormal formation of liver tissue.

Foley catheter – A plastic tube that is inserted into through the urethra into the bladder to let urine out of the body and to measure how much urine leaves the body.

Graft – An organ or tissue that is transplanted.

Hepatic – About the liver.

Hepatitis – Swelling of the liver.

Hepatomegaly – A large liver.

Hepatosplenomegaly – A large spleen and liver.

Immune system – The body’s natural defense system. It protects the body from foreign substances, such as bacteria and viruses.

Incentive spirometer – A plastic box with a flexible tube and a plastic ball that helps patients keep their lungs healthy after surgery. The patient breathes through the tubing, like sucking through a straw, to move the plastic ball upward.

Intravenous line (IV) – A tiny plastic tube (catheter) placed into a vein to give fluids or medicines or to draw blood.

Jackson-Pratt drain (JP drain) – A plastic drain placed in the abdomen during surgery. At the end of the tubing is a bulb-shaped drain to collect the extra fluids.

Jaundice – A yellow color in the skin and whites of the eyes due too much bilirubin in the blood and tissues.

Liver – The largest organ in the body; it is located in the upper right portion of the abdomen under the rib cage. The liver makes and balances body chemicals, stores energy sources (proteins, fats, sugars), stores the vitamins A, D, E, K, and minerals (copper and iron), changes potentially harmful substances into forms the body can either use or get rid of, and filters bacteria and particles from the blood.

Liver biopsy – A test in which a small sample of liver is removed to help diagnose liver problems. A needle is put through the abdomen into the liver.

MRI (magnetic resonance imaging) – A scan that shows a detailed picture of the body without x-rays. This test uses magnets and radio waves that have no known side effects and are painless.

Nasogastric tube (NG tube) – A small tube inserted through the nose, down the back of the throat, and through the esophagus into the stomach. An NG tube may be used to empty the stomach of fluid and air, or to feed formula.

Operative cholangiography – A surgical procedure in which dye is injected into the gall bladder and an X-ray is taken showing the structure of the biliary tree.

Pasteurized – The food has been heated before packaging to kill certain bacteria.

Percussion and postural drainage (P&PD) – A therapy that helps loosen and clear secretions from the lungs to prevent pneumonia. Percussion is clapping the patients back and chest with a cupped hand and postural drainage is putting the patient in a position that helps drain mucus.

Percutaneous transhepatic cholangiogram (PTC) – A procedure during which dye is injected through a catheter into a liver bile duct. X-rays are taken while the dye is injected to check for leaks, blockages, and other problems.

Perishable – Food that will go bad quickly without being refrigerated.

Pruritis – Severe itching believed to be caused by the buildup of bile salts and other by-products.

Pulse oximeter – A simple device taped to a finger or toe that measures oxygen level in the blood.

Rectal probe – A very small, protected wire placed in the rectum to monitor a patient's body temperature.

Stat – Referring to something that should be done right away. (Stat is a shortened version of the Latin term "statim.")

Teratogen – A substance that can disturb the development of any embryo or fetus.

Transplant – An organ or tissue taken from one part of the body and grafted to a another part of the body or to another person.

Ultrasound – A test that uses sound waves to take pictures of different organs and tissues in the body. A probe, which looks like a wand with a rounded tip, gently presses the skin near the area tested. No radiation is used for an ultrasound.

Urethra – The tube in the body that carries urine from the bladder to outside the body.

Ventilator – A large breathing machine that gives breaths to someone with an artificial airway (endotracheal tube).

X-ray – A special picture that shows the inside of the body using a very small amount of radiation.

Lab Tests

To help keep track of your child's recovery and to see how well the medicines are working, we draw blood many times while your child is in the hospital. Many of these tests will be familiar to you because your child's doctors have used them to check your child's liver disease. We continue to use these tests to check your child's progress.

Alb (albumin) – A protein made by the liver. Low levels in the blood may mean the liver is not working well.

Alk phos (alkaline phosphatase) – An enzyme made in the large bile ducts. High levels may mean bile duct injury. However, alk phos is also found in bone, so the alk phos level may be high during growth spurts.

ALT (SGPT) – An enzyme made in the liver and other organs. If the liver is injured, ALT can leak into the bloodstream.

Amy (Amylase) – An enzyme secreted by the pancreas into the intestine to help digest carbohydrates. Amy levels in the blood can show how well the pancreas is working.

AST (SGOT) – An enzyme made in the liver and other organs. If the liver is injured, AST can leak into the bloodstream.

Bilirubin – High levels in the blood may mean the liver is not working well.

BUN (blood urea nitrogen) – The stomach changes protein into amino acids, which the liver breaks down into urea. Urea then enters the blood and is excreted by the kidneys. BUN levels in the blood can show how well the kidneys are working.

CMV (cytomegalovirus) – Monitors for this virus in the blood.

Cr (creatinine) – A waste product made by the normal breaking down of muscle. Cr levels in the blood can show how well the kidneys are working.

EBV (Epstein-Barr virus) – Monitors for this virus in the blood.

GGTP – An enzyme produced in the small bile ducts. High levels in the blood may mean bile duct injury.

Hct (hematocrit) – Measures red blood cell content in whole blood.

Hgb (hemoglobin) – A molecule inside red blood cells, Hgb carries oxygen from the lungs to other tissues.

K+ (potassium) – An electrolyte found in the blood, which has an important role in muscle contractions.

Mg (magnesium) – An electrolyte found in the blood, which has an important role in muscle contractions and energy levels. Tacrolimus can lower your child's magnesium level.

Na (sodium) – An electrolyte and mineral found in the blood, sodium is important to keeping a good balance of fluid levels inside and outside the body's cells.

Plt (platelets) – The part of blood that helps it clot.

PT/PTT/INR (prothrombin time/partial thromboplastin time/international normalized ratio) – Measures how long blood takes to clot.

Sirolimus trough – Measures the level of sirolimus in the blood. The test must be done 30 to 60 minutes before the morning dose is due.

Tacrolimus trough – Measures the level of tacrolimus in the blood. The test must be done 30 to 60 minutes before the morning dose is due.

TP (total protein) – The total of all proteins in the blood. TP includes albumin (made in the liver) and globulin (made in other organs). TP levels in the blood can show how well the liver is working.

WBCs (white blood cells) – These blood cells fight infection and react against foreign substances in the body.

Resources

American Liver Foundation

www.liverfoundation.org
75 Maiden Lane, Suite 603
New York, NY 10038
800-GO-LIVER (800-465-4837)

Children's Organ Transplant Association

www.cota.org
2501 COTA Drive
Bloomington, IN 47403
email: supportsrv@aol.com
800-366-COTA

National Foundation for Transplants

www.transplants.org
1102 Brookfield, Suite 200
Memphis, TN 38119
email: NatFounTx@aol.com
800-489-3863

Transplant Recipients International Organization (TRIO)

www.trioweb.org
1000 16th Street, NW, Suite 602
Washington, DC 20036-5705
email: trio@primenet.com
800-TRIO386

United Network for Organ Sharing

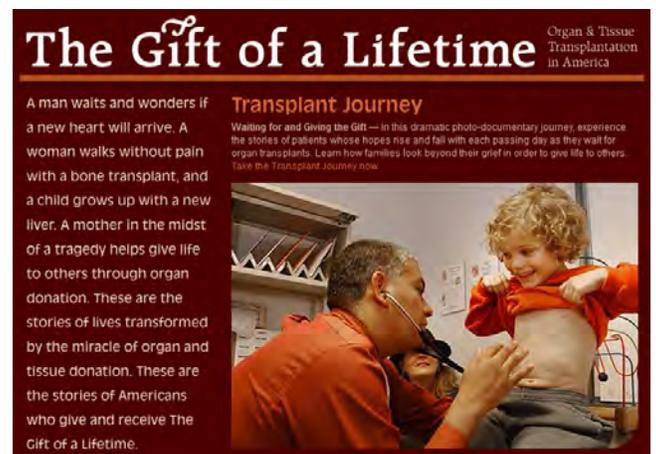
www.unos.org
1100 Boulders Parkway, Suite 500
PO Box 13770
Richmond, VA 23225-8770
888-TXINFO

Websites

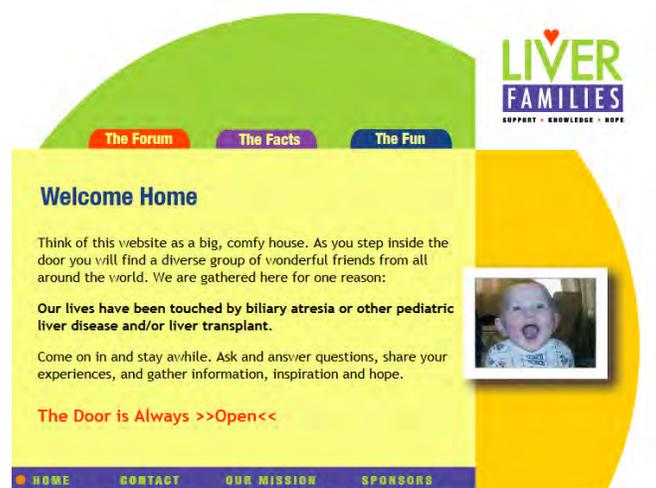
www.ChildrensHospital.vanderbilt.org



www.organtransplants.org



www.liverfamilies.com



References

Call the Liver Transplant Team at (615) 343-BILI(2454) if your child:

- has a temperature of than 100.5°F (38°C) or higher. Do not give acetaminophen (Tylenol) in the first 60 days after transplant without contacting the Liver Transplant Team first.
- is having diarrhea or vomiting. Both can affect the level of medicine in your child's blood.
- has redness, pain, swelling or pus draining from the surgical incision.
- has a cough or cold that won't go away.
- is exposed to diseases such as chicken pox, measles, etc.
- develops mouth sores.
- misses more than one dose of medicine(s).
- throws up every time he or she takes one of the medicines.
- is given too much medicine.
- has any side effects from the medicine.
- has any signs of rejection (see page 33)
- does not feel well.