



Your Child's Liver Transplant: Patient and Family Handbook

(615) 343-2454

ChildrensHospitalVanderbilt.org



Vanderbilt Transplant Center

Vanderbilt Transplant Center in Nashville, Tennessee, is one of the South's main providers of solid organ transplantation. Monroe Carell Jr. Children's Hospital at Vanderbilt offers programs in heart, kidney, and liver transplant. Our outcomes are among the best in the country. Our specialists strive to return every patient to a full and active life. Our mission is to provide end-stage organ failure patients an opportunity to lead an extraordinary life. We thank you for trusting us with your child's care.

As we treat your child, we promise to:

- include you and your child as the most important members of your health care team
- personalize your child's care with a focus on their values and needs
- work with you and your child to coordinate their care
- respect your child's right to privacy
- communicate with you and your child clearly and regularly
- serve you, your child, and your family with kindness and respect.

Dear Patient,

You are our priority.

You'll meet many different people on your health care team. Your transplant coordinator will be your guide throughout your entire transplant process. They'll help you in lots of ways. And you can always ask them questions at any time.

We hope this book will help you and your caregivers know what will happen and make the best decisions for your care.

You'll learn

- all about your transplant team
- how we'll help you
- what will happen now
- what happens during each step of the transplant process
- what you can do to get as healthy as you can.

Sincerely,

Your Liver Transplant Team



Dear Caregivers,

Our team is committed to giving you the support, resources, and education you need to care for your child. We hope this booklet will help you understand the transplant process and how to make the best decision for your child's health.

You'll find information about:

- your transplant team
- the transplant process
- potential risks of surgery and transplant
- the waitlist process
- long-term care after transplant.

As you read this booklet, you may want to write down notes or questions for your child's health care providers. Your transplant coordinator will review this booklet with you.

We're here to answer any questions. Thank you for choosing Monroe Carell Jr. Children's Hospital at Vanderbilt for your child's care.

Sincerely,

Your Liver Transplant Team



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Learn about the liver and liver transplants



What is the liver?

The liver is the largest organ in the body. It's on the right side of the abdomen, under the ribs. A healthy liver is the only organ in the human body that can repair itself if it's damaged.

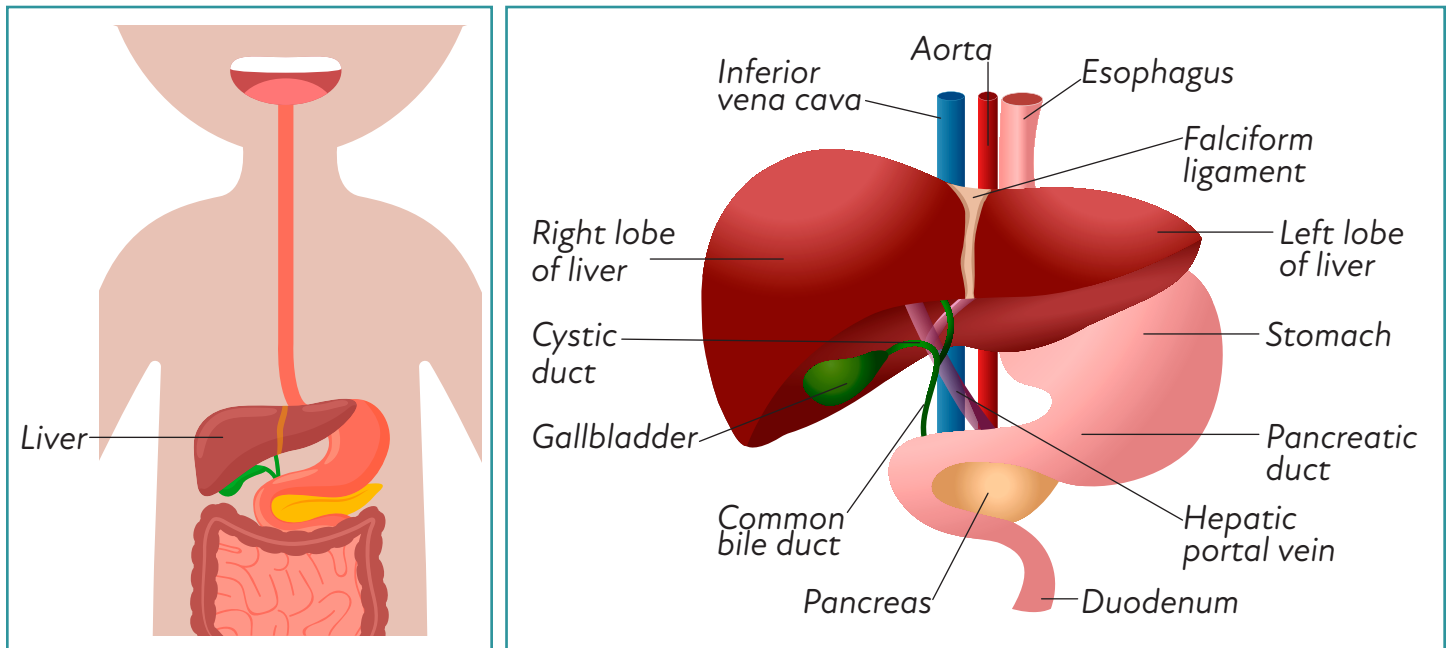
It has many important jobs. It:

- changes food into chemicals that are used to keep you alive and help your body grow
- makes proteins, such as albumin and blood-clotting factors
- breaks down medicine so your body can use it
- helps keep blood sugar levels steady

- cleans the blood to remove any poisons, drugs, and waste products
- makes bile, which helps your body digest and absorb medicines and vitamins.

How does the liver work?

All blood that flows from the intestines, stomach, and spleen also goes through the liver. Blood flows into the liver through the portal vein or the hepatic artery. Inside the liver, there's a system of smaller and smaller veins. As the blood flows through this system, the liver cells filter the blood. It removes things that can hurt the body. And changes nutrients so the body can use them. Then the blood moves out of the liver through the hepatic vein into the heart.



How do you know my child's liver is not working right?

Signs that the liver is not working right include:

- yellowing of eyes or skin (jaundice); this is caused by too much bilirubin in the blood
- very itchy skin; this is caused by too much bilirubin in the blood
- the body not getting the nutrients it needs (malnutrition); this happens when the liver does not filter and store nutrients and vitamins like it should
- delayed growth and development caused by malnutrition
- weakness and fatigue that is caused by malnutrition or shortness of breath
- loss of appetite, upset stomach (nausea), and weight loss
- fluid in the abdomen (ascites)
- blood not clotting as quickly as it should; this can cause lots of bruising or it may be hard to stop bleeding
- scarring of the liver (cirrhosis); this is caused by chronic liver disease
- repeat infections of the bile ducts (cholangitis)
- high blood pressure in the portal system; this can make someone cough up blood or cause there to be blood in the stool
- decline in brain function and confusion; this is caused by too much ammonia in the blood
- shortness of breath from ascites or end-stage liver disease.

How do you decide if my child needs a new liver?

Your child may be approved for transplant if they:

- have end-stage liver disease that has lowered their quality of life and shortened their life span
- there are no other treatments besides transplant that would improve their disease, quality of life, or help them live longer
- they have a lower risk of death with a liver transplant than they do if they continue to live with their disease
- they're healthy enough to handle the surgery, recovery, and the medicines they'll take for the rest of their life.

Your child may not be approved for transplant if:

- a new liver would not likely help them live longer or improve their quality of life
- they have another systemic disease, infection, or illness that's likely to limit or get in the way of their survival and healing after transplant
- they have other organs that aren't working right and may shorten their life span
- you and your child decide that a liver transplant is not right for them.

Are there different types of liver transplants?

Yes. Your child may need a whole or a split liver transplant.

The liver can repair itself when it's healthy. Because of this, a split liver donation may come from a living donor.

Where do the donor livers come from?

Organ donation is voluntary and usually anonymous.

A whole liver donation comes from donors who are legally brain dead (deceased donor). This means the brain no longer works. Donation often helps families deal with their grief.

Split liver donations can come from a deceased donor or from a living donor.

- If from a deceased donor, the liver may be split into 2. The part of the liver used is based on size and shape of the donor liver and the weight of the patient.
- If from a living donor, a surgeon would take part of their healthy liver to use for transplant.

Can I donate my liver?

There's a special team that works with people who want to be a living donor. They'll make sure it's safe for you to donate part of your liver.

The recovery time for a donor is usually about 8 weeks. But some people have a longer, harder recovery.

To learn more:

Living Donor Program

VanderbiltHealth.com/program/living-liver-donor-transplant

(615) 936-5321

Your child's transplant team



You'll work with many health care providers during the transplant process. We're here to:

- answer questions
- help you make decisions
- support you and your child.

Everything you talk about with us is confidential. We'll only share information with your child's other health care providers when needed.

Liver transplant coordinator

Your child's transplant coordinator will be your partner through the entire transplant process. They organize everything from start to finish. And they'll let you know what to expect. They'll also help coordinate with your child's other health care providers.

Transplant providers

The transplant liver doctors (hepatologists) and nurse practitioners (NPs) will manage your child's care. This includes all their transplant medicines. Your child will see a transplant liver provider at every clinic visit.

Transplant surgeon

A transplant surgeon will do your child's transplant surgery. They'll help you make decisions before and after transplant.

Pharmacist

The transplant pharmacist will teach you about your child's medicines.

Dietitian

The dietitian will work with you to make the best eating plan for your child. They'll help your child build healthy eating habits.

Infectious disease providers

The infectious disease providers will teach you how to help your child prevent infections. They'll also help treat them if they do get an infection.

Social worker

The social worker will give emotional support and help to you, your child, and your family. They can help you with funding, housing, transportation, and community resources.

Psychologist

The psychologist can help your child cope and adjust to their new medical plan. And they'll give support for emotional and behavioral needs as your child grows.

Child Life specialist

The child life specialist will work with your child to help them cope with being in the hospital or in a clinical setting. They'll also help them get ready for any medical procedures. They use play and age-appropriate activities.

Financial advisor

The financial advisor will talk with you about hospital billing and insurance. They can help you understand what costs to expect for the transplant, hospital stays, medicines, and other medical costs.

Nurses

Nurses will care for your child while they're in the hospital. They give you and your child information about tests so you know what to expect. And they teach you how to care for your child after transplant.

School teacher

The teacher can share information with your child's school about their absence, tutor your child while they're in the hospital, and help when they're ready to go back to school.

Specialty Providers

Your child may be seen by providers who specialize in other areas. They'll help your child when needed.

Rehab specialists

The rehab specialists will help your child get back strength and movement. Your child may work with physical, speech, or occupational therapists.

Administrative Assistant

The administrative assistant will help organize your child's care and coordinate their visits.

Case manager

The case manager will work with your insurance to help you get any equipment and services your child needs after transplant.

How to reach us

Our regular office hours are Monday to Friday, 8:00 a.m. to 5:00 p.m. But you can reach us any time of day, 7 days a week.

- **Phone:** Call us at (615) 343-2454. If you call outside of regular office hours, leave a message. Our team will call you back.
- **My Health at Vanderbilt (MHAV):** Send us a message. We check messages during regular office hours. You should not send urgent messages to us through MHAV. If your child is sick or you have an urgent concern, call us.

My Health at Vanderbilt

My Health at Vanderbilt is our secure, online patient tool. You can use it to:

- see your child's medical details
- send and get messages with their providers
- make appointments
- and more.

For more information, visit:

MyHealthatVanderbilt.com.

For help to sign up for an account, talk to your child's transplant coordinator.

Patients 13 to 17 years old:

Any patient 13 to 17 years old can have their own login for MHAV. This type of account is called a proxy account. At least 1 caregiver will need to have a MHAV account before they can set up a proxy account.

This lets both caregivers and adolescent patients get the same messages with providers. And lets everyone see information about medicines, tests results, and visits.

Once the patient turns 18 years old, they'll become their own account holder. If they want their caregiver to have access, they'll need to make them a delegate.

If you have any questions about MHAV or how to sign up, please let us know.

Call us if your child:

- has a temperature of 100.4°F (38°C) or higher
- has redness, pain, swelling, or pus draining from the surgical incision
- has a cough or cold that lasts more than 48 hours
- is exposed to any disease such as chicken pox, measles, the flu (influenza), or COVID-19
- has mouth sores
- misses a dose or takes their medicine late
- throws up after they take 1 of their medicines
- takes the wrong dose of medicine
- has any side effects from the medicine
- has any signs of rejection (see page 23)
- does not feel well
- has diarrhea or throws up for more than 24 hours.

Liver Transplant

Clinic phone: (615) 343-2454

Clinic fax: (615) 936-7816

We're on the 10th floor of Doctors' Office Tower in Monroe Carell Jr. Children's Hospital at Vanderbilt.

The evaluation process



During evaluation, your child will have many medical tests and exams. You, your child, and their other support persons will meet with members of their transplant team. This will help you and their transplant team decide if a liver transplant is the best option for your child.

Our goal is to make sure you know about:

- the risks and benefits of transplant
- the treatment options besides transplant
- the evaluations and tests your child will have done and the test results
- how the waitlist works
- how transplant recipients are chosen
- any financial or personal life (psychosocial) issues that may affect your child's ability to have a transplant
- the strict medical plan your child will have to follow for the rest of their life after transplant
- SRTR data (our transplant programs's current results and outcomes)
- where donor livers come from
- organ donor risk factors
- your right to refuse transplant for your child any time, up until surgery.

We know it's a lot to take in. We'll go over everything with you in detail.

You and your child will need a lot of support before and after surgery

A successful liver transplant requires that your child have at least 2 people in their life who can give them the support and help they'll need. You'll also need support. By having more than 1 caregiver, this will make sure you get the help you need.

The transplant team is here to support you and your child during evaluation, while they wait for a liver, during surgery, as they recover, and for the rest of their life.

A liver transplant is a life-long commitment. Your child will need to see a transplant provider for tests and exams for the rest of their life.

When can we start the evaluation?

Before we can evaluate your child for transplant, we need your informed consent. Informed consent means you know all about what will happen and you agree to it.

To give your informed consent, you need to learn:

- the risks and benefits of transplant evaluation
- what will happen during the evaluation
- what to expect as your child waits for a donor liver
- what will happen during and after transplant surgery.

You may also need to sign other consent forms during the process. This is because some tests have risks so we'll need your informed consent to do them. We'll explain these risks to you. You'll sign a separate consent form that explains the risks of each test in detail.

What happens during the evaluation?

The evaluation process is when we find out if it's safe for your child to have a liver transplant. We'll take a careful look at your child's health to learn the risk of transplant for your child. We'll find out if they have any problems that make transplant riskier or if they'll need special care at the time of transplant.

What kind of tests will my child need?

We'll let you know what tests your child needs and let you know why. Every test will be explained to you and your child before it's done.

It may take a few weeks to get all the tests done.

They may not need to do all of these. The tests we may do, include, but aren't limited to:

- CT (computed tomography) scan to look at the blood vessels and the size and shape of the liver
- pictures of the abdomen (ultrasound) to see the blood vessels, liver, spleen, and other structures of the abdomen
- liver biopsy, where we take a tiny piece of the liver to run tests (your child will be asleep for this test)
- pictures of the upper GI (gastrointestinal) tract, which include the food pipe (esophagus), stomach, and the first part of the small intestine (your child will be asleep for this test)
- heart tests to look at and measure heart function; this includes an EKG (electrocardiogram) and an echo (echocardiogram)
- urine tests
- breathing tests
- pictures of the chest (X-ray)
- tests to check their ears and eyes
- dental exam (within the last 6 months, if your child is older than 1 year old)
- labs and blood tests to:
 - see if your child has any bacteria, fungus, or viral infections, including HIV, or if they have immunity to these
 - get a better picture of how well your child's body and other organs besides the liver are working.

Your child will also need to be up-to-date with all recommended vaccinations. They may need to visit their primary care provider (PCP) to get any shots they need.

What happens after the tests are done?

The Patient Selection Committee will meet about your child's case. This committee is made up of your transplant team and any speciality providers who helped during the evaluation. They'll go over the results of the evaluation and any extra risks that your child may face if they have a transplant.

We'll also submit the evaluation to your insurance company for their approval. Insurance approval is required to be put on a transplant waitlist. This can take a few days. Or it can take up to a month.

After the committee meets, we'll let you and your referring provider know what the committee recommends. We'll also let you know all the tests results.

If they're approved for transplant, does that guarantee they'll get a new liver?

No. If they're approved for a transplant, it means that we determined that your child's life span and life quality would benefit most from a transplant instead of living with their disease. But that does not mean a donor liver will be found for your child.

If a child gets too sick before a liver is available and transplant is no longer the best option for them, they would be taken off the list. But this does not happen very often (it's very rare).

What if they aren't approved for transplant?

Not all children are approved for transplant. If this happens, they won't be put on the waitlist. Their treatment will continue. Our palliative care team will also talk to you about other medical care options.

What if we change our mind about transplant?

You have a right to change your mind and refuse transplant for your child at any time. You can do this during the evaluation process and all the way up to the time of surgery.

Waiting for a donor



If your child is approved for transplant by our committee and your insurance company, they'll be put on the waitlist.

The United States government, through an organization called UNOS (United Network for Organ Sharing), regulate the transplant process.

You can find more information about transplants from UNOS.

- The UNOS website: [UNOS.org](https://unos.org).
- The UNOS toll-free patient phone line: (888) 894-6361. This phone line:
 - is to help transplant candidates, recipients, donors, and family members understand the way organs are matched with the patients who need them
 - can be used to find data, information, and statistics about transplants
 - can be used to talk about any problems you have at your transplant center or with the overall transplant system.

SRTR data

During evaluation, your child's transplant coordinator will give you the current data about national and Vanderbilt-based transplants (SRTR data). This information will help you learn about the number of transplants that are done both nationally and at Vanderbilt and the results of these transplants.

You can visit [SRTR.org](https://srtr.org) for more information.

Medicare

We're monitored, regulated, and approved by Medicare. Medicare pays for the transplant and medicines in Medicare Part B. If we stop being in good standing with Medicare, we must tell you.

Is my child's information protected?

As you and your child go through the transplant process, members of your transplant team may access and share your medical information as permitted by law and Vanderbilt University Medical Center policies.

If your child does get a new liver, information about them, which will include their identity, will be shared with UNOS. This information may also be sent to other transplant-related agencies or companies as permitted or required by law.

Information sharing is an important part of overall transplant program success, both nationally and locally. It's expected that you and your child agree to postoperative and long-term follow-up tests and that you know this information will be shared.

How does the waitlist work?

Your child's place on the waitlist is based on their medical needs. Their status on the list can change if their health or medical needs change.

Three things are considered:

- blood type
- size
- need (the PELD or MELD score).

After your child has been approved, we'll send you a letter with their PELD or MELD score.

What is a PELD score?

Children under 11 years of age are given a PELD (Pediatric End-Stage Liver Disease) score. It ranges from below 0 to 40, with 40 given to children who are the most sick. The score is based on:

- bilirubin levels (broken down red blood cells found in the stool)
- INR (clotting factor)
- albumin (protein made by the liver)
- sodium
- creatinine
- age, height, and weight.

What is a MELD score?

Children 12 years of age or older are given a MELD (Model for End-Stage Liver Disease) score. It ranges from 6 to 40, with 40 given to children who are the most sick. The score is based on:

- bilirubin levels (broken down red blood cells found in the stool)
- INR (clotting factor)
- creatinine.

Can my child get on the waitlist at other hospitals?

Yes. You have a right to do this. Your transplant coordinator will talk to you about how to get your child on the waitlist at more than 1 transplant hospital. You'll also learn how to transfer your child's listed wait time from 1 transplant center to another so they don't lose their place on the waitlist.

What if my child needs help while they're on the waitlist?

We have program coverage at all times. This means we're always here to help.

A transplant surgeon and transplant doctor are available 24 hours a day, 365 days a year to help with patient care. We have back-up coverage for each of these people as well.

What can I do for my child while they're on the waitlist?

We can't know when a liver will become available for your child. Sometimes it happens quickly, but sometimes it takes years before a liver becomes available.

We know it can be a very emotional time. It can help to focus on what you can do while you wait.

Things that can help you and your child cope while you wait

- Try to keep your daily routine as normal as you can.
- Talk to your support system about how you feel and ask for help when needed.
- Talk to your transplant team. We're always here to help you during the entire transplant process.

Ways to help your child be in the best possible health when a liver becomes available

Make sure your child:

- does everything the transplant team has said they need to do
- takes their medicine and follows their eating plan
- goes to all their regular medical visits
- goes to their monthly transplant clinic visits
- stays up-to-date with all recommended vaccinations.
 - Your child's transplant coordinator will talk to their primary provider about the vaccines they need to get before and after transplant.
 - If your child or family members do not get the vaccines they need, it puts your child at great risk for death, life-threatening infections, and some cancers linked to virus infection.
 - Live virus vaccines should be given before transplant but are not allowed right after transplant. It may be safe for your child to get a live virus vaccine again in the future. Live virus vaccines include flu nasal spray, rotavirus, varicella (chicken pox, and MMR (measles, mumps, and rubella).
 - Make sure you talk to us before your child gets any vaccine.

You should also let us know if your child is exposed to any infectious diseases (such as chicken pox).

At the hospital



What happens when we get the call for transplant?

When a liver is available for your child, we'll call you. First, we'll ask about your child's health. We'll need to know if they have or just had a cold, flu, or fever, or if they were recently exposed to an infectious disease, such as chicken pox.

It's important your child is in the best possible health for transplant. If there are any concerns, your child's transplant coordinator will talk to the transplant team.

When a donor is found, we only have a short time to reach you

We must be able to reach you at all times. If we can't reach you, the liver may have to go to the next person on the list.

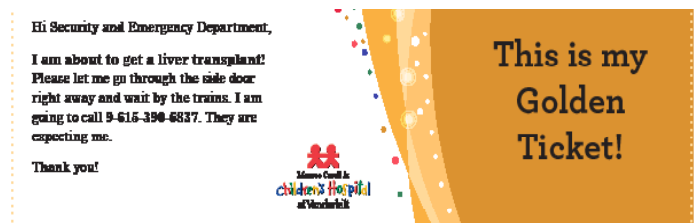
- Give your transplant coordinator all possible phone numbers for you.
- Make sure to have a phone with you at all times.

Make a travel plan

As soon as your child is placed on the waitlist, you should make a plan. You should always know how you'll get them to the hospital.

Make sure you bring your golden ticket

During evaluation, we'll give you a golden ticket. Keep it in a safe place (like the dash of your car). You should know where it's at all times. You need to bring it with you when you come in for transplant. It will help your child get admitted into the hospital quickly.



Important reminders

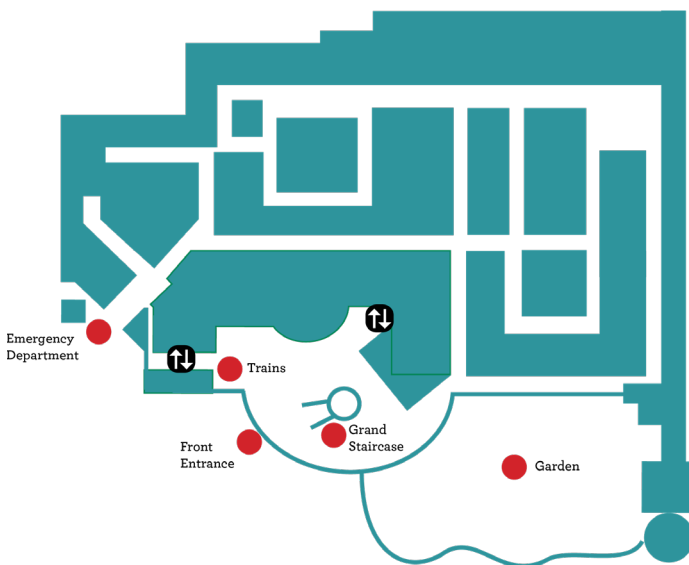
- Keep a bag packed and ready to go at all times.
- As soon as you get the call to come to the hospital, your child should not have anything to eat or drink.
- Bring all of your child's medicines and a list of their medicines.
- Bring your golden ticket to the hospital.
- Your child can bring a comfort item with them. It can be a special toy or blanket.
- Remember that there's always a chance that the transplant may be cancelled, even after you've gotten to the hospital. Sometimes this can happen after your child has been taken in for surgery. If this happens, they would not lose their place on the waitlist.

Where do we go when we get the call?

When we tell you there's a liver for your child, you need to get them to Vanderbilt Children's Hospital. You'll enter through the Emergency Department, and you'll show the security desk your golden ticket.

- If it's between 7:00 a.m. and 7:00 p.m., they'll direct you to the business office. Staff members will get your child checked in.
- If it's between 7:00 p.m. and 7:00 a.m., they'll direct you to the lobby phone by the trains (first floor). You'll use that phone to call the number on your golden ticket.

Children's Hospital, First Floor



What happens when we get to the hospital for surgery?

When you get to the hospital with your child, a few things will happen first.

- We'll check your child in.
- You'll meet with a few members of your transplant team.
 - The surgeon will talk to you about the surgery and its risks. Before we can start, you'll sign an informed consent that gives us your permission to do the surgery.
 - The doctor who makes sure your child is asleep and does not feel any pain during surgery (anesthesiologist) will meet with you. They'll talk to you about the risks of the medicine (anesthesia) they'll give your child. You'll sign a separate consent form for this medicine.
 - You'll also meet with your transplant coordinator, liver doctor, and nurses.
- We'll get them ready for surgery. We'll:
 - ask them to put on hospital clothes
 - put in a IV
 - take some blood (from the IV)
 - get a urine sample
 - do an X-ray
 - check their blood pressure, heart rate, breathing rate, and temperature (vital signs)
 - do a physical exam.

It can take a long time before we're ready to start the surgery. You may want to bring books, a tablet, or other quiet entertainment options with you.

How long will surgery last?

Liver transplant surgery usually takes 4 to 8 hours. And your child will be taken into the OR (operating room) about an hour before the surgery starts. During that time, the anesthesiologist and nurses will get them ready for surgery.

Will they need blood during surgery?

Most children need a blood transfusion during surgery. If you're interested in donating blood, it's usually best to wait until after the surgery starts. Talk to us if you want to know more. You should also let us know if you do not want your child to get a blood transfusion.

What happens during surgery?

In the OR, there are many things that happen before surgery begins.

- We'll give your child medicine called anesthesia that will make them sleep. Your child will be asleep and will not feel any pain during surgery.
- **Once your child is asleep, we'll put:**
 - in 2 more IV lines
 - in an arterial line to monitor their blood pressure and draw blood
 - in a Foley catheter (a thin flexible tube) into their urethra and bladder to keep track of their urine output
 - on a blood pressure cuff, EKG stickers, a temperature probe, and a pulse oximeter to track their vital signs
 - in a ET (endotracheal) tube in your child's nose or mouth to help them breathe during surgery
 - in NG (nasogastric) tube in their nose, down their esophagus, and into their stomach to help drain anything that's in their stomach
 - in a central line (catheter) into a large vein to draw blood.

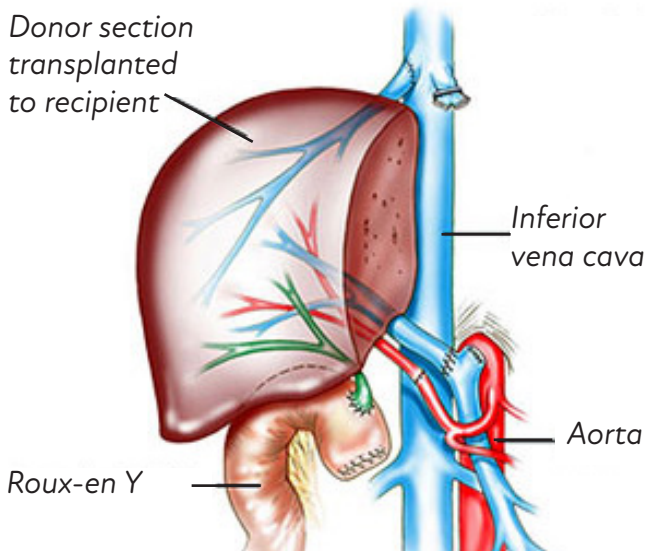
- **Once your child is prepped, the surgery will begin.**

- Your child's skin will be cleaned. Drapes will be placed around their abdomen.
- We'll make a cut (incision) in the upper part of your child's abdomen. The cut may go all the way up to their breast bone. If your child has an incision from a previous surgery, the same incision line is usually used.
- The diseased liver will be taken out. It will go to the lab to be tested.
- The new, healthy liver will be put into your child's abdomen and attached.
- The hepatic veins, hepatic artery, and the portal vein will be connected to the new liver. Once this is done, the liver will be pink and firm.

- The intestines will be connected to the bile ducts of the liver. There are 2 ways this may be done. We may use the bile duct from the donor liver. Or your child's intestine will be used to drain the bile (Roux-en Y).
- Everything will be checked carefully.
- Two or 3 Jackson-Pratt drains will be placed around the liver to remove extra fluid that happens after surgery. The drains will look like a small ball. You'll see them coming out of the incision site.

Once these steps are done, your child's abdomen wall and incision will be closed. We'll use stitches or staples. If stitches are used to close the incision, they'll dissolve on their own. If staples are used, we'll remove them a few weeks after surgery.

Split Liver Transplant



What happens after surgery?

After surgery, we'll take your child to the PICU (pediatric intensive care unit), where we'll watch over them as they wake up and start to recover. We'll let you know when it's OK for you to see them.

They'll have machines connected to them after surgery

- **Monitors.** We'll keep an eye on their vital signs. Sometimes the monitors go off. When this happens, a nurse will check on your child and see what's going on.
- **IV and arterial lines.** We'll use them to give your child fluids and medicine. The arterial line will be removed when your child is ready to move from the PICU to a surgical recovery room.
- **Central line.** It will be used to give fluids and medicines. We'll remove it before they go home.
- **ET tube.** We'll keep it in until they no longer need help to breath. They won't be able to talk, eat, or drink while it's in. Many children use hand signals or write things down to communicate while it's in. After it comes out, they'll need to do some deep breathing and coughing exercises. The exercises will help their lungs stay clear and prevent pneumonia.
- **NG tube.** It will stay in place for several days.
- **Foley catheter.** It will help us measure their urine output and see how well their kidneys are working.
- **JP drain.** It's used to help drain blood and fluid from around the liver after surgery. It will stay in place for several days.

We'll watch over them

We'll keep track of their vital signs and run many routine tests. We may do ultrasounds, X-rays, daily blood tests, and other tests to make sure their recovery is going well.

They'll meet with other providers

Your child's rehab team will start to work with them a few days after surgery. Other providers may also see your child.



This is a JP drain.



Your child's incision will be covered with steri-strips (as seen in the picture) or skin glue to help it heal. This is how your child may look 3 days after surgery.

They'll finish their recovery in a regular hospital room

Most children stay in the PICU for a few days to a few weeks. Smaller children often stay in the PICU for longer.

We'll move them to a room in the surgical recovery unit (on the 8th floor) once they're ready. Most children stay there for another 1 to 2 weeks.

The unit will feel more relaxed than the PICU. This is because your child will be more stable. They won't need to be monitored the same way as they needed while in the PICU.

Your child's recovery may be different. This will depend on how sick your child was before transplant and if they had any trouble during surgery. Your child will be able to leave the hospital when we're sure it's safe.



This is an example of what it may look like when skin glue is used. Their incision will likely look like this about 18 days after surgery.

Can we help them recover?

Yes, there are things you can do to help them as they recover.

- **Walk:** Help your child go for walks around the room and hallway. This will help build their strength.
- **Breathing exercises:** Make sure your child does all their exercises. Their nurse will show them how to use an incentive spirometer. An incentive spirometer is a plastic tube connected to a container. They'll use it to take deep breathes to help build their lung health.
- **Play:** Play is an important part of their physical and emotional recovery. Their child life specialist will help you find toys and games to play with your child during their recovery.
- **Daily care:** Your child should keep up with their daily hygiene. Their nurse can help you, if needed.
- **Eat well:** Your child will need to eat a well-balanced diet to help with their recovery. Your child's team will help you know what's safe for them to eat. And a dietitian will help make a healthy eating plan for them.

The risks of transplant



Liver transplant surgery is complex, and the risks are high. You need to know what the risks are before you can agree for your child to have surgery.

We have no way to know exactly how your child's body will react to the transplant beforehand. We also don't know in advance if all the problems caused by your child's liver disease will get better after transplant.

The success of a liver transplant will be affected by:

- how sick your child was before transplant
- how well your child is growing and if they're getting enough of the nutrients they need
- the life conditions of the donor (such as the donor's health history) and the condition of the liver when we get it in the OR (operating room) for surgery.

What are the medical risks?

Risk of transplant failure

Sometimes the transplanted liver may not work at all. If this happens, your child may need another transplant. Out of 100 pediatric liver transplants, this happens to less than 1 patient.

Risk of donor-caused infection

The risk of catching a transmittable disease or infection from a donor is very low. Before donation, all donors are tested for transmittable diseases and infections, including the HIV, Hepatitis C, and Hepatitis B viruses. However, it's important to know that no organ transplant is completely free of risk.

Even though all donors are tested, there's a small chance that they may still have an infection, even if the test says they don't. One way this could happen is if the donor had a very recent infection that doesn't yet show up on a test.

The risk of missing an infection is around 1 in ten thousand to 1 in a million (depending on the risk criteria). We'll always tell you if a donor may have had a risk of exposure that testing might have missed. When an organ is offered to your child, we'll tell you about all the risks for HIV, Hepatitis C, and Hepatitis B that are associated with that donor.

We won't give an organ to your child or move forward with transplant without talking with you about the risks of accepting that organ.

The risk of getting an organ from a donor with an infection that didn't show up on a test is very low. But it's important for you to know when a small risk exists. This is also why we'll test your child for these viruses after transplant.

Risk of bile duct problems

This surgery can cause biliary leaks or biliary strictures. The new connection may leak or become blocked. Bile can leak from a cut in the surface of the liver. Bile duct issues can cause a major infection (biloma).

Out of 100 pediatric liver transplants, this happens to about 5 to 15 patients. If this happens, we may leave the surgical drains in longer or place new drains. Sometimes another procedure or surgery is needed to fix the leak.

Risk of bleeding

It's very common for children to bleed after transplant surgery. Your child may need blood or other blood product transfusions. Sometimes, this means they'll need to go back to the OR. It's rare that bleeding will cause death in the OR. Bleeding becomes less of an issue as the liver heals, which starts to happen soon after surgery.

Risk of hepatic thrombosis

This surgery can cause the hepatic artery to narrow from a blood clot. This is a serious problem. Out of 100 pediatric liver transplants, this happens to about 2 to 10 patients.

If this happens, it can cause the new liver to fail and will need to be fixed. Your child would need surgery or a new liver.

Risk of blood vessel problems

Sometimes after transplants, the connections between the veins and arteries to the new liver don't work right. Sometimes they get narrow (stenosis) or get blood clots. If there's a blood clot, they may need surgery to remove it (thrombectomy). Out of 100 pediatric liver transplants, about 2 to 10 patients have problems with their blood vessels.

Are there other risks to transplant?

Psychosocial risks

A liver transplant can cause psychological and emotional problems for both you and your child. These may include:

- sadness and depression
- post-traumatic stress disorder (PTSD)
- generalized anxiety
- anxiety and worry about being dependent on others through the transplant process
- feelings of guilt or other psychological issues that may be made worse or caused by evaluation, surgery, recovery, or any financial and work issues that come up throughout the liver transplant process.

Going through transplant is a serious, life-changing event. It's common to feel overwhelmed, worried, confused, and scared. There are support systems available to you and your child at any time by phone or in person. Talk with your child's transplant social worker if you need help. They can help you find the resources you need.

Financial risks

Getting a transplant can affect you and your child financially, both now and in the future. During evaluation you may find out that your child has some health problems you didn't know about. You may have to spend money to treat these problems. Some of these problems could also affect your child's ability to get health or life insurance.

A liver transplant may affect your child's ability to get health or life insurance in the future. Insurance companies may decide your child has a pre-existing condition and refuse payment for medical care, treatments, or procedures.

Potential complications and risks after transplant



What is rejection?

The immune system's job is to protect the body from things that may cause harm. It looks for any foreign object and kills it. This includes bacteria and viruses.

Your child's immune system will see their transplanted liver as a foreign object. It will try to attack and kill it. This is called rejection.

To prevent rejection, your child will take medicines for the rest of their life. These medicines are called immunosuppressants or anti-rejection medicines. They'll help lower your child's immune system.

Rejection can still happen. That's why we do regular follow-up visits, medical tests, and lab work. Your child should not stop taking their medicines. Rejection will happen over time if your child stops taking their medicines as told. Their provider will let you know if their medicines need to be changed or stopped.

What are the signs of rejection?

There are some signs of rejection, but not everyone shows them. That's why it's important to keep all your child's follow-up visits and do all their lab tests. Sometimes lab test results are the only sign of rejection.

If there's a change in their lab test results, we'll do a biopsy. There are many reasons for a change in lab test results. It may not be rejection. A biopsy will let us know.

Early signs of rejection include:

- temperature greater than 100.5°F (38°C) when taken under the arm
- increase in liver enzymes
- stomach pain.

Later signs of rejection include:

- yellow color of the skin and eyes (jaundice)
- tea or cola colored urine
- white or beige colored stool.

What causes rejection?

It's important to know that most rejection is preventable, especially as more time passes after transplant. The number 1 reason rejection happens is when someone does not take their medicine exactly the way they should.

Rejection can happen at any time and sometimes without any signs.

What happens if my child has rejection?

- We'll do a liver biopsy. Liver tissue is the only way to know if there's rejection.
- We may give them steroids.
- We may need to change their dose of some medicines.
- Your child may be admitted to the hospital to get the rejection episode under control.

Are there other medical risks?

Yes, your child will be at higher risk for other illnesses after transplant for the rest of their life. The anti-rejection medicines lower their immune system. This will make it easier for them to get sick. This includes common childhood illnesses and other higher risk diseases.

They'll take medicine to stop infections. They should also follow all health and life style guidelines to help keep them healthy.

Common childhood illnesses

Chicken pox

- Chicken pox is a viral infection. It causes red spots that itch and blister (rash).
 - It often begins with a fever.
 - The rash often begins on the head. Then spreads to the belly and back, and then to the arms and legs.
 - The rash turns into small, watery blisters with red rings around them.
- It spreads easily. It moves through the air when a person with it coughs, sneezes, laughs, and talks. Or it can spread if someone touches the rash.
- 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 has been around someone with chicken pox, let us know right away. We may give them medicine to prevent them from getting sick, or to reduce how sick they get. They can show signs 10 to 21 days after they were exposed to the virus.

Thrush

- Thrush is a fungal infection. It makes white patches on the tongue, mouth, and throat.
- It's a common infection for people who take steroids.
- Let us know if your child gets it. We can give them medicine to treat it.
- Your child will take medicines to prevent this type of infection early after transplant. But they'll stop taking it once it's safe.

Cold sores

- Cold sores are a viral infection. It causes little blisters around the mouth.
- It's very common and often not serious. But children with a transplant can develop a more severe case. The blisters can spread to inside the mouth and down the throat.
- Let us know if your child gets it. Sometimes these can be caused by their anti-rejection medicines. They may need to take medicine to treat it.

Digestive Issues

- Your child may have loose stools (diarrhea) or throw up. This can happen for many reasons.
- When your child throws up or has diarrhea, it can change the medicine levels in their body.
- You should let us know if:
 - it lasts more than half a day
 - they look dehydrated
 - they're not able to drink the usual amounts
 - they throw up any of their medicines.

Higher risk illnesses and diseases

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's important that your child is not around crowds or people who may be sick for the first month after transplant.

We'll teach you what to do to help your child avoid infection, and how to watch for certain infections that are common in transplant patients. The best protection against infection is for everyone to wash their hands often and get all the recommended vaccinations.

Cytomegalovirus (CMV)

- Cytomegalovirus (CMV) is a viral infection.
- Many adults have had CMV in the past. But many children have never had it so their body hasn't learned to fight it yet (they don't have antibodies to fight it).
- Your child can get CMV from the transplant liver or from the general public. It can happen anytime after transplant.
- Most people with CMV do not have any signs. But it can cause very bad diarrhea, high fever, and cough in some transplant patients.
- Your child will take medicines to prevent this type of infection early after transplant. But they'll stop taking it once it's safe.
- We'll watch for it in your child's regular blood tests. It can be treated with medicine.

Epstein-Barr virus (EBV)

- Epstein-Barr Virus (EBV) is a viral infection. It's the same virus that can cause mononucleosis (also known as mono or the kissing disease).
- Your child can get EBV from the transplant liver or the general public. It can happen anytime after transplant.
- It can cause sore throat, fever, and swollen lymph nodes. Some people do not have any signs of the virus.
- We'll watch for it in your child's regular blood tests. It can be treated with medicine and by lowering their dose of anti-rejection medicines.
- If your child had EBV in the past, they may always have a low count of the virus in their blood. But it usually doesn't cause any future problems.

Post-transplant lymphoproliferative disease

- Post-transplant lymphoproliferative disease (PTLD) is a disorder in the blood and lymph nodes.
 - The infected lymph nodes can be located anywhere in the body. This includes the intestines, tonsils, and solid organs (liver, spleen).
 - The immune system causes a type of white blood cell (lymphocytes) to grow very fast and in a way that's different than they should (abnormal growth).
 - This type of overgrowth may not cause any harm. But it could develop into lymph node cancer (lymphoma).
- It can happen anytime after transplant.
- It can cause swollen lymph nodes, fever, and bloody stools. Some people do not have any signs.
- PTLD most often happens after there have been high levels of EBV in the blood. But this isn't always the case.
- If your child has high levels of EBV in their blood, we'll do other testing to look for PTLD. We may do a CT scan, endoscopy, or lymph node biopsy.
- To treat PTLD:
 - if it's found early, we can lower their dose of anti-rejection medicines
 - if lymphoma develops, they may need chemotherapy.

Cancer

- Cancer is when cells in the body grow differently than they should.
- A normal immune system watches for this type of cell growth and stops it. But your child's anti-rejection medicine lowers their body's ability to do this.
- It can happen anytime after transplant.
- Skin cancer is the most common type of cancer that transplant patients get.
- To prevent skin cancer, your child should:
 - wear sunscreen everyday, regardless of the weather
 - use SPF 30 or greater on their skin and lips
 - wear hats and clothing to help protect them from the sun
 - avoid midday sun (10:00 a.m. to 2:00 p.m.)
 - get a yearly skin screening once they're an adult.
- They should also:
 - get all other recommended cancer screenings done
 - get all recommended vaccines, such as the HPV (human papilloma virus) vaccine. HPV can cause cancer of the cervix, vulva, vagina, penis, anus, and back of the throat (oropharynx).

Poor kidney function

- The kidneys remove waste and extra fluid. They help keep the body balanced with what it needs. They also help to control blood pressure.
- Sometimes, the kidneys do not work as well after someone takes anti-rejection medicine for a long time.
- It can happen anytime after transplant.
- To help protect the kidneys, your child should not take ibuprofen (Motrin and Advil) and naproxen (Aleve).
- We'll test your child's kidney function in regular blood and urine tests.

High blood pressure

- High blood pressure (hypertension) is when blood pushes too hard against the artery walls.
- Many anti-rejection medicines and over-the-counter medicines can cause it.
- It can happen anytime after transplant.
- We'll watch for it in your child's regular blood tests. It can be treated with medicine.

Bone disease

- Many anti-rejection medicines can cause bones to weaken over time.
- Your child will get special X-rays (bone density studies) done on a regular basis to check for bone loss.
- They may need to take medicine to prevent broken bones.
- They may also need to take calcium and vitamin D supplements to support bone health.

Medicines: Guidelines and helpful tips



We'll work with you to make a medicine plan and daily schedule to help you keep track of your child's medicines. They'll need to take all their medicines exactly as told and at the same time every day.

It's important that you tell us their home and school schedules and any special situations that may change when they can take their medicines.

It's helpful that all medicines are given at home to avoid mistakes or missed doses. Your child's school nurse may be able to give them their medicine when they're at school, but we try to avoid this.

You and their other caregivers need to understand why and how each medicine is given.

We know it's a lot to learn. It may also be hard to get your child to take their medicines as they need to each day. We're here to help. Call us if you have any trouble with their medicine plan or schedule.

VUMC Children's Outpatient Pharmacy

Phone: (615) 936-6337

Hours: 7:00 a.m. to 11:00 p.m.; 7 days a week
Hours may change on holidays.

How do we order their medicines?

You should call your pharmacy to get refills at least 1 week before you run out of medicine.

Try to plan ahead and order refills before weekends and holidays. It can be harder to get refills during these times. But if you do need them on a weekend or holiday, call us at (615) 343-2454. We'll need to know the phone number of the pharmacy and for each refill the:

- name of the medicine
- form (pill or liquid)
- strength
- dose.

Keep an eye on how many refills you have left for each medicine. When you need refills added to their prescriptions, let your transplant coordinator know. You can:

- tell them at a clinic visit
- send a message through My Health at Vanderbilt (MHAV)
- call (615) 343-2454.

It's your responsibility to make sure your child does not run out of their medicines. If you have trouble, let us know. We can help give you tips to keep up with their refills.

What if my child won't take their medicines?

It can be hard to get your child to take their medicines as they need to every day. But you need to be firm with them so they don't miss any doses. It's very important they take their medicine exactly as told.

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

- Give them choices. You can let them decide what medicine to take first and what to drink with the medicine.
- Stick to their medicine schedule.
 - Make medicine time part of their daily schedule and routine. This helps children be ready to take their medicine.
 - You can also remind them before it's time to take their medicine. This will help your child feel more in control. For example: “After breakfast, it's time to take your medicine.”
- Help your child learn to swallow pills.
 - Some liquids can taste bitter, so pills may be easier for them.
 - Pills are easier to refill than liquid.
 - It's easier to travel with pills than liquid.
- Be positive about their medicine.
 - Be easy-going and upbeat when you talk about their medicines.
 - They'll pick up on your emotions. If you stay positive, it will help them be positive.
 - When needed, be honest about negative feelings. Talk about ways to make it easier for them to take their medicines.
- Help them understand why they need it.
 - Use simple, honest language about the medicines. For example: “This medicine helps fight the germs that can make you sick.”
 - Use play to help them learn. For example: Let your child pretend to give medicine to a stuffed animal or doll. Ask them to say why it's important to take it.
- Give praise and rewards.
 - Have your child work towards a goal. For example: Use a sticker chart and let your child put stickers on it after they take each medicine. This can also be a visual reminder.
 - Give praise or a hug after they take their medicine.

For babies, toddlers, or preschoolers:

- Let them sit on your lap when they take their medicine. It can give your child a sense of comfort and control.
- Let them hold a comfort item, like a blanket or toy.

Tips for liquid medicines

- For young children, use a syringe to give the medicine. You can get a syringe from your child's primary provider or pharmacist.
- Let them suck on a popsicle or ice before they take their medicine. The cold will numb their taste buds.
- Let your child eat some peanut butter or pancake syrup before they take their medicine. It will coat the tongue and make the medicine taste less bitter.

Tips for pills

It can be hard for children to swallow pills. There are things you can do to help them learn.

- Ask for pills in gel caps. The gel coating hides the bitter taste of the pill.
- Practice with candy first.
 - Use small candy such as cupcake decorations, mini chocolate dots, candy-coated hard mints, or fruit-flavored dots.
 - Start with a size your child is comfortable with and move up to larger candy after they're able to swallow that size 5 times.
 - **Important:** Candy can help your child learn to swallow pills. But be sure to teach your child that medicine is not candy, even though it may look like it sometimes.
- Try a pill-swallowing cup. You can get one from your pharmacist.

- For some pills, you can try these tips. Talk to your pharmacist first. Not all medicines can be taken with food or crushed up.
 - Put the pill in gelatin or pudding to help the pill slide down the throat. Practice just swallowing the food first. Then add the pill.
 - Chop pills up into smaller pieces. Give your child 1 piece at a time.
 - Crush pills into a powder and mix with food or liquid. Use only a small amount so you can be sure all the medicine was taken. You might try applesauce, yogurt, sherbet, pudding, ice cream, fruit-flavored syrup, or juice. You can let your child pick what they want to use.

What if they still won't take their medicine?

There may be times when your child won't want to take their medicine. Sometimes none of the ideas and tips will work.

Your child may need a break. Wait for a few minutes, then ask if they're ready. If they're still not ready after 15 minutes, remind them that the medicine is not a choice and you have to give it to them. At times you'll need to be firm.

You can also:

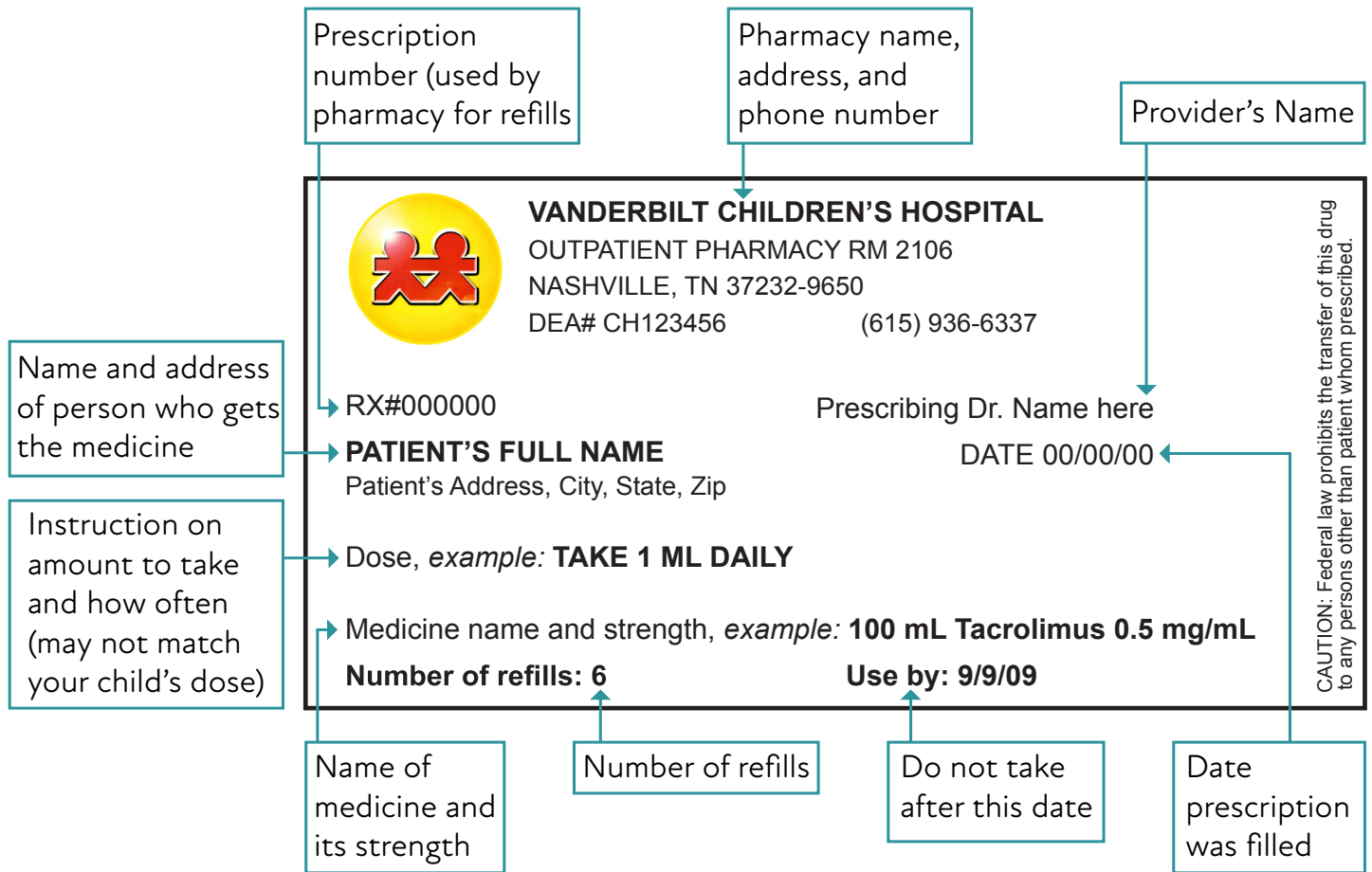
- Ask someone else to help you. One person will hold your child in their lap and hug them. The other person will give the medicine.
- Hold your child's mouth closed until medicine is swallowed. Have your child sit up straight to help them swallow.

How do I avoid mistakes?

- Make sure you update your medicine plan with the right dose. The dose of each medicine will change over time. It's important to have all current doses and instructions written down. You should give each medicine as we tell you. This may be different than what it says on the medicine bottles.
- Use a syringe to measure and give liquid medicines. Ask your pharmacy for measuring syringes.
- Measure liquid medicine in milliliters (mLs or mL).
- Do not use a kitchen teaspoon (tsp) or tablespoon (Tbsp). It's not safe. They're not a correct way to measure medicine. And you could give too much or too little.
- Remember that milligram (mg) is not the same as milliliter (mL). Milligram tells how much medicine should be given, but milliliter is how much liquid to measure out of the bottle.
 - The amount of medicine in a liquid is different than the total amount of liquid.
 - For example: Your child needs 2 mg of medicine. This medicine has 0.5 mg of medicine for every 1 mL of liquid. Then you'll need to measure 4 mL of liquid out of the bottle.
 - This will take time to learn. Be very careful when you measure any liquid medicines.
- Shake liquid medicine. The medicine will settle to the bottom of the bottle between doses. Make sure you mix it up before you give it. This helps you give the right amount of medicine each time.
- Remove the cap from syringes before you give your child medicine from a syringe. Children can choke on a syringe cap if it gets squirted into their mouth by mistake. Children can also find the caps and try to swallow them. Throw caps away or keep them away from children.
- Use the same pharmacy for every refill. Liquid medicine is usually made from crushed pills combined with liquid (compounded). Pharmacies use different recipes to make them, which can change the dose. It can change your child's blood level of certain medicines.
- Tell us if your child's pills look different than their last fill. The pharmacy may have made a change to how they make that medicine. We may need to do lab work after the change is made to see if we need to adjust the dose.
- We can help you find a pharmacy that will be able to fill all your child's prescriptions. Not all pharmacies can. If you need to switch pharmacies, let us know.
- You may want to try mail order prescriptions. This is a good way to avoid running out of medicine.
 - Many pharmacies ship medicines to your home. And some insurance companies give a discount when you fill a 90-day supply.
 - About 6 months after transplant, we won't need to change the dose of their medicines as much. This will make it easier to use mail order, even with liquid prescriptions.

How do I read a prescription label?

The labels on medicine bottles have a lot of information on them. Below is a sample prescription label. Each part is labeled so you know what they mean. Talk to us or your pharmacist if you have any questions.



Important - Make sure that the name of the medicine and its strength match what we told you. If not, do not give it to your child. Call us so we can make sure your pharmacy has the right dose for your child.

Transplant medicine guide



Your child will take medicines to prevent rejection and infections. They'll take some medicines for the rest of their lives. Other medicines may be stopped after a year, or when it's safe for them. It's common for transplant patients to take 10 to 12 medicines every day.

We'll teach you how they need to take their medicines. You'll need to make sure you give your child their medicine exactly as you're told every day.

We'll also teach you what over-the-counter medicines they can take and what they cannot take. Talk to us before you:

- start, stop, or change the medicines they take
- start a new medicine another provider prescribes them
- give them any herbals, supplements, or use any home remedies.

Any change to their medicines can change the blood levels of their anti-rejection medicines, raise blood pressure, or cause other side effects.

Call us if you have any questions or need help with their medicines.

Anti-rejection medicines

Anti-rejection medicines are used to prevent rejection of transplanted organs. They'll take a combination of anti-rejection medicines for the rest of their life.

They may need to avoid some foods and drinks while on some anti-rejection medicines (tacrolimus, cyclosporine, or sirolimus).

Tacrolimus (FK506, Prograf)

- Your child will take it 2 times a day, 12 hours between each dose. They should take it the same time each day.
- They may take it on an empty stomach or with a meal. But they'll need to take it the same way each day.
- The dose is adjusted based on blood levels.

Special directions

- On days they get blood tests done, we need to draw their blood 30 to 60 minutes before they take their tacrolimus dose.
- Make sure you get to the clinic in time for this blood draw. You should bring their tacrolimus dose with you and give it to them after the blood draw.

Possible side effects

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

Cyclosporine (Gengraf, Neoral, and Sandimmune)

- Your child will take it 2 times a day, 12 hours between each dose. They should take it the same time each day.
- They may take it on an empty stomach or with a meal. But they'll need to take it the same way each day.
- The dose is adjusted based on blood levels.

Special directions

- On days they get blood tests done, we need to draw their blood 30 to 60 minutes before they take their cyclosporine dose.
- Make sure you get to the clinic in time for this blood draw. You should bring their cyclosporine dose with you and give it to them after the blood draw.

Possible side effects

Possible side effects are tremors (especially in their hands), kidney damage, high blood pressure, increased gum growth, and increased hair growth.

Sirolimus (Rapamune)

- Your child will take it 1 time a day, 24 hours between each dose. They should take it the same time each day.
- They may take it on an empty stomach or with a meal. But they'll need to take it the same way each day.
- The dose is adjusted based on blood levels.

Special directions

- On days they get blood tests done, we need to draw their blood 30 to 60 minutes before they take their sirolimus dose.
- Make sure you get to the clinic in time for this blood draw. You should bring their sirolimus dose with you and give it to them after the blood draw.

Possible side effects

Possible side effects are high blood pressure, headache, 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 or ankles, constipation, and rash.

Mycophenolate mofetil (Cellcept, MMF)

- Some patients take this as well as tacrolimus and prednisone.
- Your child will take it 2 times a day, 12 hours between each dose. They should take it the same time each day.
- They may take it on an empty stomach or with a meal. But they'll need to take it the same way each day.

Possible side effects

Possible side effects are upset stomach, diarrhea, infections, and low white blood cell count.

It may cause birth defects if your child becomes pregnant:

- when they're on it
- within 6 weeks after taking it.

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

- They're a steroid that lowers the body's ability to reject transplanted organs.
- Your child will take it 1 time a day. Or you can divide the dose and give it 2 times a day.
- If they do not have an autoimmune disease, we'll lower their dose over time. And they may be able to stop taking it.
- Do not stop or change the dose unless we tell you.
- They can take it with milk or food to help prevent an upset stomach.

Possible side effects

Possible side effects are high blood pressure, upset stomach, stomach ulcer, increased appetite, weight gain, puffy face, acne, high blood sugar, emotional changes, insomnia, and fluid retention.

Side effects usually happen with high doses and will lessen when the dose is lowered or stopped.

Infection Prevention Medicine

Co-trimoxazole (Trimethoprim, Sulfamethoxazole, Bactrim, Septra)

It's an antibiotic to prevent bacterial infections (pneumocystis pneumonia).

Possible side effects

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

Nystatin

- It's an antifungal medicine to prevent thrush.
- It only comes as a liquid.
- Your child will take it at least 3 times a day.
- They should move (swish) the liquid around in their mouth then swallow it. If your child is unable to swish the medicine, use an oral swab to coat your child's mouth.
- They should not eat or drink for 30 minutes after they take it.

Possible side effects

Possible side effects are digestive problems (upset stomach, throwing up, and diarrhea).

Fluconazole

- It's an antifungal medicine to prevent fungal infections, such as thrush or candida.
- Your child will take it 1 time per day for about 30 days after transplant.

Possible side effects

Possible side effects are digestive problems (upset stomach, throwing up, and diarrhea) and higher tacrolimus levels.

Ganciclovir

- It's an antiviral medicine to prevent and treat cytomegalovirus (CMV).
- It's given through an IV.
- Your child may get it 1 time per day while in the hospital.

Possible side effects

Possible side effects are low platelet count, low white blood cell count, rash, and high creatinine.

It can cause birth defects. It can affect the reproductive system (sperm and eggs) in all genders.

Valganciclovir

- It's an antiviral medicine to prevent CMV.
- Your child may take it 1 time a day for 3 to 6 months after transplant.

Possible side effects

Possible side effects from are low platelet count, low white blood cell count, rash, and high creatinine.

It can cause birth defects. It can affect the reproductive system (sperm and eggs) in all genders.

Acyclovir (Zovirax)

- It's an antiviral medicine that prevents herpes simplex virus (HSV) and cytomegalovirus (CMV).
- Your child can take on an empty stomach or with a meal.

Possible side effects

Possible side effects are upset stomach, throwing up, and headache.

Other medicines

Your child may be prescribed other medicines.

- Aspirin is used to stop blood clots from forming in blood vessels. They would take it 1 time a day (usually in the evening).
 - Magnesium supplements if they take tacrolimus. They would take it 1 to 4 times a day.
 - Calcuim supplements if they have low bone density.
 - Antacid medicines are used to protect the stomach, if they take steroids.
 - They should take it on an empty stomach 30 minutes before their first meal of the day.
 - If in a capsule, it can be opened and the contents sprinkled on applesauce or yogurt, or put in fruit juices or water.
 - Do not chew, crush, or mix contents into food.
 - It may cause headache, upset stomach, throwing up, and diarrhea.
- Over-the-counter medicines
 - Acetaminophen (Tylenol) can be given for a cold or fever, as long as your child's liver is working normally. Make sure you give them the right dose based on their age and weight.
 - Ibuprofen (Motrin or Advil) should not be given after transplant. It can affect their kidneys and blood clotting.
 - Please be careful when you give over-the-counter medicines. They can hide important signs of health problems.
 - Call us before you give any over-the-counter medicines.

Over-the-counter medicines

Call us before you give your child over-the-counter medicines.

Be careful when you give them over-the-counter cold medicines. They may hide important signs of other health problems.

For cold, congestion, and cough:

Yes, can take	No, do not take
Dextromethorphan Name brands: Delsym, Robitussin DM	Pseudoephedrine (-D) Name brand: Sudafed D
Diphenhydramine Name brand: Benadryl	Phenylephrine (PE) Name brand: Sudafed PE
Guaifenesin Name brands: Robitussin, Mucinex	Ibuprofen (and other NSAIDS) Name brands: Motrin, Advil, Aleve
Acetaminophen Name brand: Tylenol	Naproxen Name brand: Aleve
Saline nasal spray Name brand: Ocean Nasal Spray	

For allergies:

Yes, can take
Diphenhydramine Name brand: Benadryl
Loratidine Name brands: Claritin
Cetirizine Name brand: Zyrtec

Stay healthy: Medical care



What kind of care will my child need after we leave the hospital?

The transplant clinic will need to follow your child's progress for the rest of their life.

When your child goes home from the hospital, they'll have regular clinic visits and lab tests. They'll also need other medical tests done on a regular basis.

- For 1 to 2 months after they go home, they'll have clinic visits with us 1 to 2 times a week.
- We'll slowly move them to 1 clinic visit per month. We'll see them at least 1 time each month for the first year.
- After the first year, they'll have 1 clinic visit every 6 months.
- They'll need lab tests more often than clinic visits. After the first year, they'll likely need lab work done every 2 to 3 months.

Clinic visits

When you arrive to your child's clinic visit, come to our office on the 10th floor of the Doctors' Office Tower. We'll get your child checked in. Then we'll send them to the lab to get their blood drawn.

We'll draw their blood for lab work at every clinic visit before they're seen by a provider. This will help us know if their medicines and liver are working the way they should.

The transplant team will review your child's lab results and let you know if:

- changes to their medicine are needed
- more lab tests need to be done.

Important: We need to draw blood 30 to 60 minutes before some medicines are given. Please make sure you get to the clinic in time to have their blood drawn and bring these medicines with you:

- tacrolimus (Prograf)
- sirolimus (Rapamune)
- cyclosporine (Neoral).

Lab work

Sometimes lab tests may be needed between their follow-up visits. These can be done at the hospital or at a lab close to your home. They'll need lab work done more often right after transplant. Overtime, this will happen less often.

Some of the lab tests we'll do are:

Alb (albumin): Monitors this protein that is made by the liver. Low levels in the blood may mean the liver is not working well.

Alk phos (alkaline phosphatase): Measures this enzyme made in the large bile ducts. High levels may mean bile duct injury, or a growth spurt.

ALT (SGPT): Monitors this enzyme made in the liver and other organs. If the liver is injured, it can leak into the bloodstream.

Amy (Amylase): Measures this enzyme secreted by the pancreas into the intestine. It helps digest carbs. Amy levels can show how well the pancreas is working.

AST (SGOT): Monitors this enzyme made in the liver and other organs. If the liver is injured, it can leak into the bloodstream.

Bilirubin: Monitors bilirubin in the blood. High levels may mean the liver is not working well.

BUN (blood urea nitrogen): Measures BUN levels in the blood. It can show how well the kidneys are working. The stomach changes protein into amino acids. Then the liver breaks those down into urea. Urea then enters the blood and is eliminated by the kidneys.

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

Cr (creatinine): Measures the levels of waste product in the blood. Cr is 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: Measures the levels of 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): Measures a molecule inside red blood cells. Hgb carries oxygen from the lungs to other tissues.

K+ (potassium): Measures this electrolyte found in the blood. K+ plays an important role in muscle contractions.

Mg (magnesium): Measures this electrolyte found in the blood. Mg plays an important role in muscle contractions and energy levels. Tacrolimus can lower your child's magnesium level.

Na (sodium): Measures this electrolyte and mineral found in the blood. Sodium helps keep a good balance of fluid levels inside and outside the body's cells.

Plt (platelets): Measures 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): Measures 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): Measures these blood cells. WBCs fight infection and react against foreign substances in the body.

How do we care for their incision?

After their liver transplant you'll need to make sure their incision is kept dry and clean so it can heal. This can be a challenge, especially if your child is young.

How to clean the incision

- It's best for your child to shower, not take a bath.
- Use clean running water and mild soap to wash the incision.
- If a shower isn't possible, you can give your child a bath.
 - You should not let the incision soak under water.
 - Use a clean washcloth and fresh bath water to clean the incision first.
 - Then wash the rest of the body.
- The incision can be patted dry with a clean towel or cloth.
- Do not rub the incision to dry it.
- The incision may itch a little. Try to keep your child from scratching it.
 - Keep your child's fingernails clipped short.
 - They should wear clothing that makes it hard for them to scratch it.
- Clean the incision right away if clothing or diapers make the area around it dirty.

Things to remember

- It's common to see light yellow drainage from the incision for the first few days after transplant. The skin should heal quickly.
- Keep the incision clean and dry.
- Do not use ointments, lotions, or creams on it.
- 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. Call us at (615) 343-2454 right away if:
 - the incision is red or hot to the touch
 - there's swelling around the incision
 - there's pus coming from the wound
 - the incision comes apart
 - there's any tissue that pushes out or feels different around the incision
 - your child's temperature is 100.5°F (38°C) or higher.



Your child's incision will likely look like this about 3 months after surgery.

How can we help them stay healthy after transplant?

It's important that your child see their primary provider on a regular basis. They'll help keep your child healthy and take care of any common illnesses, like a cough or runny nose.

If your child does get sick, you should let us know as well as their primary provider.

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

Things to do

- Teach your child:
 - to cough and sneeze into their sleeve
 - how to wash their hands the right way. For more information, see page 45.
- Keep hand sanitizer and tissues on hand.
- Keep a couple of working digital thermometers on hand.
- Do not let your child be around sick people, when possible.
- Keep your child out of day care for the first 3 months after transplant, longer if possible.
- See your child's primary provider at least 1 time each year.
- We suggest that your child wear a medical ID (identification) bracelet at all times.
 - In case of an emergency, it will let the medical team know that they had a liver transplant. It will also tell them how to contact us.
 - You can order a medical ID bracelet online or at most local medical supply stores.

Take care of their teeth

For 6 months after transplant and any time they're on a high dose of steroids, your child should not have any routine dental work or cleaning done. But after that, they should visit the dentist every 6 months. They should start to see a dentist by age 2.

Your child should brush their teeth at least 2 times a day. It's most important to brush before bedtime. The bacteria that causes cavities can do a lot of damage to teeth overnight.

Your child's dentist may put fluoride on their teeth, which helps prevent tooth decay.

For a year after transplant, your child will need to take a prescription antibiotic 30 to 60 minutes before any dental cleaning or procedure.

If they have artificial shunts in place (which is not very common), they'll need to continue to take an antibiotic before their dental visits even after 1 year.

If they take cyclosporine, they can develop gum overgrowth. To prevent gum disease caused by overgrowth, they should visit the dentist at least 3 times a year.

Let us know before they have any dental procedures (such as a root canal or extraction). They may need to take medicine before the procedure is done.

Make sure your child gets all their vaccines

Your child should continue to get their regular vaccinations from their primary provider. This includes a flu vaccine every year and, if eligible, the COVID-19 vaccine. They should get the recommended number of doses.

Right after their transplant, they should not get a live virus vaccine. These include:

- Measles, mumps, and rubella (MMR)
- Varicella (chicken pox)
- Small pox
- Polio oral vaccine
- Influenza (nasal spray)
- Oral rotavirus vaccine.

Your child may be able to get a live virus vaccine again in the future. Your transplant team will let you know what's safe for them.

Make sure your household gets all their vaccines

Family members and people who live in the same house as your child, should also get regular vaccinations. This includes a flu vaccine every year and, if eligible, the COVID-19 vaccine. Everyone should get the recommended number of doses.

They should not get a vaccine that contains a live virus for small pox, polio oral vaccine, or influenza as a nasal spray.

But family members or people who live in the same house as your child, can get a vaccine with a live virus for measles, mumps and rubella (MMR), varicella (chicken pox), and oral rotavirus vaccine. The risk that your child will get these viruses from a person who got the vaccine are very low. And it helps protect the entire home from these viruses.

Your child should not touch diapers of children who got an oral rotavirus vaccine for 7 days after they got it.

It's safe for your child, family, and people who live in the same home to get these vaccines:

- Dtap (Tetanus, Diphtheria, and Pertussis)
- Haemophilus Influenzae Type B (HIB)
- Pneumovax/Prevnar
- Hepatitis A and B
- Human Papilloma Virus (HPV)
- Polio (injected vaccine)
- Influenza (injected vaccine)
- Meningococcal
- COVID-19 (if eligible)
- Typhoid (if traveling).

It's very important that all family members receive yearly flu vaccines. If anyone in your family is diagnosed with the flu, please let us know right away. We'll prescribe a medicine to protect your child from the virus or to treat them if they get it.

It's very important to protect your child from COVID-19. They'll be at a higher risk to get it, get very sick from it, and spread it to others.



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. Scrub all parts of your fingers, palms, and backs of your hands. Remember to get between your fingers, too!
3. Scrub your hands for 20 seconds. It helps to say the A, B, C's so you know how long to wash.
4. Rinse off the bubbles.
5. Dry your hands on a clean towel.

It's very important to wash your hands:

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

How do we take their temperature?

There are a few ways you can take your child's temperature. You should use the method that's safe for their age and works best for your child. If you're not sure what method to use, talk to their primary provider.

If your child is:	Ways to take their temperature:
newborn to 3 months	bottom or forehead
3 months to 3 years	bottom, armpit, or forehead
4 years and older	bottom, armpit, mouth, or forehead

Things to remember

- Use a digital thermometer, when you take their temperature in their bottom, armpit, or mouth.
 - A digital thermometer shows the temperature on a display window.
 - Do not use a glass thermometer with mercury in them. They're not safe.
 - If you take their temperature in their bottom (rectally), label it as a rectal thermometer. Do not use it in your child's mouth. It could make them sick.
- You should wash the digital thermometer before and after you use it.
 - Use warm, soapy water and rinse with clean water.
 - Wipe dry or let it air-dry.
 - You should wash it each time you use it.
- Wait 15 minutes to take their temperature by mouth if they ate or drank anything hot or cold.
- Use a temporal thermometer when you take their temperature on their forehead.

How to take their temperature in their bottom

Talk to their provider before you use this method to make sure it's safe.

- After you wash and dry the rectal thermometer, put some water-based lube (lubricant) on the tip of the thermometer. This will help it slide inside the rectum (the opening where bowel movements come out).
- Put your child in the position that works best for you. You can:
 - place them on their back on a firm surface and hold their ankles and lift both legs
 - place them face down across your lap and use 1 hand to part their butt checks.
- Gently slip the tip of the thermometer into the rectum. You should only put in 1/4 to 1/2 inch of the tip inside their rectum.
- Hold the thermometer in place until it beeps. Then slide it back out. Read the temperature on the display window.
- Wash and dry the thermometer before you put it away.



How to take their temperature in their armpit

- After you wash and dry the thermometer, make sure it's at room temperature.
- Put your child in the position that works best for you. You can:
 - hold them on your lap
 - put them on their back on a firm surface
 - have them sit up, if they're older.
- Place the tip of the thermometer in their armpit. You need to make sure the tip touches their skin on all sides.
- Hold their arm tightly against their side and hold the thermometer in place until it beeps. Lift your child's arm to remove the thermometer. Read the temperature on the display window.
- Wash and dry the thermometer before you put it away.



How to take their temperature in their mouth

- After you wash and dry the thermometer, make sure it's at room temperature.
- Your child can stand, sit, or lie down.
- Place the tip of the thermometer under their tongue. Put it as far back as you can, but don't go too far that it hurts your child.
- Your child should close their lips around the thermometer. Hold it still until it beeps. Remove it and read the temperature on the display window.
- Wash and dry the thermometer before you put it away.



How to take their temperature on their forehead

There are many types of temporal thermometers. Follow the directions that came with yours.

We can help if you're not sure how to use it.



What can we do for our mental health?

The challenges of a liver disease and transplant can cause a lot of stress. It's normal to have many emotions. You may feel scared, worried, sad, and many other emotions. There's no right or wrong way to feel.

Some days everything may seem great and then the next day you may feel down. This up-and-down range of emotions is very common after transplant.

A support system can help you cope. You, your child, and your family members need to know you're not alone. If you need help, let us know. We can help get you the resources and support you need.

Emotions you may feel

Anxiety, worry, or fear

Anxiety is when you feel worried or afraid. It's how your body reacts to stress. Some anxiety is normal. But too much can make it hard to work, care for yourself, or care for your family.

It can be stressful to not know what your child's life will be like after transplant. You may also have fears about their recovery, the costs, medicines, or organ rejection.

Guilt

You or other family members may feel guilty:

- if you think you caused your child's illness
- because you're healthy
- someone else needed to give your child the donated liver.

It's important that you know you did not cause your child's liver illness.

Depression or grief

Depression is when you feel sad most of the time. You may also have less interest in things you used to enjoy. You may not have enough energy or interest to work, enjoy yourself, or care for others. It can be different for each person.

Depression or grief can change family routines. It can make family members feel lonely or apart from each other.

Excitement

It may also be an exciting time for everyone in the family. As your child recovers, they'll be able to run, jump, and play with more energy.

Things you can do

- Find time to talk to a partner or friend. Talk about topics other than the transplant.
- If your child is in the room, always include them in conversations about their transplant.
- Do activities that reduce stress, such as read, watch a funny movie, or play a game.
- Take a walk. Walking is good exercise, and it helps your body handle stress.
- Talk to other transplant patients or parents of children who have had transplants or join a transplant support group.
- Take breaks from full-time care of your child. Ask someone to help. This gives you time to relax. And it lets other caregivers feel needed and involved. It can also reduce feelings of separation between family members that can happen when 1 person is more involved in the care.
- Talk with your spiritual leader, if you have one.
- Talk to someone on your child's transplant team such as a transplant coordinator, social worker, nurse, or child life specialist.

Stay healthy: Home and lifestyle



What activities can my child do after transplant?

There will be some limits to what your child can do at first so their incision can heal. After it has healed, your child can be as active as other children.

They'll need to build up their strength. Make sure they start with easy exercises and slowly build up.

Walking is a great exercise to start with after their surgery. They'll likely get tired easily and will need to take many rest breaks at first.

Over time they'll build strength and have more energy. It's common for children to have more energy after transplant than they had before. This is because their liver is working the way it should. This means their body is able to use nutrients the way it needs.

Most children can go to school and normal social activities 2 months after transplant.

Things your child should not do

- Play any contact sports for 3 months after surgery.
- Drive while they take prescription pain medicine (narcotics).
- Drive until your child's surgeon says it's OK.
- Do sit-ups or ab (abdominal) exercises for 3 months after surgery.
- Swim for at least 3 months after surgery. Before your child can swim, their incisions must be completely closed and healed.

After it's safe for them to swim:

- It's best if they swim in chlorinated water. It has a low risk of infection. But they should not swim in a public kiddy pool.
- They can swim in lakes or oceans, but there's a higher risk of infection.

How do we adjust to our new normal as a family?

The transplant process has a big impact on the entire family. Your family may find it hard to adjust to a new normal after transplant.

Your child

Your child may find it hard to go back to school or social activities. But it's important they get back to a regular routine and spend time with people their own age. You'll want to help them find activities they enjoy.

Ways to help your child adjust

- Have your child share activities they want to try with their transplant team.
- Ask to meet with our psychologist or a child life specialist. They can help your child adjust and cope with their new normal.
- Ask our school teacher to work with their school so they can get back to school. They can also help your child catch up on any school work, if needed.

Siblings

If you have other children, our child life specialists can work with them as well.

Spouses and partners

Your child's care takes a lot of time and energy. It's common for partners to find it hard to take time for their relationship. Frustrations are often taken out on each other. Partners can sometimes grow apart because they're stressed and tired.

Ways 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. When you know how each other reacts, it can help you know how to support each other.
- Share how you feel with each other. Don't keep your feelings bottled up.
- Be on the same page with your child's recovery. Have a plan for how you'll make decisions about their health care.
- Change roles in the family, if needed. You may need to change who takes care of what. Now that your child is in recovery, their needs are different. You may need to adjust expectations of each other and your other family members.

Co-parents

Co-parenting can be hard and a sick child can make it harder. It's important that you're both involved with your child's recovery and care.

Ways to help you work together

- Meet with us together. This can help avoid confusion about the plan of care.
- If you share joint custody, you both must learn all transplant education before your child can go home after transplant.
- Ask for 2 copies of patient education materials, medicine plans, visit schedules, and other materials.
- Let us know if your child has any behavior problems. We can help or ask a child life specialist to work with you.

How can I help my teenager take ownership of their health care?

We take care of transplant patients of all ages and support each family's needs at every stage of life.

Once they're ready, we'll help them learn to take ownership of their health care. We usually start at least by the age of 12. We'll help them:

- know what happened to them in the past (their medical history)
- learn about their medicines
- be active in their care
- talk openly with us
- ask questions
- know how to keep their liver healthy.

Ways to let them manage their health care

- Make sure they have access to their My Health at Vanderbilt and MAP accounts.
- Show them how to see their medical details in their accounts.
- Set alarms or reminders on their phone for their clinic visits.
- Show them how you schedule their visits. Once they're ready, they can schedule them.
- Give them a copy of their insurance card. Talk to them about their insurance coverage and paperwork.
- Encourage them to ask questions and share how they feel at their visits. It's important they learn to share about new signs and concerns.

Ways you can help them learn about their medicines

They'll need to know all their medicines, what they do, and how to take them.

- Show them each medicine bottle to find the name and the amount they take (dose).
- Give them the list of their medicines and ask them to read how each one helps them.
- Have them ask questions during their clinic visit when their medicines are reviewed.

Ways to let them manage their medicines

- Set alarms or reminders on their phone for when to take their medicines and get refills.
- Tell them what pharmacy you use and where it's located.
- Show them how to call for refills.
- Have them go with you to pick up refills.
- Once they're ready, they can call for refills and pick them up.

Will you talk to them about drugs, cigarettes, and alcohol?

Yes. We'll talk to your teenager about how drugs and alcohol can hurt their liver. They'll learn that:

- tobacco (in any form) is bad for their health and can lead to cancer and heart disease
- nicotine hurts their lungs and it can change how well their medicine works
- second hand smoke is also harmful
- even legal drugs and medicines can change how well their medicine works. This includes CBD products.

Stay healthy: Food and drink



Does their diet matter?

Yes. It's important that your child eats a healthy diet. The transplant dietitian will work with you to build an eating plan for them.

It's important to remember that your child's eating habits may change after the transplant. Their appetite may be better or worse. This happens for many reasons.

Will they need to take a supplement?

Most of the time, your child can get what they need from a well-balanced diet of fruits, vegetables, low-fat proteins, and a multi-vitamin. But some children will need to take other dietary supplements.

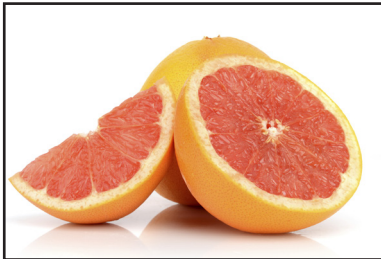
Sometimes, children are not able to eat enough to get the calories and nutrients they need, either before or after transplant. A dietary supplement can help make sure they get what they need.

Dietary supplements can be:

- a high-calorie drink
- a feeding tube
- a vitamin or mineral supplement. Vitamin D, calcium, magnesium, and iron are common supplements for children with transplants.

Are there foods they should not eat?

Yes. There are some foods that could change how well some of their medicines work. This could be dangerous and possibly life threatening. They **should not** eat or drink grapefruit or grapefruit products.



Grapefruit



Pomegranate



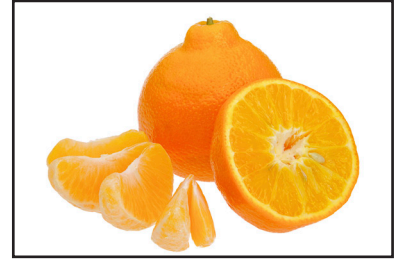
Star fruit



Grapefruit-flavored candy



Pomelo



Tangelos (also called Honeybell)



Grapefruit-flavored drinks This includes Sun Drop, Fresca, Sunny D, IZZE, Mountain Dew, and grapefruit juice.



Seville oranges and marmalade

How can we make sure their food is safe for them to eat and drink?

- Your child should always wash their hands before they eat.
- 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.
- Make sure that fresh fruits and vegetables have been washed well under running water.
- When you eat out, ask your server to tell you how the food is prepared, if needed.
- Your child should not eat:
 - raw or undercooked seafood
 - raw sprouts, including alfalfa sprouts
 - soft cheeses like brie, unless it's baked
 - cold, smoked fish
 - foods that contain raw eggs, such as hollandaise or Caesar dressing.

Cook foods correctly

- Use a food thermometer to make sure 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.
 - Use the guide to the right to know the correct internal temperatures.
 - You can buy a food thermometer 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.

Type of Food	Safe Temperature When Cooked
Beef, veal, lamb	At least 145°F (63°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)

Keep foods at safe temperatures

- Store all perishable foods in the refrigerator or freezer.
- Keep meat and fish away from raw fruits and vegetables
- Thaw frozen meat and fish in the refrigerator.
 - Do not thaw meat or fish on the counter or in the sink.
 - If you're in a hurry, you can thaw meat in the microwave, but you must cook it right away.
 - Do not re-freeze meat that you have thawed. Cook it right away, or throw it away.
- Pay attention to expiration dates of foods. Do not give your child food that is out of date.

Keep different foods apart

You should not use the same cutting boards, bowls, or utensils for different types of foods. Use 1 set of tools for meat and fish, and another set for fruits and vegetables.

If you use the same tools for all foods, germs can spread from raw meat to other foods. This is called cross-contamination.

To keep foods from being cross-contaminated:

- wash your hands with soap and warm water after you handle each type of food
- rinse fresh fruits and vegetables well with running water before you eat them
- wash everything that touched meat or fish. This includes: knives, cutting boards, and counters that you used to prepare the food.

Keep foods safe at a picnic

- Only take 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) .
- Take your food thermometer with you. Make sure grilled meat is cooked to a safe internal temperature.
- Store leftovers in an ice chest. Throw away any food that was left out for more than 1 hour.

Only drink safe drinking water

- Most city water is safe out of the faucet. A filter is not needed.
- Well water must be boiled to a rolling boil for at least 10 seconds. Make sure it's cooled to room temperature before your child drinks it.
- They should not swallow lake water. Most children swallow water when they swim. This is why there's more risk to swim in lakes. Your child should be careful if they swim in lake water.

Resources



American Liver Foundation

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

Children's Organ Transplant Association

Cota.org
2501 Cota Drive, Bloomington, IN, 47403
Supportsrv@aol.com
(800) 366-COTA (2682)

National Foundation for Transplants

Transplants.org
1102 Brookfield, Suite 200, Memphis, TN 38119
NanFounTx@aol.com
(800) 489-3863

Transplant Families

TransplantsFamilies.org

Transplant Recipients International Organization (TRIO)

Trioweb.org
1000 16th Street, NW, Suite 602
Washington, DC 20036-5705
Trio@primenet.com
(800) 874-6386

United Network for Organ Sharing (UNOS) and Organ Procurement and Transplantation Network (OPTN)

Unos.org
1100 Boulders Parkway, Suite 500,
PO Box 13770
Richmond, VA 23225-8770
(888) 894-6361

Liver Transplant Team

(615) 343-2454

ChildrensHospitalVanderbilt.org

