



# Evaluating Your Child for Heart Transplant

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[ChildrensHospitalVanderbilt.org](http://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.

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*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 Heart Transplant Team



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*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 Heart Transplant Team



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# The path to heart transplant: An overview



## The doctor says your child needs a new heart

You've been told that a transplant is the best way to repair your child's heart problems. Medicine and surgery are no longer good options.

Some of the reasons a child needs a new heart are:

- the heart has been damaged by a virus or other heart disease
- the heart muscle is too weak to work like it should, even though its structure is normal
- the structure of the heart has problems that are too complex to repair
- an earlier surgery has made the heart muscle too weak
- the child has already had a heart transplant, and now they need another one.

## *How will a new heart help?*

A heart transplant may help your child:

- go back to regular activities, such as going to school and playing with other children
- have more energy instead of being so tired all the time
- feel better
- live longer.

## *What happens if my child doesn't get a new heart?*

If your child doesn't have a transplant, we'll continue to treat their symptoms, but:

- they'll keep having heart problems
- their life will likely be much shorter
- their quality of life will be lower.



## You'll decide if transplant is right for your child

*There are 4 major steps in the transplant process:*

- education and evaluation
- waiting for a donor organ
- surgery
- life-long care.

### *Informed consent*

Before we can evaluate your child for transplant, we need your informed consent to do so. Informed consent means you know all about what it is you're agreeing to before you agree to it.

You have a lot to learn, and we're here to help. To give your informed consent, you need to learn about the risks and benefits of transplant evaluation, what will happen during the evaluation, what to expect as your child waits for a donor heart, and what will happen during and after transplant surgery. A heart transplant is a lifelong commitment.

After you and your child have learned all about the transplant and evaluation process, you'll need to sign a consent form if you want them to be evaluated.

## If we have your consent, the next step is evaluation

Our goal is to find out if your child is medically, surgically, emotionally, and mentally well enough to get a new heart. We also need to find out if you and the rest of your child's support system are emotionally and mentally able to go through transplant with them.

During evaluation, your child will have many medical tests and exams. You, your child, and their other support people will also meet with members of the transplant team. The team includes the:

- transplant heart doctors (cardiologists)
- transplant nurse practitioners
- transplant nurse coordinators
- transplant dietitian
- transplant pharmacist
- palliative care specialist
- infectious disease specialist
- transplant psychologist
- transplant social worker
- transplant financial coordinator
- and any other specialists who need to examine your child.

## Reasons your child may be considered for a transplant

Your child may be approved for transplant if they:

- have cardiomyopathy (a disease that makes it hard for the heart to pump blood through the body)
- have congenital heart disease (with or without prior surgery)
- need a new transplant.

It must also be true that:

- the cause of their problems is heart disease and a new heart will help
- they would only have 1 year or less to live, or their quality of life would be very bad and get worse without a transplant
- there are no other treatments besides transplant that would improve their disease or quality of life.

## If your child is approved for transplant, they'll wait for a new heart

If the transplant committee decides that your child is approved for transplant, we'll put them on the waitlist for a donor heart.

We don't know how long your child will have to wait. Their medical treatment will continue during this time.

## When a donor heart is found, it's time for transplant

When a donor heart is found, it's time for you to bring your child to the hospital.

When you get to the hospital, your child's surgeon will talk with you about all the risks and benefits of the surgery. You'll sign a consent form for surgery before we can start.

### *Sometimes a transplant may be cancelled*

There are times when patients are called in for a transplant, but for some reason, we find that the donor heart is not right for transplant. If this happens, your child's surgery will be cancelled. Although this is disappointing for patients and their families, your child's health is our main concern.



## After surgery, life with a new heart begins

A transplant is the first step in a lifelong process. After transplant for the rest of your child's life, they'll have to follow a strict medical plan. This plan will include follow-up visits, blood tests, and medicines they'll take every day for the rest of their life.

## You'll need a lot of support before and after transplant

You and your child can't go through the transplant process alone. A successful transplant requires that your child has at least 2 people in their life who can give them the support and help they'll need. They need this support during evaluation, while they're on the waitlist, and long-term after their transplant.

### *Before transplant*

You and your child's support persons will need to do a couple things.

- You'll have psychosocial evaluations. This is when we'll learn about all the things that make up your daily life. We'll talk to you about your work, support systems, financial situation, and more.
- You'll learn all the things your child will need after surgery. This includes when they're in the hospital and long-term.

### *After transplant*

At the hospital, you and the other support persons will:

- be with your child when we give them their medicines, once they're out of the PCICU (pediatric cardiac intensive care unit)
- learn about all your child's medicines, what they're for, and their side effects
- learn how to care for your child's chest incision as it heals.

By the time your child leaves the hospital, you and the other support persons will:

- know how to count your child's heart and breathing (respiratory) rate
- know how to take your child's blood pressure (depending on their age)
- know all about their medicines and their side effects
- be able to help them take their medicines exactly how they're supposed to
- have learned about the signs of organ rejection, medicine side effects, and how to watch out for other medical issues
- be ready to take your child to their transplant clinic visits and to all the other medical visits they'll need.

Your child needs reliable, committed support to successfully go through the transplant process.

## You can change your mind about transplant at any time

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 the surgery.

## Your child's eligibility may change as they wait for a new heart

While your child is on the waitlist, it's possible they'll get worse and no longer meet the requirements for transplant. If this happens, we'll let you know right away.

## Being evaluated doesn't always lead to a new heart

One risk of evaluation is that your child will not be approved for transplant. If this happens, they won't be put on the waitlist. Their treatment will continue.

You'll learn more on page 10 about why some children are not approved for transplant.

## Transplants can fail

It's always possible that the donor heart will fail or that your child's body will reject the organ. If this happens, your child may be eligible for another transplant in the future. This will depend on:

- the reason for the organ failure
- your child's health.

## We're here every step of the way

This overview has probably given you an idea of how much you have to learn. We know it's a lot to take in. We're here to help. Please read the rest of this book carefully. It covers everything we'll talk with you about—from evaluation to life after transplant.

As you read, write down any questions you have. This book is just 1 small piece of your transplant education. Come to us with any questions you have.

# Step 1: Education and evaluation



## What do I need to learn?

Now it's time to learn the details of the transplant process. This will help you decide if evaluation and transplant are right for your child and your family. Our goal is to make sure you know about:

- the risks and benefits of transplant
- the treatment options your child has besides transplant, including medical management and palliative care
- the evaluations and tests your child will have done and the results of these
- how the waitlist works
- how transplant recipients are chosen
- any psychosocial or financial 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
- current results and outcomes of our transplant program
- where donor hearts come from
- organ donor risk factors
- your right to refuse transplant for your child at any time, up until surgery.

## How long does evaluation take?

This depends on each child. Many factors affect how long it will take. We can't say in advance how long your child's evaluation will take. But we will keep you updated throughout the process.

## What happens during the evaluation?

This is when we find out if it's safe for your child to have a heart transplant. We'll take a careful look at your child's health and do a lot of tests. Every test will be explained to you and your child before it's done.

Some tests have risks. We'll explain these to you and will need your informed consent to do them. This means you'll have to sign separate consent forms that explain the risks of each test in detail.

## Meeting with your transplant team

You, your child, and their other support person will meet the transplant team for different tests and evaluations. The people you'll meet include the:

- transplant heart doctors (cardiologists)
- transplant nurse practitioners
- transplant nurse coordinators
- transplant dietitian
- transplant pharmacist
- palliative care specialist
- infectious disease specialist
- transplant psychologist
- transplant social worker
- transplant financial coordinator
- and any other specialists who need to examine your child.

## Other providers your child may see

We may need to do more tests than the ones we usually do. This will depend on your child's medical history. If this is the case, we may refer your child to other specialists. They may need to see:

- a lung doctor (pulmonologist)
- a kidney doctor (nephrologist)
- a liver doctor (hepatologist)
- a digestive system doctor (gastroenterologist)
- a brain doctor (neurologist)
- a diabetes doctor (endocrinologist)
- an eye doctor (ophthalmologist).

If your child needs to see any of these specialists, we'll explain the reasons why.

## What kind of tests and exams will my child need and why?

### Medical tests

These tests help us learn their risk of transplant. We'll find out if your child has any problems that make transplant riskier or if they'll need special care at the time of transplant. The tests we may do, include, but aren't limited to:

- tests to look at and measure heart function, including cardiac catheterization, echocardiogram, and electrocardiogram
- pictures of the chest (x-rays) that look at your child's heart and lungs
- kidney tests, including urine tests and ultrasound
- tests that look at your child's head and brain, including a CT scan, ultrasound, or MRI of the head
- liver function tests, including an ultrasound or MRI of the liver, or extra pressure measurements that are done during a cardiac cath test
- neuropsychological tests
- drug screens

- labs and blood tests to:
  - learn your child's blood type for organ matching
  - see if your child has any viral infections, including HIV, or if they have immunity to these viruses
  - get a better picture of how well your child's body and other organs besides the heart are working
  - check your child's immune system to see if it's already sensitized and would react to some tissue types. (This is more common in children who have already had heart surgery.)

### Dental exam

Dental diseases can cause infections or other problems after transplant. Your child will need to go to the dentist to make sure any dental problems they have are fixed before surgery.

We require a written statement from your child's dentist showing that any dental work your child needs has been done. You'll give this document to your transplant coordinator.

## *Nutrition evaluation*

During evaluation, you and your child will meet with a dietitian. They'll learn about your child's eating habits to decide if your child is eating the foods that are best for them and their health.

Our goal is for your child to be as strong as possible for surgery. We'll help you and your child make any diet changes they need.

## *Tobacco, alcohol, and illegal drug evaluation*

If your child uses tobacco, alcohol, or illegal drugs, they can't be approved for transplant. If your child has a current or recent history of use, these things are required:

- Your child can't use any of these substances for 6 months before transplant evaluation. This must be documented by 6 months of negative drug, nicotine, and serum alcohol tests that are done at random.
- Your child can't use any of these substances during evaluation or while they're on the waitlist for transplant.
- Your child must complete a tobacco, alcohol, or drug rehab program.
- Your child must take part in an ongoing support program.

You're also required to give us official written documents that prove your child:

- has finished a tobacco, alcohol, or drug rehab program
- continues to take part in an ongoing support program.

## *Psychosocial evaluation*

A social worker will meet with you, your child, and the rest of your child's support team for what is called a psychosocial evaluation. At this meeting, your social worker will:

- do an in-depth evaluation of your life and social circumstances. They'll talk to you about your:
  - employment
  - finances
  - mental health history
  - substance abuse history (if your child has one)
  - legal history
- decide if you're able to understand and agree to the risks, benefits, and expected results of a heart transplant for your child
- talk about why you've decided to seek a heart transplant for your child
- decide how well you, your child, their support people, and your family will be able to handle the emotional, financial, and physical stress of transplant
- make sure you and your child will have the social support needed to go through the transplant process.

## What happens after evaluation?

When the evaluation is done, the Patient Selection Committee will meet about your child's case. This committee includes the transplant heart doctors and surgeons, as well as the transplant coordinators, the transplant dietitian, the transplant pharmacist, and the transplant social worker. They'll go over the results of the evaluation, including any extra risks that your child may face if they have a transplant.

After the committee meets, we'll contact you by letter and phone to tell you what the team has decided. One of 3 things will happen:

- **Your child is approved for transplant**  
We'll ask you if you want us to put your child on the waitlist. If there are any special risks your child could face with transplant, we'll tell you about them at this time.
- **We need to do more tests**  
Your child may still be approved for transplant, but we need to do more tests to decide for sure.
- **Your child isn't approved for transplant**  
This can happen when a child is too sick for transplant, or when a child is too well to have a transplant right now. If your child is too healthy for transplant now, they may be considered for transplant in the future if they get sicker.

If your child isn't approved, we'll explain all the reasons why.

Some reasons a child may not be approved for transplant are:

- They have very high pressure in the lungs (pulmonary hypertension) that can't be treated.
- They have kidney, liver, or lung problems that aren't caused by their underlying heart failure. These problems can't be fixed with a new heart.
- They have 1 or more active infections in their body.
- They have active peptic ulcer disease that's caused recent bleeding in the digestive tract or bleeding in the throat (esophageal varices).
- They have another systemic disease that is likely to limit or get in the way of their survival and healing after transplant.
- They have a BMI higher than 35.
- They have to take insulin for their diabetes and it has caused problems in another part of their body, such as kidney, eyes, or nervous system.
- They, or their support system, have a history of very bad psychiatric illness or behavior patterns that would make it hard for them to follow the strict medical guidelines that are part of transplant.



## Step 2: Waiting for a donor



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If your child is approved for transplant, they'll now wait for a donor. During this time, the transplant cardiologist will oversee your child's care. Our waitlist patients are often managed by their primary cardiologist as well.

### How does the waitlist work?

The transplant coordinator will explain in detail how the transplant waitlist works and how it's decided who gets a heart when one becomes available. Five things are considered:

- blood type
- body size and weight
- your child's priority status
- donor location
- how long your child has been on the waitlist.

### Where do new hearts come from?

Organ donation is anonymous and voluntary. All our hearts come from donors who are legally brain dead. This means they have brain damage that can't be fixed. Donation often helps families deal with their grief.

### How are donor hearts chosen?

Donor hearts are ones that are healthy and work well. Good heart function is the most important thing we consider when a donor heart becomes available. Donor hearts are not matched by sex, race, or culture.

The matching of donor hearts to recipients is regulated by the United States government through an organization called UNOS (United Network for Organ Sharing).

## How long does it take to get a new heart?

We can't know in advance how long your child will have to wait. It can take a very long time. Many weeks or months can go by before a match is found. It's possible for a patient to die while they wait for a new heart.

## What can be done for my child while they wait for a heart?

If your child gets sicker while they wait for a heart, we may decide that their heart needs extra support until a donor is found. The type of support we suggest would be based on your child's age, size, and their heart problem.

- We may suggest ECMO (extracorporeal membrane oxygenation) support.
  - ECMO is similar to a heart-lung bypass machine that is used during transplant surgery. While on ECMO, blood is pumped outside the body into the machine to add oxygen and then back inside the body.
  - If your child is put on ECMO, they would have to stay in the hospital until a donor is found.
- Or we may suggest a ventricular assist device (VAD).
  - A VAD is a pump that helps move blood to the rest of the body. The pump can be put inside or outside the body.
  - If they get a VAD, they may be able to go home until a donor is found. It will depend on the type of VAD they need.

Their doctor will let you know what is best for your child.

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

Help your child do everything the transplant team has said they need to do. They should:

- take their medicines
- eat a heart-healthy diet
- follow all rehab therapy plans
- go to all clinic visits
- follow all other parts of their treatment plan so they can be as healthy as they can be at transplant.

## 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 any list.

## How is it decided who's highest on the waitlist?

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

There are 3 priority categories:

- **Priority status 1A.** These patients are the sickest and have the most urgent medical transplant needs.
- **Priority status 1B.** This level is not as urgent, but the patient is not in a stable condition and is still very sick.
- **Priority status 2.** A patient with this status needs a transplant but is stable. A transplant is not as urgent as status 1A or 1B.

## Will my child ever be taken off the waitlist?

While your child is on the waitlist, we keep close track of their health. If their health ever gets worse and it's no longer safe for them to have a transplant, we may have to remove them from the waitlist.

## Does our family need to stay close to Vanderbilt while we wait for a heart?

- It's best if you and your child stay within a 4-hour drive from Nashville. This is because the donor heart must be transplanted within a 4-hour window to have the best possible function.
- If you live further than a 4-hour drive, you can still get on the waitlist. But you must arrange to have air transportation to Vanderbilt when a donor heart becomes available.
  - It's your responsibility to pay for these costs if your insurance doesn't cover it.
  - The transplant coordinator or social worker will give you the contact information for several air ambulance companies.
  - When you choose the company you'll use, give the names and contact phone numbers to your transplant coordinator.

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

We have program coverage at all times. This means we are always available to help.

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

If your child needs help at any time while they're on the waitlist, a surgeon or doctor will always be able to get to Vanderbilt within 60 minutes.

## What happens when we get the call for transplant?

When we tell you there's a heart for your child, you need to get your child to Vanderbilt Children's Hospital as fast as you can. 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 you 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 the back of your golden ticket.

### *You'll need your golden ticket*

During evaluation, the transplant coordinator will give you your golden ticket. Keep it in a safe place so you know where it is at all times. You need to bring it with you when we call you in for transplant. It will help you get admitted into the hospital quickly.

### *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, we may have to decline the heart.

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

### *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 else to eat or drink.
- Bring all of your child's medicines and a list of all the medicines they take with you.
- 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.

## Step 3: At the hospital



### What happens when we get to the hospital for surgery?

When you get to the hospital with your child, 2 things will happen first:

- We'll check your child in and get them ready for surgery.
- The surgeon will meet with you and talk with you about the surgery and its risks. Before we can start the procedure, we'll need you to sign an informed consent that gives your permission to do it.

When we have your informed consent and we've prepped your child, we'll take them into surgery.

### What happens during surgery?

In the operating room:

- We'll give your child medicine called anesthesia that will make them sleep.
- Your child will be asleep and not feel any pain during the procedure.
- When your child is asleep, the surgery will begin.
  - The transplant surgeon will make an incision in the middle of your child's chest and cut through their breast bone.
  - The diseased heart will be taken out of your child's chest.
  - The new, healthy heart will be put into your child's chest and attached.
  - Once the new heart is beating, the surgeon will close your child's chest and incision.

## Who will do the surgery?

One of our transplant surgeons will do the surgery. We have several who do transplants. You may have even met with one of them during evaluation. But, the one who does your child's surgery may not be the one you met. The surgeon who does it will depend on who's available on the day we find your child's new heart.

## How long will surgery last?

Heart transplant surgery usually takes 6 to 10 hours.

## What happens after surgery?

After surgery, we'll take your child to the PCICU (pediatric cardiac intensive care unit), where we'll watch over them as they wake up and start to recover.

### *They'll have machines connected to them after surgery*

- A breathing machine (ventilator) with a breathing tube. One end of the tube is connected to the breathing machine. The other end goes into your child's mouth and down their throat. The machine helps them breathe until they can do it on their own.
- Chest tubes. These tubes are placed in the chest through the skin. They're used to help drain blood and fluid from around the heart and lungs after surgery. The tubes are usually removed 2 to 3 days after surgery.

- IV tubes. These tubes go under the skin and into the veins. We'll use them to give your child medicine. The tubes may be in your child's hands, arms, neck, or directly into their heart.
- Urinary catheter. This tube carries urine from the bladder into a container. It will be removed when:
  - your child is able to go to the bathroom on their own or they're able to use diapers or pullups; and
  - we no longer need to get an exact measurement of how much urine their body makes.
- Pacer wires. These temporary wires will be hooked to a pacemaker. They'll be taken out before your child leaves the hospital.

### *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 need to see your child as needed.

### *They'll finish their recovery in a regular hospital room*

They'll stay in the PCICU right after surgery. But we'll move them to a regular hospital room once they're ready.

## How will my child feel after surgery?

### *Pain*

After surgery your child will have pain. This may include:

- gas pains
- sore throat
- soreness in different parts of their body
- backaches
- chest bone pain
- incision pain.

Most heart transplant patients are pain-free about 2 weeks after the surgery. But some children have pain for a longer time.

### *Confusion*

Your child might be confused for a short time after surgery. This is common. It's caused by the medicines we've given them.

## How long will my child be in the hospital?

Heart transplant patients are usually in the hospital for at least 7 to 14 days, or longer. This may change depending 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 their doctor is sure it's safe.

## Can we go back home when we leave the hospital?

It depends on where you live. Your child will need to stay in the Nashville area for at least 6 weeks after surgery. If you don't live in the area, you'll need to find a local place to stay during this time. Your social worker will help you with this.

If you live out of town, your child's heart doctor or nurse will let you know when it's safe for you to go home.



## Step 4: Life after transplant



### What kind of care will my child need?

#### *Long-term follow up*

Even though we'll make every effort to move your child's routine medical care to their primary care provider, the transplant clinic will need to follow your child's progress for the rest of their life.

#### *Biopsies*

From time to time, we may need to do biopsies of your child's heart. These are tests where we take a bit of tissue from the heart and check it for rejection signs.

#### *Cath tests (catheterizations)*

Sometimes, we'll also do cardiac cath tests. These tests let us see in more detail how your child's heart is working.

#### *Lab work and clinic visits*

Your child's regular lifelong follow-up will also include:

- frequent lab work
- clinic visits that happen at least every 6 months.

How often we do tests, labs, and clinic visits will depend on your child's age and health. If your child has any complications at any time, we may need to see them more often.

### Are there precautions my child will have to take after transplant?

The medicines your child will take for the rest of their life make it easier for them to get infections. Because of this, they need to take special steps to stay healthy.

There are some precautions your child will always have to take. At first, they may also have other restrictions that will be lifted in time. Your child's transplant doctor or nurse will talk with you about what you can expect.

## Tips for preventing infection after transplant

Your child should follow these guidelines.

- Wash hands with soap and water before they eat and after they go to the bathroom.
- Shower or bathe regularly. As they heal after surgery, make sure their incision is washed the same as any other part of their body. Do not use lotions or powders on the incision.
- Clean cuts and scrapes right away with soap and water. Then apply an antiseptic and a bandage.
- Keep fingernails and toenails clean and trimmed. If toenails are ever hard to manage or are ingrown, have your child see a foot specialist.
- Never change the litter in the cat box or a birdcage. This could cause a serious viral infection. Avoid cat scratches.
- Always wear gloves when they garden or dig in the dirt to help avoid fungal infections.
- Do not use community whirlpools or hot tubs.
- Do not swim in lakes or ponds.
- Your child should not smoke. And you should never expose them to any second-hand smoke.
- Stay away from people who are sick. This includes colds, the flu, Covid-19, chicken pox, and stomach illness.
- Avoid being around people who are sick with the mumps or measles, as well as other infections for which there are vaccines.

- Get all their vaccines.
  - They should have a flu vaccine every year.
  - If eligible, they should get the COVID-19 vaccine. They should get the recommend number of doses.
- They should never get any vaccine that contains a live virus. Ask their doctor if you want a printed list of these vaccines. The vaccines they SHOULD NOT have are:
  - smallpox
  - chicken pox
  - MMR
  - FluMist
  - oral polio vaccines
  - rotovirus.

To help protect your child:

- you, your entire family, and their other caregivers should get a flu vaccine every year
- talk to their doctor if anyone in your house is going to get a live virus vaccine for a disease that your child hasn't been vaccinated for
- if eligible, you, your entire family, and their other caregivers should get the COVID-19 vaccine. Everyone should get the recommend number of doses.

# The risks of transplant



Heart 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.

For all transplants, there are 3 main types of risk:

- medical
- psychosocial
- financial.

## Many things affect the success of a transplant

We can't know exactly how your child's body will react to transplant until after it happens. We also don't know in advance if all the problems caused by your child's heart disease will get better after transplant.

The success of a heart transplant will be affected by:

- how sick your child was before transplant
- how well your child followed the treatment plan that was prescribed to them before surgery
- the life conditions of the donor, such as the donor's health history and the condition of the organ when we received it in the operating room for surgery.

## What are the short-term medical risks?

### *Cancelled surgery*

It's possible for your child to come to the hospital for transplant and find out that the surgery can't be done. Reasons for these types of cancellations include finding out that the donor heart is not healthy enough.

When a transplant is cancelled, the patient goes home and will stay on the waitlist. They won't lose their place on the waitlist.

### *Interrupted surgery*

Sometimes a surgery has to be stopped after it's started. The surgeon may choose to do this at any time if the surgery has become too risky or if it turns out the heart isn't right for transplant.

### *Risk of organ rejection*

The risk of rejection is highest from the time of surgery through the first year. The good news is that rejection can usually be treated. The treatment may be given at home or may require a stay in the hospital.

After transplant, your child will take medicine to lower the risk of organ rejection. They'll have to take these medicines for the rest of their life.

### *Anesthesia risks*

This surgery will be done under general anesthesia. This is a medicine that will make your child sleep and keep them from feeling pain during surgery. Any time general anesthesia is used there are risks. The doctor who gives this medicine during surgery is called an anesthesiologist. They'll explain the risks to you and give you a separate consent form to sign.

### *The risks of being on a heart-lung bypass machine*

During surgery, your child's body will be attached to a machine called a heart-lung (cardiopulmonary) bypass machine. This machine moves blood through the body and carries oxygen to all the organs. It does the work of the heart and lungs during surgery.

A heart-lung machine makes it possible to do the surgery, but it has risks. Your child's transplant surgeon will explain these to you. The risks will also be described on the surgical consent form that you'll sign before your child's heart transplant.

### *The risks of blood transfusion*

Your child may need donor blood during or after their surgery. Even though we check all blood for HIV, hepatitis, and other diseases, anytime a person gets blood, there's a risk of being infected.

### *Risk of pain, bleeding, or injury*

Transplant surgery can cause pain, bleeding, or damage to other organs in the belly.

### *Risk of sickness or infection*

This surgery can cause sickness and infection, including:

- feeling sick to the stomach
- fevers
- pneumonia or other lung infections
- bladder and urinary tract infections
- infections from IV catheters.

### *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 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 ever 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 blood clots*

This surgery may cause blood clots in your child's legs. This is dangerous since clots can move to the lungs and make it hard to breathe.

To help keep blood clots from forming, we may put special devices on your child, such as plastic boots that inflate and deflate to keep the blood in their legs flowing during and after surgery. We may also give your child a blood thinner until they're able to move around and their IVs are taken out.

### *Risk of nerve damage*

This surgery can cause nerve damage. If this happens, it can cause numbness, weakness, paralysis, or pain in your child's body. Most of the time, these problems last only a short time and go away on their own. In rare cases, the problems can last for longer periods of time or even be permanent.

Nerve damage may include harm to the vocal cords, a weak voice, a hard time swallowing, and paralysis of the diaphragm (the muscle that helps us breathe).

### *Risk of death*

Like any surgery, there's the risk of death. This is especially true with heart transplant given how serious the surgery is.

- In general, the risk of death right after transplant is 5 percent. How sick your child is may raise this risk.
- If your child has had other surgeries in the past, this may also affect their risk. Your cardiologist or surgeon can talk to you more about your child's risk of death.

### *Risk of transplant failure*

If your child's transplant fails for any reason, they may be placed on the United Network for Organ Sharing (UNOS) list to wait for another heart. During this waiting time, it's possible they could die.

### *Additional surgery risks*

Other things that can happen are:

- injury to structures of the chest
- pressure sores on the skin caused by the position of the body during surgery
- burns caused by the electrical equipment used during surgery
- damage to arteries and veins
- heart attack
- stroke
- seizures
- a scar from the chest incision made during surgery.

## **Are there long-term medical risks to transplant?**

### *Risk of organ rejection and death*

The risk of organ rejection is something your child will have for life. There's always a chance their immune system will attack their new heart. Because of this, a child can die of rejection at any time. This risk is lower after the first year.

### *Changes to life span after transplant*

We don't know how long a person will live after heart transplant. However, 85 to 90 percent of transplant recipients are still alive 3 years after surgery.

### *Risk of infection*

Infection risk will be higher for the rest of your child's life. This is because of the medicines your child will take to prevent organ rejection. This is why it's so important for them to take every step they can to prevent infection.

### *Increased cancer risk*

Children on medicines that suppress the immune system have a long-term risk of getting cancer, especially a cancer of the blood called lymphoma. They also have a greater chance of getting skin and other types of cancer.

### *Higher risk of heart disease*

When a child has a heart transplant, there's a risk that the arteries of the heart will narrow. These arteries are the tubes that take blood and oxygen from the body to the heart muscle. The changes that can happen to the arteries after transplant are like those that happen to older adults. The arteries get smaller, which means the heart doesn't get the oxygen it needs. This can lead to heart attacks. Some children even die from this problem. Others end up needing a second transplant. If the arteries get really narrow, another transplant is often the only treatment.

### *High blood pressure*

The medicines your child will take to fight rejection can raise blood pressure. They may have to take medicines to help the problem.

### *Diabetes*

Anti-rejection medicines can cause high blood sugar. If your child develops diabetes, they may have to take insulin to control it.

### *Kidney problems and failure*

The medicines your child takes to fight rejection can be hard on the kidneys. Over time, the kidneys can become very damaged. On rare occasions, some transplant recipients will eventually need a kidney transplant.

### *Future pregnancy risks caused by transplant medicines*

Some transplant medicines raise the risk of birth defects or pregnancy loss. There are specific concerns with the medicines mycophenolate mofetil, and mycophenolic acid. Other medicines may also cause premature birth, pregnancy loss, and birth defects.

In the future, your child must talk to their provider before they try to have their own biological children.



## Psychosocial risks

A heart transplant can cause psychological and emotional problems for you, your child, their other support person, and your family. 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 heart transplant surgery 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.
- Getting a heart transplant may affect your child's ability to get life or health insurance in the future. Insurance companies may decide your child has a pre-existing condition and refuse payment for medical care, treatments, or procedures.

# Common medicines after transplant

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After transplant, your child will need to take different kinds of medicines for the rest of their life. This includes the anti-rejection medicines they'll take to help their body accept their new heart.

They need these anti-rejection medicines because the natural response of the body is to attack any foreign tissue. At first, your child will take large doses of these medicines. The doses will gradually be lowered as your child's body accepts the new heart.

After transplant, patients usually go home taking 2 or 3 types of anti-rejection medicines. This is in addition to their other medicines.

## Your child must take their medicines exactly as told

The medicine schedule after transplant is very strict. You need to make sure your child follows it every day. If they do not take all their medicines or skip a dose, it can cause your child's body to reject their new heart.

You, your child, and their other support persons will need to know the names of these medicines, how much they're supposed to take, when they should take them, and what the pills look like.

Your nurse will help you and their other support persons learn all about your child's medicines so you know how to give them to your child on your own.

## Anti-rejection medicines

The 3 most common anti-rejection medicines for transplant patients are:

- Tacrolimus (Prograf)
- Mycophenolate (Cellcept)
- Sirolimus (Rapamune)

These medicines are very good at lowering the risk of rejection. But they also have a number of possible side effects. These include:

- lower ability to fight infection
- higher risk of cancer
- increased risk of birth defects
- nausea or diarrhea
- high blood sugars.

There are other side effects as well. We'll talk with you about them.

After transplant, we'll give you detailed information about the specific medicines your child will be on and how they'll take them.

## Steroid treatment

Prednisone is a steroid that's commonly given to transplant patients. At our center, most transplant patients do not have to take prednisone long-term. But, if your child was on prednisone before transplant, or if they're at a high risk of rejecting the transplanted organ, they'll be sent home on a daily prednisone dose.

# Financial considerations



## Paying for your medicines

Without their medicines, your child's body will reject their new heart. You're going to need enough money to pay for their medicines or have enough prescription drug coverage at the time of the transplant. Without adequate drug coverage, the estimated costs for your child's medicines are about \$5,000 a month (\$60,000 a year) for the rest of their life. Because these costs are so high, it's important for you to tell us about any changes to your child's prescription plan. It's also important that your child always has prescription coverage.

## Fundraising

If you think you're going to have trouble paying for any major costs that won't be covered by insurance (like prescription co-pays, travel, and lodging), we encourage you to think about fundraising. The earlier you get started on this, the better.

These 3 organizations help transplant families raise money:

- NFT (National Foundation for Transplants):  
(800) 489-3863  
[Transplants.org](http://Transplants.org)
- Help Hope Live (Formerly National Transplant Assistance Fund):  
(800) 642-8399  
[HelpHopeLive.org](http://HelpHopeLive.org)
- COTA (Children's Organ Transplant Association)  
(800) 366-2682  
[COTA.org](http://COTA.org)

These organizations have made quite a difference in the lives of many of our patients. They're often able to help patients and their families before, during, and even years after their transplants.

## Your financial coordinators

We know this can be a lot of information to process all at one time. Your financial coordinators will give you support throughout the entire transplant process. They will:

- keep everyone at Vanderbilt informed about your current insurance coverage
- get all the necessary authorizations and approvals required from your insurance throughout the process
- help you in any way possible with your insurance questions and concerns.

## *Tell your financial coordinators right away if:*

- you begin or end the coverage you have through COBRA
- you sign up for any new insurance
- any of your current insurance policies change or end.

# Resources and patient tools



## UNOS: the United Network for Organ Sharing

You can find more information about transplant from UNOS.

- The UNOS website: **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.

## National and local transplant data

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

## Information sharing

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 heart, 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.

## Learn more

American Heart Association

**Heart.org**

Children's Cardiomyopathy Foundation

**Dev.ChildrensCardiomyopathy.org**

Children's Organ Transplant Association

**COTA.org**

Coalition of Donation

**ShareYourLife.org** or **DonateLife.net**

National Foundation for Transplant

**Transplants.org**

National Transplant Assistance Fund

**TransplantFund.org**

Pediatric Heart Transplant Study

**PHTSFoundation.org**

Transplant Recipients International Organization

**TRIOWeb.org**

Vanderbilt Heart Transplant Program

**VanderbiltHealth.com/transplant**





# Heart Transplant Team

(615) 322-7447

[ChildrensHospitalVanderbilt.org](http://ChildrensHospitalVanderbilt.org)

