



# After Your Child's Heart Transplant

(615) 322-7447

[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. You can always ask them questions at any time.

We hope this book will help you and your caregivers know what will happen when you go home after your heart transplant.

**You'll learn**

- all about your transplant team and how to reach us
- the medicines you need to take and how they'll help you
- what you can do to stay healthy.

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 what to expect when your child goes home after their heart transplant.

**You'll find information about:**

- your transplant team and how to reach us
- potential complications
- your child's medicines
- how to stay healthy.

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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# 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.

Your child's transplant team may include:

- heart transplant coordinators
- transplant heart doctors (cardiologists) and nurse practitioners
- transplant surgeon
- transplant pharmacist
- transplant dietitian
- social worker
- psychologist
- palliative care
- child life specialist
- transplant financial coordinator
- nurses
- school teacher
- case manager
- rehab specialists
- speciality providers.

## *Heart transplant coordinators*

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

You may contact them any time you have questions or concerns. Everything you talk about is confidential. They'll only share information with your child's other health care providers when needed.

## *Transplant providers*

The transplant heart doctors and nurse practitioners will manage your child's care. This includes all their transplant medicines. Your child will see a transplant heart provider at every clinic visit. They'll see other heart doctors when they have a cardiac cath (catheterization) or stay in the hospital.

## *Transplant surgeon*

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

### *Pharmacist*

The transplant pharmacist will teach you about your child's medicines and answer your questions about their medicines.

### *Dietitian*

The dietitian will work with you to make a heart-healthy diet for your child. They'll help your child build healthy habits.

### *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 will help you and your child develop skills to manage the stress of heart transplant. They can help you find community resources for ongoing care.

### *Palliative Care*

The palliative care team will help you and your child talk through any stress you may have. They'll also give you support for your goals, hopes, fears, and wishes.

### *Child Life specialist*

The child life specialist will work with your child to help them cope with being in the hospital. 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. They also help 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 with the transition back to school.

### *Case manager*

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

### *Rehab specialist*

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

### *Specialty providers*

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

## 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.

### *For non-urgent concerns or questions*

- **Phone:** Call us at (615) 322-7447. 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.

### *For urgent concerns and questions*

- **During regular clinic hours:** call (615) 322-7447 and leave a message. Our team will call you back.
- **After hours:** call (615) 322-7447 or (615) 322-5000 and ask to leave a message for the pediatric cardiologist on call. The on call cardiologist will call you back.

## 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](http://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 9)
- does not feel well

### Heart Transplant

**Clinic phone:** (615) 322-7447

**Clinic fax:** (615) 875-1746 or (615) 322-2210

The heart transplant clinic is on the 5th floor of Doctors' Office Tower in Monroe Carell Jr. Children's Hospital at Vanderbilt.

### Hospital Operator:

(615) 322-5000, ask for the pediatric cardiologist on call

- has diarrhea or throws up for more than 24 hours.

# Follow-up Care



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

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

Your transplant coordinator will schedule your child's follow-up visits for the first 4 to 6 weeks before they leave the hospital. After that, at the end of each clinic visit, you'll set their next one.

Over time and as your child recovers, they'll need less follow-up care. We'll do our best to move your child's routine medical care to their primary provider. But a transplant cardiologist will need to follow your child's progress for the rest of their life.

### Follow-up visits

Your child will need regular follow-up visits to make sure everything is working like it should. Our post-transplant follow-up visit schedule:

- **First 4 weeks:** Every Monday and Thursday
- **4 to 8 weeks:** 1 visit per week
- **2 to 4 months:** 1 visit every 2 weeks
- **4 to 6 months:** 1 visit every 4 weeks
- **6 months to 1 years:** 1 visit every 6 weeks
- **After 2 years:** 1 visit every 4 to 6 months.

They may need to be seen more often. It will depend on how well their recovery goes.

### Lab tests

Your child will have lab tests done before each of their follow-up visits. This will help us know if their medicines are working right and how their heart is doing.

We'll draw their blood on the 10th floor of the Doctors' Office Tower before every clinic visit.

**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).

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.

The transplant team will review your child's lab results the day of the clinic visit. Your transplant coordinator will let you know if:

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

**Some of the lab tests are:**

**ABO titers:** Monitors for development of antibodies against the blood type of the new heart.

**BNP (brain natriuretic peptide):** Measures levels of a protein made by the heart. It can be elevated for many reasons. Elevated BNP can be a sign of problems with the heart.

**BUN (blood urea nitrogen):** Measures BUN levels in the blood. It can show how well the kidneys are working.

**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.

**Cyclosporine trough:** Measures the level of cyclosporine in the blood. The test must be done 30-60 minutes before the morning dose is due.

**DSA (donor specific antibodies):** Monitors for development of antibodies against the new heart.

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

**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 an electrolyte found in the blood. K+ plays an important role in muscle contractions.

**Mg (magnesium):** Measures an electrolyte found in the blood. Mg plays an important role in muscle contractions and energy levels. Some of your child's medicines can cause low magnesium levels.

**Na (sodium):** Measures an 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.

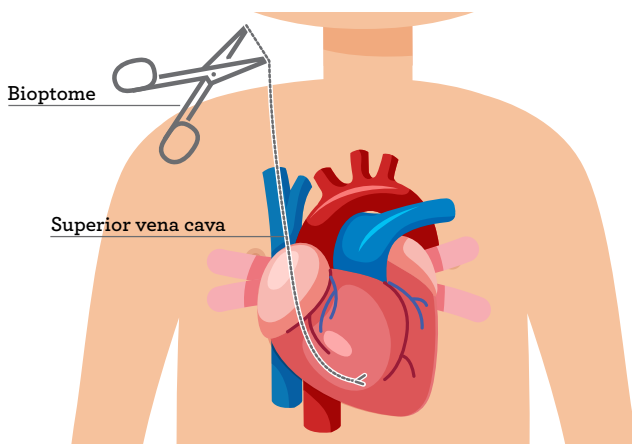
**WBCs (white blood cells):** Measures these blood cells. WBCs fight infection and react against foreign substances in the body.

## Biopsy

A biopsy is when we take a small bit of tissue from the heart. We check the tissue for signs of rejection or swelling (inflammation) in the heart. We'll also do a biopsy after a rejection episode to see how well a treatment worked.

It takes about 30 to 45 minutes. It's done in the Cardiac Catheterization Laboratory by a cardiologist. Before the test, your child will be given some medicine to help them relax.

To do a biopsy, we put a small tube into a vein in the right side of your child's neck, leg, or groin. A tool is put inside the tube and pushed into the right ventricle. The tool takes a small bit of heart muscle tissue from the wall of the right ventricle.



After we're done, we'll take the tool and tube out. Then we'll put gentle pressure where we put the tube in to stop any bleeding. If there is any swelling or bleeding, we may add more pressure.

## If we go through the vein in their neck

They'll need to keep their head up for 2 hours after the biopsy. This will help prevent bleeding.

You should let us know right away if they have any swelling or bleeding, or if they have unusual shortness of breath, chest pain, fever, or feel dizzy.

## If we go through a vein in their groin

They'll need to lie down with their leg straight for about 4 hours. This is most often done in infants and small children.

## How often they'll need a biopsy

How often we do biopsies depends on the age your child was when they got their transplant and how their recovery goes. If there are signs of rejection, we'll need to do them more often.

- **If they were younger than 2 years old, they'll get a biopsy done at:**
  - 1 year
  - 3 years
  - 5 years
  - then as needed.
- **If they were 2 to 10 years old, they'll get a biopsy done at:**
  - 6 weeks
  - 3 to 6 months
  - 1 year
  - 3 years
  - 5 years
  - then as needed.
- **If they were 10 years old or older, they'll get a biopsy done at:**
  - 2 weeks
  - 6 weeks
  - 3 months
  - 6 months
  - 1 year
  - every 1 to 2 years until 5 years
  - then as needed.

### *Cath test and coronary arteriogram:*

A cath test (cardiac catheterization) checks your child's heart pressure and blood flow. A coronary arteriogram takes pictures of their blood vessels.

Your child may have several cath tests in the first year after transplant. How many they'll need will depend on their age and diagnosis.

After the first year, they'll have a cath test every 1 to 3 years.

If your child needs a biopsy, it's done during a cath test. They may not need a biopsy each time they have a cath test.

### *Chest X-ray:*

A chest X-ray takes pictures of the chest. They'll have 1 only when needed.

### *Echocardiogram*

An echocardiogram uses ultrasound waves to take pictures of your child's heart. It helps the cardiologist see how well the heart is working.

Your child will have an echocardiogram at every follow-up visit.

### *EKG:*

An EKG (electrocardiogram) checks the electrical signals from your child's heart. They'll get an EKG at every follow-up visit.

# Potential Complications



## What is rejection?

The immune system's job is 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 heart 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.

**There are 2 major types of rejection:**

- **Acute cellular rejection** happens when a type of immune system cell (lymphocyte) attacks the heart muscle.
- **Antibody mediated rejection** happens when the immune system cells make antibodies. The antibodies attack the heart muscle and blood vessels of the heart.

## What happens if my child has rejection?

- We'll do a heart cath test and biopsy. The biopsy can test for both types of rejection.
- We'll 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.

## What causes rejection?

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

One of the most common causes of rejection is not giving the right dose of medicines at home or not taking the medicines at all. Rejection can happen at any time and sometimes without any symptoms. So it's important to give the medicines exactly as told and get all lab tests done as scheduled.

## What are the signs of rejection?

There are some signs of rejection. But not everyone shows any signs. Sometimes lab test results are the only sign of rejection.

Some signs of rejection are:

- **Changes in heart rate or rhythm (such as skipped beats):** You'll listen to their heart beat every day for the first few days after they leave the hospital. This will help you know what their normal heart beat sounds like. If you have a concern later, you'll count their heart rate to make sure it's beating at its regular pace.
- **Swelling (edema):** Swelling around the eyes (puffy eyelids), face, belly, legs, feet, or ankles.
- **Changes to skin:** Cool, moist skin.
- **Fever:** temperature greater than 100.4°F (38°C) when taken by mouth (orally) or 101°F (38°C) rectally (bottom).

## More signs for older children

- **Palpitations:** a "fluttery" feeling in your chest caused by a fast heart rate (more than 140 beats per minute).
- **Change in breathing:** Shortness of breath or hard time breathing.
- **Dizziness or "blackout spells."**

## More signs for infants

- **Tachycardia:** A heart rate more than 160 beats per minute when they're at rest.
- **Working hard to breathe:** a faster rate of breathing when they're at rest, pulling in of the chest when they take a breath, or looks very weak and tired.
- **Poor feeding:** They're not eating a lot or less than normal.
- **Persistent irritability:** They get upset a lot and you can't calm them down.

## 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. You should follow all health and lifestyle guidelines to help keep them healthy.

## Denervation

The transplanted heart works just like any other normal heart, but the transplanted heart is denervated. This means it's not connected to the central nervous system in the same way. The nerves that connected their heart to the central nervous system were divided when it was removed.

The heart is still able to pump without this connection. But the way it knows how fast or slow to pump will be different.

When the heart is connected to the central nervous system, it can change its rate quickly. Without that connection, the heart uses other ways to know when to change how fast or slow to pump blood. It uses substances (catecholamines) released into the blood from a gland on the kidney. This method takes longer for the heart to know when it's time to change pace. This means the heart rate will change gradually. It will take more time to speed up and to slow down. This usually does not limit activity for most children.

Denervation also means that your child will not be able to feel chest pain if heart disease develops. This is why it's very important that your child keep a healthy diet and keep all their regular follow-up visits and tests.



## Common childhood illnesses

### 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 3 months after transplant. They should also follow these guidelines when they're treated for rejection with certain medicines.

Your child's transplant coordinator will teach you what to do to avoid infection. And how to watch for certain infections that are common in transplant patients. The best protection against infection is for everyone to wash their hands often and get all recommended vaccinations.

#### Signs of Infection:

- Temperature greater than 100.4°F (38°C)
- Cough or hard time breathing
- More mucous than normal
- Fatigue, headache, or body aches
- Irritability or poor feeding in infants
- Redness, swelling, or drainage around the incision.

### 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 may begin on the head. Then spread to your child's belly and back, and then to their 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 reduce how sick they get. They can show signs 10 to 21 days after they were exposed to the virus.
- Shingles is caused by the same virus as chicken pox. If your child is around someone with shingles:
  - make sure they cover all their blisters
  - make sure your child does not touch the blisters.

## The flu (influenza)

- The flu is a viral infection. It can cause problems in the mouth, nose, lungs, and the passages between them (respiratory tract).
- It spreads easily. It moves through the air in droplets when a person with the flu coughs, sneezes, laughs, and talks.
- Your child can get it if they:
  - breath in the virus
  - touch a surface where virus droplets landed and then touch their eyes, nose, or mouth
  - touch used tissues, or share utensils or food with someone with the flu.
- If your child has been around someone with the flu, let us know right away. We may give them medicine to prevent them from getting sick, or reduce how sick they get.
- To prevent a flu infection:
  - Your child and all members of your home should get the flu vaccine every year.
  - Everyone should only get it as a shot (injectable) and not through the nose (intranasal). The shot is an inactivated form of the virus and does not put your child at risk.
  - Your child can get their shot at the transplant clinic or their pediatrician's office. We have them on hand starting in September each year.

## 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 them.

## Digestive Issues

- Your child may throw up or have loose stools (diarrhea). This can happen for many reasons.
- When your child throws up or has diarrhea, it can change the drug levels in their body.
- You should let us know if:
  - it lasts more than 24 hours
  - they look dehydrated
  - they're not able to drink the usual amounts
  - they throw up any of their medicines.
- Some of your child's medicines may cause diarrhea. We'll work with you to manage this side effect.

## Skin problems

Skin problems are common in transplant patients. There are a variety of bacterial, fungal, and viral skin infections your child may get.

Let us know if they have any rashes or skin lesions (changes to their skin). We'll work with you to manage skin issues.

Some types of skin problems are:

- **Eczema:**
  - Many transplant patients experience new or worse eczema after transplant.
  - We can help you find an over-the-counter treatment to use. These include:
    - steroid creams
    - anti-itch cream
    - lotions such as Aquaphor and Eucerin.
- If bad enough, we may have your child see a skin specialist (dermatologist).

- **Warts:**

- Warts are common after transplant.
- To treat, you can:
  - use topical treatments
  - have your pediatrician or dermatologist use freezing therapy (cryotherapy).

- **Molluscum contagiosum:**

- Molluscum contagiosum is a virus that causes skin lesions (mollusca).
- They're small, raised bumps. They can show up anywhere on the body. They may become itchy or sore.
- They can spread between people. Or it can spread if your child scratches it and then touches other parts of their body.
- You should call us if they have more than a few bumps, or if the bumps spread.

## Higher risk illnesses and diseases

### Cytomegalovirus (CMV)

- Cytomegalovirus (CMV) is a viral infection. It's a common infection in heart transplant patients.
- 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 for it).
- Your child can get CMV from the transplanted heart or from the general public. It can happen anytime after transplant.
- Most healthy people with CMV do not have any signs. But it can cause very bad diarrhea, high fever, and cough.
- Your child will take medicines to prevent this type of infection early after heart 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). It's a common infection in heart transplant patients.
- Your child can get EBV from the transplanted heart or from 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.
- 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 a common type of cancer in transplant patients.
- 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.).
- 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.
- 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) or 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 clinic visits. We may treat it with medicine.

### Heart disease

- Coronary allograft vasculopathy (CAV) is when the arteries of the heart get 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.
- We'll do regular cardiac cath tests to check their arteries. And your child may take medicine (such as aspirin or a statin) to help protect their arteries.
- To help prevent heart disease, your child should keep good health habits. These include:
  - regular exercise
  - a healthy diet that is low in salt, cholesterol, and saturated fat
  - keeping a healthy body weight
  - no smoking (of any kind).

# 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 few months. 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. 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)

- It comes in capsules or liquid.
- 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, and higher risk of infection.

## *Cyclosporine (Gengraf and Neoral)*

- It comes in capsule or liquid.
- 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)*

- It comes in tablets or liquid.
- Your child will take it 1 time a day, 24 hours between each dose. They should take it in the morning.
- 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.
- If your child is scheduled for a surgical procedure, let us know. They may need to stop taking this medicine for a short time before and after surgery.

### *Possible side effects*

Possible side effects are high cholesterol levels, slower wound healing, and mouth ulcers.



### *Azathioprine (Imuran)*

- It comes in tablets or liquid.
- Your child will take it 1 time a day.
- It can be taken with food or after a meal to prevent an upset stomach.

#### *Possible side effects*

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

### *Mycophenolate mofetil (Cellcept, MMF)*

- It comes in capsules, tablets, or liquid.
- Your child will take it 2 times a day, 12 hours between each dose. They should take it the same time each day.
- They can take it with food or after a meal to prevent an upset stomach.

#### *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 they take it.

Caregivers who are pregnant should not have direct contact with it or breathe it in.

### *Methylprednisolone, prednisone or prednisolone (Orapred)*

They're a steroid that lowers the body's ability to reject transplanted organs.

- Methylprednisolone is given through an IV right after transplant or to treat rejection.
- Prednisone and prednisolone are given by mouth. They come in tablets or as a liquid.
- Your child may take it 1 or 2 times a day. Their provider will let you know.
- Do not stop or change the dose unless we tell you.

#### *Special instructions*

They can take prednisone or prednisolone with milk or food to prevent an upset stomach.

#### *Possible side effects*

Possible side effects are high blood pressure, upset stomach, stomach ulcers, 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

### *Trimethoprim or Sulfamethoxazole (Bactrim, TMP-SMX, Co-trimoxazole)*

- It's an antibiotic to prevent bacterial infections (toxoplasmosis and pneumocystis pneumonia).
- It comes in a pill or liquid.
- Your child will take it 1 time a day on Monday, Wednesday, and Friday.
- They may take it for 6 months to 1 year.
- They may take it on an empty stomach or with a meal.

#### *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 comes as a liquid.
- Your child will take it 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 10 minutes after they take it.

#### *Possible side effects*

Possible side effects are nausea from the taste.

### *Ganciclovir*

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

#### *Possible side effects*

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

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

### *Valganciclovir (Valcyte)*

- It's an antiviral medicine to prevent or treat CMV.
- It comes in a tablet or as a liquid.
- Your child will take it 1 time a day for 3 months after transplant. If they have an active CMV infection, they'll take it 2 times a day.

#### *Possible side effects*

Possible side effects are low platelet count, low white blood cell count, 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).
- It comes in a pill or liquid.
- 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.

## Statins

- These are used to:
  - reduce swelling (inflammation)
  - prevent cardiac allograft vasculopathy (CAV).
- It comes in a tablet.
- Your child will take it 1 time a day at night.
- They may take it on an empty stomach or with a meal.

## Other medicines

Your child may be prescribed other medicines.

- Aspirin is used to prevent CAV. They would take it 1 time a day in the morning.
- They may take magnesium supplements if they take tacrolimus. They would take it 1 to 4 times a day.
- If they take steroids, antacid medicines are used to protect the stomach.
  - 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 headaches.
- Diuretics are used to help the body get rid of extra fluid and salt. They may need to take this type of medicine for a short time after transplant.

## 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.

**The only over-the-counter pain medicine your child should take is acetaminophen (Tylenol).**

### *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
Acetaminophen Name brand: Tylenol	Naproxen Name brand: Aleve
Saline nasal spray Name brand: Ocean Nasal Spray	

### *For allergies:*

Yes, can take	No, do not take
Diphenhydramine Name brand: Benadryl	Phenylephrine (PE) Name brand: Sudafed PE
Loratidine Name brands: Claritin	Ibuprofen Name brands: Motrin, Advil
Cetirizine Name brand: Zyrtec	Naproxen Name brand: Aleve
Fexofenadine Name brand: Allegra	

# 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. We also need to know about 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.

## How do we order their medicines?

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

It can be harder to get refills on weekends and holidays. Try to plan ahead and order them before weekends and holidays.

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
- call (615) 322-7447.

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.

### *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.

## 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 medicines 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 provider or pharmacist.
- Let them suck on a popsicle or ice before they take their medicine. The cold will numb their taste buds.
- For some medicines: Mix the medicine with a strong-flavored liquid, such as chocolate syrup, cherry syrup, or pancake syrup. Ask your pharmacist if flavoring can be added to the medicine.
- Let your child eat some peanut butter or pancake syrup before they take their medicine. It will coat the tongue and make it 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 or at the Champ's Corner Store on the 2nd floor of Children's Hospital.

- 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.

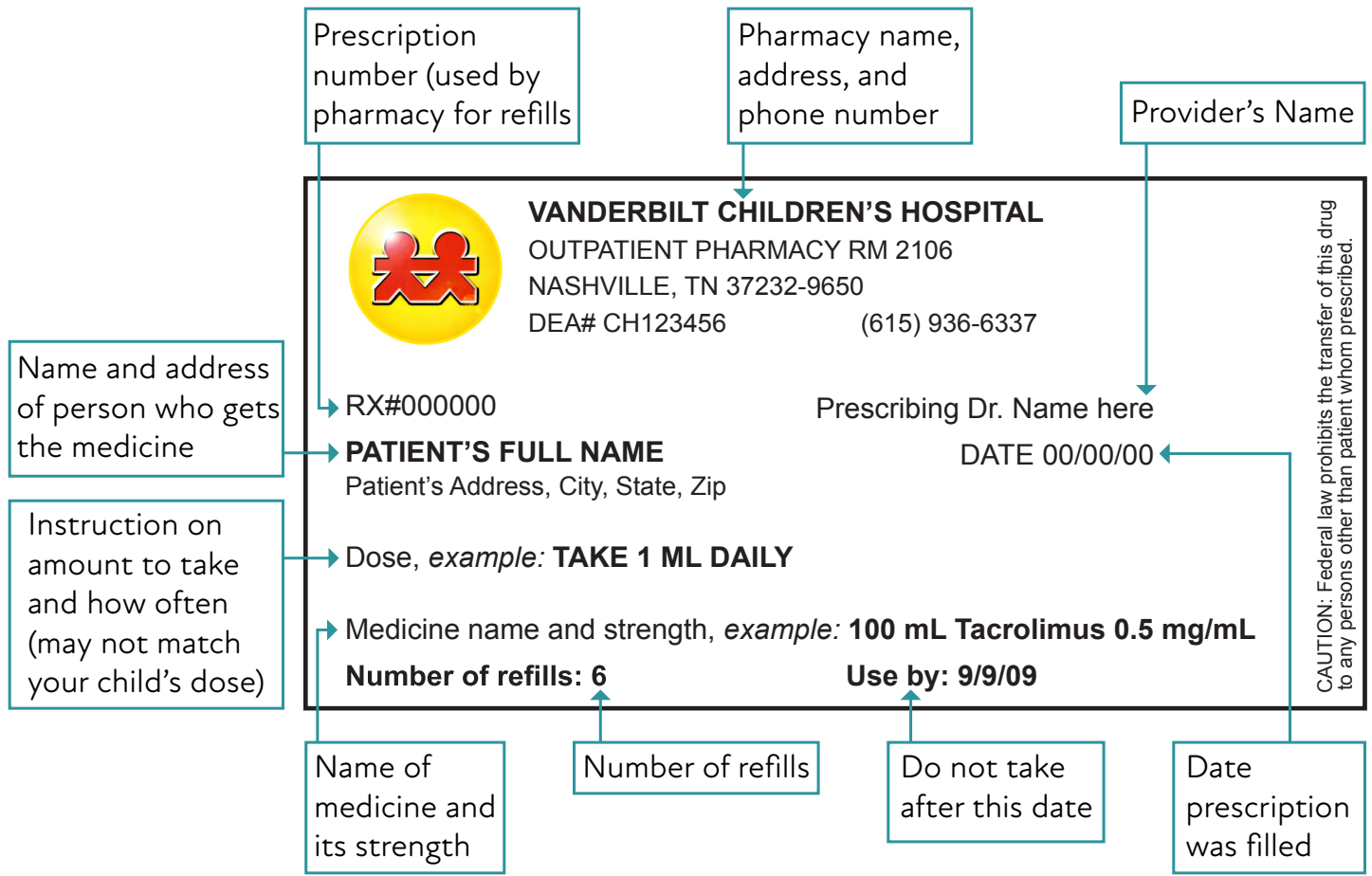
## How do I avoid mistakes?

- Make sure you update your medicine list 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. 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 will help you give the right dose.
- 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 pharmacy changes the manufacturer of your child's anti-rejection medicines or if the pills look different from 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.
  - The Vanderbilt Pediatric Outpatient Pharmacy can mail prescriptions to your home if you live in Tennessee.
  - 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 it should be. 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.

# Stay Healthy: Medical Care



## How do we care for their incision?

After their heart 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 area 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*

- 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) 322-7447 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 100.4°F (38°C) or higher.

## How can we help them stay healthy?

It's important that your child see their primary care provider (PCP) on a regular basis. They'll help keep them 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 31.
- Keep hand sanitizer and tissues on hand.
- Do not let your child be around sick people, when possible.
- For the first 3 months after transplant and 3 months after a rejection episode:
  - they should wear a mask when they go to the hospital
  - you should limit time in crowded areas (restaurants, malls, events).
- See your child's primary provider at least 1 time a year.

## Take care of their teeth

For 6 months after transplant, your child should not have any routine dental work or cleaning done. But after that, they should visit the dentist on a regular basis.

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 the teeth, which helps prevent tooth decay.

Let us know before they have any dental procedures. They may need to take medicine before the procedure is done.



- 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.
- Rub your hands together. Scrub all parts of your fingers, palms, and backs of your hands. Remember to get between your fingers, too!
- Scrub your hands for 20 seconds. It helps to say the A, B, C's so you know how long to wash.
- Rinse off the bubbles.
- 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!

## *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.

## *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)
- Pneumococcal (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 gets 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.

## What if they had an ABO incompatible heart transplant?

If your child received an ABO incompatible heart transplant (a heart with a different blood type from their own), we may need to test their blood more often.

We'll give you a laminated card to keep. If your child needs a blood transfusion, show the medical team that card. They'll need to contact the Vanderbilt University Medical Center Blood Bank at (615) 322-2233 to make sure they give your child the correct blood. They won't be able to test their blood to confirm what blood type they need.

If your child needs blood products urgently, they may receive trauma products.

## Do they need to have a medical ID (identification) with them?

Yes, we suggest that your child wear a medical ID bracelet at all times.

In case of an emergency, it will let the medical team know that they had a heart 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 or pharmacies.

If they received an ABO incompatible heart transplant, they'll also need to keep the laminated card we give you with them.

## Can my child have their own children?

In the future, your child should talk to their provider before they try to have their own biological children. It will be important that any pregnancies are well-planned to protect both parent and child.

Some transplant medicines can raise the risk of:

- premature birth
- pregnancy loss
- birth defects.

Their transplant team can talk to them about their specific risks. There's also a chance their child could be at risk for an inherited heart disease.

If your child becomes sexually active, it's important they always use reliable birth control.

## What about my child's menstrual cycle?

If they have cramps, they can take acetaminophen (Tylenol). It's the only safe pain medicine. If that does not help their pain, they should talk to their provider or a gynecologist about other options.

Oral birth control is often OK to take. It can help relieve period pain and other symptoms.

We recommend yearly visits with a gynecologist to manage birth control and check for cancers of the reproductive system.

## What can we do for our mental health?

The challenges of a heart illness 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
- because someone needed to die so your child could have a new heart.

It's important that you know you did not cause your child's heart 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 for help. This gives you time to relax. It lets other caregivers feel needed and involved. And 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: Food and Drink



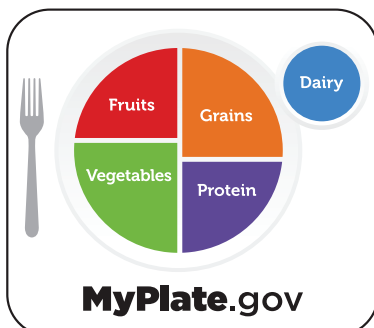
## Does their diet matter?

Yes. It's important that your child eats a healthy diet and keeps a healthy weight.

A good diet will help their recovery and help keep their new heart healthy and strong. And it can help them avoid some of the side effects of the anti-rejection medicines. Those side effects include:

- weight gain
- protein loss
- higher blood sugar
- high cholesterol and triglyceride levels
- high blood pressure
- swelling (inflammation)
- thinning of the bones (osteoporosis)
- increased infection risk. This includes sickness from bacteria in foods.

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.



## What should they eat?

The transplant dietitian can work with you to build a healthy diet for your child.

You may need to pay extra attention to the amount of magnesium and phosphorus they get from their diet. You'll find a list of foods high in magnesium on page 35 and foods high in phosphorus on page 36.

## 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. 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.



## Foods that are high in magnesium

Your child may need to add more magnesium to their diet. This is because some of their medicines can cause lower magnesium levels. Their provider will let you know.

The amount of magnesium is not always listed on food labels. These foods are high in magnesium. Talk to the transplant dietitian if you need help to make sure your child gets enough in their diet.

Food	Magnesium (mg)	Food	Magnesium (mg)
Almonds, 2 Tbsp .....	86	Multigrain cereal, 2/3 cup.....	16
Apricots, 3 medium .....	8	Oatmeal, 1 cup .....	55
Artichoke, 1 medium.....	180	Okra, 1 cup.....	41
Avocado, 1 medium.....	71	Oysters (cooked), 3 oz.....	19
Banana, 1 medium .....	33	Peanut Butter, 2 Tbsp.....	51
Black-eyed peas, 1/2 cup.....	43	Plantain, 1 medium .....	49
Bran muffin.....	60	Potato, 1 medium.....	55
Brazil nuts, 2 Tbsp.....	4	Pumpkin seeds, 2 Tbsp.....	152
Broccoli, 1/2 cup.....	19	Scallops, 3 oz.....	23
Brown Rice, 2/3 cup.....	57	Sesame seeds, 2 Tbsp.....	101
Cashews, 2 Tbsp.....	74	Soy milk, 1 cup.....	46
Cereal, whole grain, 1 oz.....	50	Soybeans, 1/2 cup.....	74
Chicken 3.5 oz.....	27	Spinach, 1/2 cup .....	78
Chickpeas, 1/2 cup.....	40	Sunflower seeds, 2 Tbsp.....	100
Halibut, 3 oz. ....	90	Swiss chard, 1/2 cup.....	76
Kiwi fruit, 1 medium.....	23	Tofu, 1/2 cup.....	118
Lentils, 1/2 cup.....	35	Whole-wheat bread, 1 slice .....	24
Lima beans, 1/2 cup.....	40	Whole-wheat English muffin.....	47
Mackerel, 3 oz.....	65	Whole-wheat pasta, 1 cup.....	42
Milk, 1 cup.....	34	Yogurt (low-fat), 1 cup.....	26

## Foods that are high in phosphorus

Your child may need to add more phosphorus to their diet. Their provider will let you know.

The amount of phosphorus is not always listed on food labels. These foods are high in phosphorus. Talk to the transplant dietitian if you need help to make sure your child gets enough in their diet.

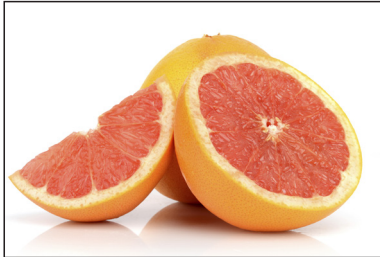
Food	Phosphorus (mg)
All-bran cereal, ½ cup .....	345
Almonds, ¼ cup.....	84
Beef, 3 oz. ....	225
Beef liver, 3 oz. ....	412
Brazil nuts, 1 oz. (6 to 8 nuts).....	206
Buttermilk, 1 cup .....	218
Cheddar cheese, 1 oz.....	145
Chicken, 3 oz .....	216
Cottage cheese (low fat), 1 cup .....	302
Crab, 3 oz. ....	240
Crowder peas, 1 cup.....	268
Crystal light "classic orange," 1 cup.....	100
Great northern beans, 1 cup.....	292
Halibut, 3 oz.....	244
Lentils, 1 cup.....	356
Lima beans, ½ cup.....	105
Milk (skim), ½ cup .....	247
Oat bran (cooked), 1 cup.....	261

Food	Phosphorus (mg)
Oat bran muffin, 1 .....	214
Oatmeal, 1 cup .....	178
Pancake, plain, 2 4-inch .....	254
Peanut butter, 2 Tbsp.....	120
Pork chop, 3 oz .....	215
Salmon, 3 oz.....	214
Sesame seeds, 2 Tbsp.....	124
Shrimp, 3 oz.....	174
Soy milk, 1 cup.....	118
Sunflower seeds, 2 Tbsp.....	200
Tuna, 3 oz .....	139
Turkey, 3 oz .....	214
Vitamin water, "revive fruit punch," 1 cup.....	261
Waffles, plain, 2 4-inch .....	278
Whole-grain cereal, 1 oz.....	100
Whole-wheat bread, 1 slice .....	64
Whole-wheat muffin.....	167
Yogurt (low-fat), 1 cup.....	250

## 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.

Your child **should not** eat these foods or drink these drinks:



**Grapefruit**



**Pomegranate**



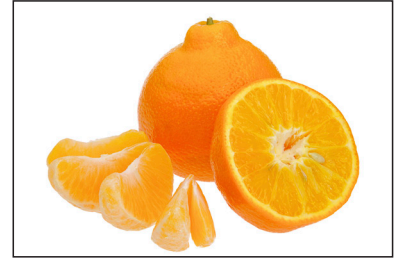
**Star fruit**



**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**



**Energy Drinks**

## Drinks with grapefruit or grapefruit juice extract

Your child **should not** drink these drinks.

Coca Cola Products	Dr. Pepper/7-Up Products	Pepsi Products
Canada Dry Citrus Blend	7-Up (all flavors)	Citrus Blast
Fanta Grapefruit	Country Time Lemonade	IZZE Sparkling Grapefruit
Fanta Grapefruit Lemon	Crush (all citrus flavors)	IZZE Fortified Sparkling Grapefruit
Fanta Grapefruit Lemon-Lime	Orangina	Lipton Diet Green Tea with Citrus
Fanta Grapefruit Pineapple	Ruby Red Squirt	Mountain Dew
Fanta Grapefruit Raspberry	Snapple (all citrus tea flavors)	Ocean Spray Ruby Red Grapefruit Juice Drink
Fresca and Diet Fresca	Squirt and Diet Squirt	Propel-Citrus Punch with Calcium
Full Throttle Citrus Blend	Stewart's (all citrus flavors)	Season's Harvest Grapefruit Juice Beverage
Fuze Tangerine Grapefruit	Sun Drop and Diet Sun Drop	Sierra Mist (multiple flavors)
Minute Maid Grapefruit Juice	Sunkist (all citrus flavors)	Sobe Energy Citrus Flavor
Nestea Citrus Green Tea		Tropicana Pure Premium Golden Grapefruit Juice
Nestea Grapefruit Honey Green Tea		Tropicana Pure Premium Golden Grapefruit Juice with Vit D
Powderade Citrus Blend		Tropicana Pure Premium Ruby Red Grapefruit Juice
Simply Grapefruit		Tropicana Ruby Red Grapefruit Juice and Drink
Vitamin Water Tropical Citrus		Tropicana White Grapefruit Juice

## 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 explain 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.
- Thaw frozen meat and fish in the refrigerator.
  - Keep meat and fish away from raw fruits and vegetables.
  - 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 the raw meat to the 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 tested every year to make sure it's safe. Or it should 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 river or lake water. Most children swallow water when they swim. This is why there's more risk to swim in rivers and lakes.

In most cases after a heart transplant, children are able to do things like other children. But there are things you'll need to do differently in your home and when you travel.

# Stay Healthy: Home and Lifestyle



## What activities can my child do?

There will be some limits to your child's activities at first so the incision can heal. After it has healed, your child can be as active as other children. Most children can go to school and normal social activities 3 months after transplant.

But 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 before.

## Things your child should not do

- Lift anything more than 5 pounds or wear a backpack until their breastbone is healed. This usually takes about 6 weeks.
- Play any contact sports for 3 months after surgery.
- Drive while they take prescription pain medicine (opioids).
- Drive until your child's surgeon or transplant cardiologist says it's OK.
- Swim for at least 3 months after surgery.
  - Before your child can swim, their incision must be completely closed and healed.
  - They should not swim in a public kiddy pool, river, or a lake. It's OK to swim in the ocean.
  - It's safe to swim in chlorinated pools. But it's best not to go to large water parks.

## Can we travel?

After your child has fully recovered, it's usually safe to travel. You should talk with us before you travel outside the country or on trips longer than 2 weeks. You or your child may need special vaccinations or medicines before you go.

We can also help make a plan before you go in case something happens while you're there. You should know where the closest hospitals are to where you'll stay on your trip.

### *Tips for travel:*

- Make sure you'll be able to communicate during your trip. You need to be able to contact us at all times. If something comes up while you're gone, we can talk to the local healthcare providers and make sure your child gets the care they need.
- Pack plenty of medicine to last you for the entire trip. You should take more than you need in case there are unexpected delays.
- If you travel by plane keep medicines with you. You should pack them in your carry-on luggage. There's risk that a checked bag may be lost, delayed, or stored at an unsafe temperature.
- Airports, buses, and other crowded areas put your child at increased risk for infection. Keep hand sanitizer and sanitizing wipes with you.
- It's a good idea for you child to wear a mask in crowded areas.

## Can we have a pet?

Some pets can be safe to keep in your home. But some animals carry diseases that can be dangerous for your child.

Before you get a pet, talk to us. We'll let you know if there are any risks for your child. And we'll teach you how to prevent infections.

To help keep your child safe, you'll need to:

- take your pet for regular visits to the vet (veterinarian)
- give your pet all their recommended vaccinations and preventative medicines
- make sure your child never comes in contact with the pet's bodily fluids
- make sure everyone always washes hands after they touch your pet. This is very important before you touch or prepare food.

### *Types of pets*

- Cats are usually safe pets, but your child should not empty the litter box. Older cats are safer than kittens. Indoor cats pose a lower risk than outdoor cats.
- Birds, reptiles, and other exotic animals are a greater risk for infectious diseases. They're usually not recommended as pets for children with transplants. You should also limit your child's contact with these types of animals.

### *Medical care for injuries from animals*

- Clean any scratches with soap and water.
- Tell us if your child is bitten by an animal.



## 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 the 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 heart 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 heart. 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.

# Resources



## Can I write to my child's donor family?

Yes. Tennessee Donor Services is a non-profit organization that was chosen by the federal government to manage organ donation in Middle Tennessee. The organization helps transplant recipients and donor families communicate in writing. All communication is completely anonymous and all identities are kept private (confidential).

The decision to write to your donor's family is a very personal one. Whether or not you decide to write to the donor family is your choice.

### *Information you might share*

If you decide to write a letter, you may want to include:

- the state you live in (not city)
- your family situation, such as the number of siblings your child has
- your child's hobbies or interests.

You should sign your letter with first names only.

### *Information you should not include*

To keep everything confidential, you should not include:

- your child's last name
- your address, city, or phone number
- the name or location of your hospital or your provider(s)

You won't know anything about your donor family's religious beliefs (or if they have any religious beliefs at all). Please keep that in mind if you include religious comments.

## Talk about your experience

It's best to use simple language. Some things you might include:

- your gratitude for the family and their gift
- how long your child waited for a transplant
- what the wait was like for your child and your family
- how the transplant has improved your child's health
- how your lives have changed, for example:
  - trips your family has been able to take
  - the activities your child can do now that they couldn't do before their transplant
- what has happened in their life since their transplant.
  - Did they celebrate another birthday?
  - Did they return to school, join a sports team or start a new hobby?

## How do I send my letter?

When you're ready to mail your letter, you'll send it to us first.

- Place your card or letter in an unsealed envelope.
- Write your child's full name and date of their transplant on a separate piece of paper.
- Place these items in another envelope, and mail everything together. Or you can bring it with you to your child's transplant clinic visit.

Talk to your heart transplant coordinator for more instructions or if you have any questions.

## What happens after I mail my letter?

When we get your letter, we'll forward it to the donor coordinator at Tennessee Donor Services.

A coordinator will read your letter to ensure confidentiality. They'll contact the family to offer them the option to receive your letter.

If the family wishes to receive your letter, it will be mailed it to them. It may take a few weeks before they get it.

## Will I hear back from the donor family?

If you write a letter, you may or may not hear back from your donor family.

Some donor families have said that it helps their grieving process to write about their loved one and their decision to donate.

Other donor families want to receive a card or letter. But they prefer privacy and choose not to write back.

Some donor families choose not to receive a card or letter.

## Other resources

### *Children's Organ Transplant Association*

#### **Cota.org**

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

### *Enduring Hearts*

#### **EnduringHearts.org**

3600 Dallas Highway, Suite 230-350  
Marietta, GA 30064  
(240) 343-2781

### *National Foundation for Transplants*

#### **Transplants.org**

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

### *Organ and Tissue Transplantation in America*

#### **OrganTransplants.org**

### *Transplant Recipients International Organization (TRIO)*

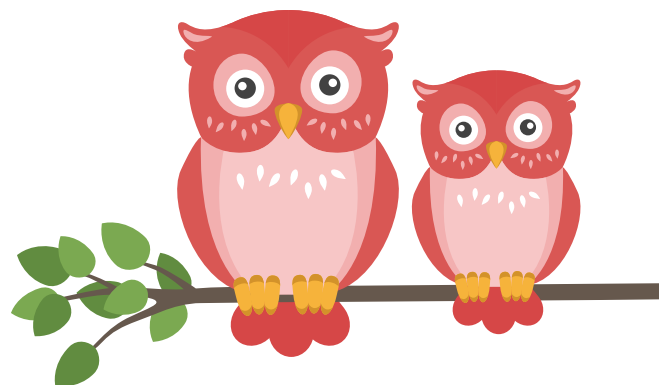
#### **Trioweb.org**

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

### *United Network for Organ Sharing*

#### **Unos.org**

1100 Boulders Parkway, Suite 500,  
PO Box 13770  
Richmond, VA 23225-8770  
(888) TXINFO



# Heart Transplant Team

(615) 322-7447

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

