



Pediatric Heart Transplant Society Foundation

Children's



Cardiomyopathy  
Foundation

# Pediatric Heart Transplants

A guide for patients and families

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Original Artwork by Kennedy Heiman



## Endorsements

The following organizations have reviewed and endorsed these educational guidelines.



*“Dedicated to promoting the advancement of the science and practice of transplantation through children worldwide.”*

[www.iptaonline.org](http://www.iptaonline.org)



*“Dedicated to finding causes and cures for pediatric cardiomyopathy the support of research, education, and increased awareness and advocacy.”*

[www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org)



Pediatric Heart Transplant Society Foundation

*“Dedicated to raising and administering funds to support the science and treatment of children while listed for and following heart transplantation.”*

[www.phtsfoundation.org](http://www.phtsfoundation.org)



Enduring Hearts  
HEALTHY KIDS • STRONGER HEARTS • LONGER LIVES

*“Dedicated to funding pediatric heart transplant research to help children live longer, healthier, and happier lives.”*

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*“Dedicated to supporting pediatric transplant patients by providing them information to connect to existing transplant support groups and information”*

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# What is the Pediatric Heart Transplant Society?

## History

The Pediatric Heart Transplant Society (PHTS), formerly the Pediatric Heart Transplant Study Group was started in 1993 by a group of doctors who wanted to improve the lives of children who needed a heart transplant.

The primary purposes of the organization were to:

- create and maintain a database for heart transplantation,
- encourage and promote basic and clinical research in the field of pediatric heart transplantation, and
- promote new therapeutic strategies.

The ultimate goal was to improve the lives of pediatric heart transplant patients.

With more than 25 years of data collection, the information PHTS has gained has significantly increased their understanding of pediatric heart transplantation and has allowed pediatric heart transplant doctors and nurses to help children live longer and have a better quality of life after heart transplant.

## Mission

The Pediatric Heart Transplant Society is a multidisciplinary, professional organization dedicated to advancing the science and treatment of children during listing for and following heart transplantation.

## Purposes

- Maintaining a database to follow children at the time of listing and following a heart transplant
- Promoting collaboration among professionals in the field of pediatric heart transplantation
- Encouraging and inspiring new research in the field of pediatric heart transplantation
- Promoting new therapeutic strategies
- Providing educational resources for patients and families
- Hosting twice yearly a meeting to discuss the current topics in pediatric heart transplantation
- Developing best practices and procedures for caring for children after heart transplant
- Awarding research grants for the study of pediatric heart transplantation
- Making available limited datasets for approved research projects
- Increasing awareness of pediatric heart transplantation
- Providing annual quality assurance reports and benchmarking for participating hospitals



# Acknowledgements

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Thank you to all of original and current contributors for their knowledge, experience, and time writing this material.



## Notice

**This educational material is a general guide only. It does not replace the skill, knowledge and experience of a qualified medical professional dealing with the facts, circumstances, and symptoms of a particular case.**

**Every transplant center has its own protocols and every child's situation and treatment plan will be different. Your transplant team is always available to answer questions about your child's situation. Their goal is to keep you well informed and make sure your child recovers quickly and remains healthy and happy after their heart transplant.**

**The authors assume no responsibility for any loss, injury, and/or damage to individuals or property because of, or related to, any use of the material in this manual.**





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# Contents

<b>Before your child's heart transplant .....</b>	<b>11</b>
How is someone referred for a heart transplant? .....	12
Assessing your child for a transplant.....	12
Why does my child need an assessment? .....	12
Where will my child have the assessment? .....	12
How is my child assessed? .....	13
Transplant team .....	15
Transplant cardiologist .....	15
Transplant surgeon .....	15
Pathologist.....	15
Transplant nurse or nurse practitioner .....	15
Pharmacist .....	15
Social worker .....	16
Financial coordinator (US only).....	16
Physiotherapist/physical therapist .....	16
Occupational therapist.....	16
Dietitian/Nutritionist .....	16
Child life specialist.....	16
Psychologist / Psychiatrist.....	16
Palliative care team .....	17
Chaplains or pastoral care .....	17
What happens after the assessment?.....	17
How does my child get on the heart transplant waiting list? .....	18
What information about my child goes on the waiting list? .....	18
What happens when my child is listed for a heart transplant?.....	18
How does the transplant team find a heart? .....	20
How do these organizations match a donor with my child? .....	20
Must my child's blood group match the donor's blood group?.....	20
Where do donated hearts come from? .....	20
Can I contact the donor family? .....	21
How long does it take to get a heart?.....	21
Waiting at home .....	21
Waiting in the hospital .....	21
What happens while my child waits for a new heart? .....	22
Emotions and feelings .....	22
Activities .....	22
Vacations.....	22
Nutrition .....	23
Medical tests.....	23
What happens if my child gets sicker while waiting for a heart? .....	24
How will a transplant change my child's life? .....	25



<b>The heart transplant .....</b>	<b>26</b>
How do we prepare for the heart operation? .....	27
Preparing for the hospital stay .....	27
Tips for talking to your child about their transplant surgery .....	27
Fears and concerns about surgery and recovery .....	27
Maintaining routine during hospital stays .....	27
What happens on the day of surgery? .....	28
Finding out about a donor heart .....	28
Arriving at the hospital .....	28
If my child is called for transplant, is the surgery definitely going ahead? .....	29
What happens in the operating room? .....	29
Preparing for surgery .....	29
Removing your child's heart .....	29
Transplanting the new heart .....	30
Where do I wait during my child's surgery? .....	30
What happens in the intensive care unit (ICU)? .....	30
What to expect when you first see your child .....	30
When does my child leave the ICU? .....	31
Working with your child's healthcare team .....	31
Your child's emotional and psychological recovery .....	32
Going home after the transplant .....	32
<b>After the heart transplant .....</b>	<b>33</b>
Life after the heart transplant .....	34
Clinic visits and routine testing .....	34
Clinic visits .....	34
Heart tests .....	35
Other tests and procedures .....	35
Transplant medications .....	36
Types of transplant medications .....	36
Understanding your child's medications .....	37
Guidelines for taking medications .....	37
Why it is important to stick to one brand of medicine .....	38
Immunosuppressant medications .....	39
Induction immunosuppression .....	39
Maintenance immunosuppression .....	42
Other immunosuppressants .....	50
Medications to prevent and treat infections .....	52
Vitamins and supplements .....	59
Other common medications .....	61
Infection-control .....	61
Diuretics .....	61
Anti-hypertensives (blood pressure medications) .....	63
Statins (cholesterol and lipid-lowering medications) .....	66
Anti-arrhythmics (medications to control heart rhythm) .....	66
Anti-ulcer medications .....	67
Anti-platelet medications .....	68

Medications to prevent and treat blood clots .....	68
Immunizations .....	69
When will my child get their immunizations after transplant? .....	69
Rejection .....	70
Can rejection happen anytime? .....	70
What are the common signs and symptoms of rejection? .....	70
How can the transplant team identify rejection without any visible signs? .....	71
How can I help to prevent rejection? .....	71
What types of tests diagnose rejection? .....	71
Transplant cardiac allograft vasculopathy (CAV) .....	74
Infections and diseases .....	75
How do I help prevent my child from getting infections? .....	76
What signs of infection should I watch for? .....	76
Serious viral infections .....	76
Kidney issues .....	80
Hypertension .....	81
Following a healthy lifestyle after transplant .....	81
Physical activity and exercise .....	81
Heart-healthy eating .....	83
Your child's wellbeing and school performance .....	85
Assessment for emotional support .....	85
Assessment in relation to school performance .....	86
Commonly asked questions .....	86
How long will the new heart last? .....	86
When can my child return to daily activities, including school? .....	87
Does my child need a special skin care routine? .....	87
Will medications affect my child's hair? .....	87
What type of dental care should my child have after transplant? .....	88
Can my child go out in the sun as usual? .....	88
What if my teen wants to get a tattoo or piercing? .....	88
Can my child have a pet? .....	89
Can my child travel? .....	89
My child still has trouble sleeping. Is this normal? .....	89
My child has started wetting the bed at night. Why is this? .....	89
Adolescence .....	90
Transition from pediatric to adult care .....	91
Early transition (10-13 years) .....	91
Middle transition (15-17 years) .....	91
Late transition (18-23 years) .....	92
Research .....	92
Why do research in children? .....	92
Why are children different than adults? .....	92
Why are clinical studies important? .....	93
How can my family help? .....	93
<b>Additional resources .....</b>	<b>94</b>

# Before your child's heart transplant

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Original artwork by  
Asiya, age 10

## How is someone referred for a heart transplant?

A heart transplant is offered not only to help a child live longer but also to improve their quality of life.

Heart transplants are offered when no other medical or surgical options are available to fix a failing heart without serious risk. A transplant can work well in these situations, but it is not a cure and comes with many new responsibilities.

A child may need a heart transplant for several reasons, including:

- cardiomyopathy (weak heart muscles),
- congenital heart disease (heart disease that a child is born with) that cannot be operated on without serious risk,
- continued heart problems following surgery for congenital heart disease, such as the heart not working properly or the valves being too leaky,
- complications or diseases that result from some congenital heart surgeries, such as protein-losing enteropathy, or
- life-threatening abnormal heart rhythms that cannot be controlled any other way.

If your child's heart problems fall into one of these categories, your child's cardiologist will consider referring your child to a heart transplant team to be assessed for a heart transplant. This will need to happen in a center with a pediatric heart transplant program.

At this stage, your child's cardiologist is only asking the transplant team for their opinion. The team will consider if your child:

- needs, or qualifies for, a heart transplant,
- needs a transplant right at that moment, and
- is able to have a heart transplant.

## Assessing your child for a transplant

### Why does my child need an assessment?

A heart transplant assessment lets healthcare professionals decide if a transplant:

- is possible,
- is the best treatment, and
- is the right option for your child at this time.

It also helps the team to see if your child will have any special needs at the time of or after a transplant.

### Where will my child have the assessment?

Most patients have their assessment as an outpatient of the hospital over one or two weeks. This means they have appointments in the hospital but do not stay overnight.

Some transplant centers prefer to admit children and assess them over two or three days. If your child already needs care as an inpatient, they may have their assessment while in the hospital.

Sometimes children are so sick that they are in the cardiac critical care or intensive care unit when they need an assessment. In these cases, assessments may be shorter and may not include all of the testing that you will read about in this manual.

Every child is different. Your transplant nurse or cardiologist will discuss your child's assessment with you in detail.

## **How is my child assessed?**

Your child will have a number of medical tests, and you will be asked questions about your child's medical history by different members of the transplant team. You will also meet with several other healthcare professionals to make sure your child is physically and emotionally ready for a heart transplant.

The tests your child will have may depend on:

- their age,
- what is wrong with their heart,
- how long they have been sick,
- how sick they are, and
- whether they have been seen at the transplant center before.

Tests also may vary according to your healthcare system or country. The results of the tests will give an idea of your child's overall health.

### **Medical tests**

#### *Blood tests*

These include tests to identify your child's:

- blood group (a transplant donor and recipient should usually have compatible blood groups,
- levels of B-type natriuretic peptide (BNP), a hormone that reaches high levels in cases of heart failure,
- levels of HLA antibodies (human leukocyte antigen antibodies) and how strong they are, which can help decide if your child has a higher risk for rejection. These antibodies may make it harder to find a suitable matching donor, so the test also helps predict if your child might have to wait longer for a donor heart.

#### *Heart tests*

These include:

- an electrocardiogram (ECG or EKG) to examine the rate and regularity of your child's heart beats,
- an echocardiogram (echo) to look at the structure of your child's heart and measure how well it is working,
- cardiac catheterization to check the pressure in your child's heart and blood vessels using a thin tube (see p. 35),
- an exercise test or a six-minute walk, and
- MRI (magnetic resonance imaging) or CT (computer tomography) of the heart to look at the heart's chambers and blood vessels.

### *Tests on other parts of the body*

Your child may also have the following tests on other parts of their body:

- pulmonary function tests, to see how well the lungs are working,
- liver function tests,
- kidney function tests (such as creatinine clearance or glomerular filtration rate, GFR), to see how well your child's kidneys filter waste,
- bone mineral density, to check the strength of your child's bones,
- an ultrasound of the liver and kidney, to check that these organs have developed normally, and/or
- an ultrasound of the blood vessels, to look for blood clots or blockages.

### *Infection-related tests*

The team will do blood and skin tests to check if your child has been exposed to the following infections (but there could be others).

- Hepatitis A, B and C
- HIV
- Cytomegalovirus (CMV)
- Epstein-Barr virus (EBV)
- Herpes simplex virus
- Tuberculosis (TB)

### **Interdisciplinary team assessments**

These involve meetings and tests with different healthcare professionals that may include:

- a physiotherapist,
- an occupational therapist,
- a dietician/nutritionist,
- a social worker,
- a doctor in adolescent medicine,
- a psychologist, and/or
- a psychiatrist.
- a pharmacist.
- a surgeon

These roles are outlined on the next few pages.

Again, whether your child will meet all these professionals depends on their personal situation and where they are being assessed.

### **Medical consultations (as needed)**

Your child will also see other doctors in the hospital, including:

- an anesthesiologist (the doctor who gives your child sleep medicine before an operation),
- a nephrologist (kidney doctor),
- a hepatologist (liver doctor),
- a respirologist or pulmonologist (lung doctor), and/or
- a neurologist (nervous system doctor).



These doctors will make sure your child's other organs are working well and will plan the safest anesthetic for the transplant operation.

The palliative care team is another important team that is often included in the assessment. This team helps you make the best decisions for your child and your family.

## Transplant team

The transplant team includes many healthcare professionals. These people may meet you while your child is being assessed and will work together to manage your child's care after transplant.

Note that the actual transplant team might differ from one hospital to another. The team in your hospital might not include all the professionals listed here or might include professionals who are not listed here.

### Transplant cardiologist

A transplant cardiologist is a doctor specially trained to take care of heart transplant patients. They manage your child's care after transplant surgery and are often also involved in your child's care while they are on the transplant waiting list.

### Transplant surgeon

The transplant surgeon is the doctor who operates on your child to give them their new heart. You and your child will meet the surgeon when you are called in for the transplant surgery. You may meet the surgeon a short time before the transplant to discuss the transplant surgery from their perspective.

### Pathologist

A pathologist is a doctor who specializes in examining tissue (including muscles such as the heart). After a transplant, they will evaluate heart biopsies for rejection (see p. 70). Pathologists are also commonly involved before the transplant to help diagnose the underlying cause of heart failure.

### Transplant nurse or nurse practitioner

A transplant nurse, sometimes called a transplant coordinator, helps to manage all the parts of the assessment and follows up with your child before and after surgery.

A nurse practitioner or advanced practice nurse has special additional training to do certain tests and prescribe some medications. This person works closely with the transplant nurses and the rest of the transplant team.

### Pharmacist

The pharmacist helps the transplant team with the medications your child must take to have a successful transplant. They will work with the doctors and nurses to adjust your child's medications. They will also teach you how to manage and store your child's medications at home.

## **Social worker**

The social worker's role is to help you, your child, and your family to cope with personal and family issues. They may also offer help and support with finances, accommodation, school, and other issues that may arise while you are away from home.

## **Financial coordinator (US only)**

Your transplant program may have a financial coordinator who can help you understand the cost of transplant, your individual health benefits, and any forms you may need to complete.

## **Physiotherapist/physical therapist**

A physiotherapist (PT) will assess your child's lungs and muscles and look at how your child moves and exercises. They may give you ideas for activities or exercises to keep your child as fit and healthy as possible while they wait for their new heart. After the transplant, they will work closely with your child and help to get them back to a normal level of activity.

## **Occupational therapist**

An occupational therapist (OT) looks for ways to prevent problems with day-to-day activities such as feeding, walking, and dressing. They will help maintain and improve your child's ability to feed and take care of themselves at a normal level for a child their age. These therapists may work with you and your child before and after transplant.

## **Dietitian/Nutritionist**

A clinical dietitian or nutritionist is trained to give you advice about what your child needs to eat and drink to grow and remain healthy.

## **Child life specialist**

Child life specialists support patients and families through the hospital experience. They are experts in child development, children's reactions to being in the hospital, and the importance of play. Child life specialists focus on the social and emotional impact of illness and hospital stays and work to make the experience as comfortable for children as possible.

## **Psychologist / Psychiatrist**

A psychologist/psychiatrist will see patients referred to the heart transplant team to:

- assess how your child thinks, behaves, and processes their emotions,
- help coordinate responses within your child's school if your child has any special learning or health needs,
- provide recommendations about any education diagnosis such as a learning disability.
- check a child's or teen's understanding of their illness and need for transplant,
- assess if a child or teen is depressed or is anxious about medical procedures,
- help a child deal with any challenges in following their treatment plan;
- identify any other behaviors that may affect a child's ability to work with the transplant team.

## **Palliative care team**

Palliative care is sometimes also called comfort care, supportive care, or end-of-life care. Palliative care does not mean the physician thinks your child is going to die and it does not mean that the medical team will stop providing medical care to your child. It is in addition to usual medical care. Palliative care is about helping children and families who are facing serious illness. These providers help the child and family discuss with each other and the medical team what a good quality of life means to them. They ask about goals of care and talk about ways to help the patient and family make decisions about medical care, emotional support, and spiritual support. Palliative care specialists help the medical team remember that the patient is still a child who wants to do things that healthy children do even though they are sick or in the hospital. This team can help you explore ways to maintain a “normal” life for your child. They care for your child along with the transplant team.

## **Chaplains or pastoral care**

Hospital chaplains are available to support patients and families with any faith and spiritual issues that arise during the transplant experience.

# **What happens after the assessment?**

After the consultations and tests, the whole transplant team (see p.15) meets to decide if your child is a suitable candidate for a heart transplant. The team will make sure to discuss every treatment option for your child's case.

If a transplant is recommended, the team will then decide how quickly your child needs it and when to put your child on a heart transplant waiting list. The team will develop a treatment to give your child the best chance of having a successful transplant.

If your child is able, they, along with you, should take part in making decisions about their plan. Receiving and living with a transplant is a big commitment, one that will stay with your child for the rest of their life.

Your child will go on the transplant waiting list only if the transplant team agrees transplant is the best option for your child **and** you agree for your child to have the transplant.

## How does my child get on the heart transplant waiting list?

Once your child's assessment is done and your transplant center has decided your child qualifies for a heart transplant, your child's name and information will be placed on a ***national*** transplant waiting list.

A member of the transplant team will tell you when your child has been placed on this list. Like many families, you might have lots of questions about this process. Your transplant team will discuss everything with you and your family.

### What information about my child goes on the waiting list?

The waiting list will include details about your child's:

- blood group,
- weight, and
- height.

Sometimes it will also include information about what type of donor is acceptable for your child. If this is important for your child, the transplant team will explain it to you.

### What happens when my child is listed for a heart transplant?

Your child will be given a listing "status." This status is based on:

- your child's current medical condition, and
- how much medical support your child needs for their condition.

Your child's listing status can change over time based on how they are doing medically. The heart transplant team will discuss your child's listing status with you.

Each country has its own guidelines for when a child is placed on the transplant waiting list. However, in most countries, the waiting list system is designed to meet the needs of the sickest children first and make sure organs are allocated fairly.

In the United States, for example, the UNET Wait List has three active status levels (1A, 1B and 2) and one inactive level (7). Each level has very specific guidelines, which are set by the United Network for Organ Sharing (UNOS), the organization that manages the list.

### **Status 1A**

This is for a child registered in UNOS before age 18 who meets *at least one* of the following conditions:

- needs help breathing with a ventilator and is admitted to the listing hospital,
- needs support with a mechanical device such as ECMO, intra-aortic balloon pump, or ventricular assist device (VAD),
- has a complex congenital heart disease with multiple low-dose or single high-dose inotropes and is admitted to the listing hospital, and/or
- needs a stent or prostaglandin infusion to keep their patent ductus arteriosus (a fetal vessel between the pulmonary artery and the aorta) open to allow blood circulation to the body or lungs and is admitted to the listing hospital.

Note: 1A exceptions are made on a case-by-case basis.

*\*\*Inotropes are medication given through an iv that help the heart pump more blood to the body. Inotropes include medications like dopamine, dobutamine, milrinone, and epinephrine. Prostaglandin is a medication given through an iv to babies with certain heart defects who need to keep a blood vessel open that connects the pulmonary artery to the aorta, called a patent ductus arteriosus, or PDA)*

### **Status 1B**

This is for a child registered in UNOS before age 18 who meets *at least one* of the following conditions:

- continuous inotrope infusion and does not meet UNOS 1A criteria (cardiomyopathy diagnosis or complex congenital heart disease but not admitted to listing hospital), or
- is less than one year-old at the time of listing and has a diagnosis of hypertrophic or restrictive cardiomyopathy.

### **Status 2**

This is for a child registered in UNOS before age 18 who does not meet the criteria for Status 1A or 1B.

### **Status 7**

This is for a child who is inactive on the transplant list (they are too sick or too well to currently accept an organ).

In Canada, the national transplant waiting list has four status levels. These also reflect a child's diagnosis and the level of medical treatment they need, especially if they need intensive care in hospital.

In the United Kingdom, the transplant waiting list has two status levels: urgent and non-urgent. These levels depend on the child's age and amount of medical treatment they need for their heart failure.

## How does the transplant team find a heart?

Finding a heart for your child is called “organ matching.”

In the United States, organ matching is managed by the United Network for Organ Sharing (UNOS). People needing a transplant from all over the United States are on this list.

Canada has the National Organ Waiting List (NOW), which is managed by Canadian Blood Services. Provincial organ procurement organizations (OPOs) find heart matches for patients on the waiting list.

There are similar organizations in every country in the world that perform transplants.

### How do these organizations match a donor with my child?

They consider:

- the donor's blood group (O, A, B or AB),
- the donor's weight and height,
- the donor's age,
- how quickly the organ can be transplanted once it is obtained from the donor (including travel and operating time), and
- if your child has any antibodies that could attack the donor heart.

Hearts are then matched to people on the transplant waiting list according to their wait list status. The sickest patients get suitable organs first.

### Must my child's blood group match the donor's blood group?

In general, people who receive a heart need a donor whose blood group is compatible with (matches) their own. It does not need to be exactly the same or identical. This is called an “ABO-compatible” transplant.

However, in babies and sometimes in young children, it is possible to successfully transplant a heart from a donor with an incompatible blood group. This is called an “ABO- incompatible” transplant and has been done successfully in many hospitals around the world. If this is an option for your child, the team will discuss it with you before your child is listed for a heart transplant.

### Where do donated hearts come from?

Heart donors can be anyone (a child or an adult) whose brain has been so damaged by injury or disease that the brain dies, even with the best medical care. When someone has reached this stage, it is called being “brain dead.” The donor might have been injured in a car accident or a fall or by drowning, for instance, or they might have had a brain tumor or other serious medical condition affecting their brain.

Although the donor is no longer alive, their major organs can be saved for a short time with medications and machines so they can be removed and transplanted into someone else.

The donor's organs are removed only with the permission of their family. The donor families often see the donation of their family member's organs as giving the gift of life to another person.



You and your child may have a lot of questions about the donor, but please remember that the donor's information is confidential. The members of the transplant team only know the information they need to carry out the transplant safely. For example, they do not know the heart donor's name or where they lived.

## **Can I contact the donor family?**

It is natural for some families to want to thank the donor family. However, confidentiality is very important, and some donor families do not want to have any contact with the family of the person who receives the donated organ. It is important to respect the privacy of the donor family's choice to donate a heart for your child.

If you would like to thank the donor family, the best way is to write a letter without including any identifying information. Your transplant coordinator, social worker, or donor services can help you with your letter. They can then pass it to the donor coordinator who dealt with the donor family and can find out if they want to read it.

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

There is no way to know how long your child needs to wait for a donor heart; it could be a few days or many months to years. Your child's wait time can depend on their age, weight, blood group, and status on the waiting list.

The wait for transplant can be an anxious and emotional one. It is important to continue to find balance and a sense of normalcy for yourself, your child and the rest of your family.

## **Waiting at home**

Transplants can happen at any time, day or night, depending on when a suitable donor organ is found. It is extremely important for the transplant center to have all your contact phone numbers (home, cell, work, and school, and at times those of other family members, friends, or neighbors) so they can reach you as soon as possible. If you have a cell phone, keep it charged and with you at all times. If a family does not have a cell phone, some transplant centers can provide a pager to enable contact 24 hours a day.

You will need to be ready to leave your home as soon as possible after the transplant center tells you an organ is available. Plan well in advance for this by:

- arranging reliable babysitting or child care for any other children,
- lining up other transportation if the person driving you is unavailable,
- organizing how to tell family members – we suggest you call one member who can then contact others,
- packing a bag for the hospital stay ahead of time. The bag may include toiletries, pajamas, and some of your child's personal items (such as pictures, a favorite blanket, and a stuffed animal).

## **Waiting in the hospital**

If you are preparing to wait for transplant in the hospital, talk to the transplant team about bringing in personal items (such as a computer, gaming system, movies, and/or personal photos) to make the hospital room feel more like home. We also recommend you bring enough clothing and toiletries for at least two to three weeks at a time. Some transplant centers let families use their laundry services.

## What happens while my child waits for a new heart?

### Emotions and feelings

Many families say the waiting period is the hardest part of the transplant journey. It is important to recognize that the serious illness of one family member affects the whole family in different ways. To prevent burnout, it is essential to care for yourself and your other family members as well as you can.

While you wait for a new heart for your child, it is natural to experience a range of feelings, including anxiety, hope, anger, sadness, and powerlessness. When so much is out of your control, use the supports available to you, whether family and friends, your faith community, professional supports (such as a counselor or therapist), and the transplant team. Also try to exercise, do activities you enjoy, rest, eat regularly, and take time for yourself.

Illness and hospital stays are both stressful, and a stay in the hospital can be difficult for a child at any age. Hospital stays disrupt a child's life and can interfere with their normal development. While they are in the hospital, children may miss their friends and family and be bored or afraid. They might also not understand why they are in the hospital or have false beliefs about what is happening to them.

Talk to the transplant team about meeting another transplant family with a child of similar age. This might help an older child find out how they will look and feel after a transplant and give you the chance to ask questions about the family's experiences on the transplant journey.

### Activities

It is important your child and family do as many normal activities as possible during the waiting period. All activities will naturally depend on your child's health. Your cardiologist will help you identify what your child can or cannot do.

If your child is waiting at home, it is important for them to go to school, even for only half days. The goal is to keep as normal a schedule as possible so your child can maintain their physical and emotional wellbeing. If your child's physiotherapist has provided any exercise routine, follow it to keep your child as strong as possible before the heart transplant. Some patients will even be prescribed a formal exercise rehabilitation program.

Waiting for a transplant in the hospital can be particularly hard, especially if you are from out of town. It often feels like your whole life has been put on hold. During this time, your child will follow a set schedule that often involves physical therapy, occupational therapy, speech therapy, therapeutic recreation (games or drawing), and school tutoring if applicable. Staff members at the hospital will work with you and your child to deal with the difficulties of a long hospital stay.

### Vacations

The question of going away for a vacation may arise while your child is listed for a heart transplant. This is often possible, but you will need to discuss it with your individual transplant center.

Sometimes going on vacation means your child will be put “on hold” on the transplant waiting list while you are away. This could delay the matching of a donor to your child, but you and your family may decide that you can manage this risk if your family needs a vacation to maintain a certain quality of life. Your transplant team will help you make this decision.

## **Nutrition**

Patients waiting for a heart transplant often find it hard to take in enough energy (calories) to grow. For instance, infants and young children may breathe very quickly. This both burns more calories and makes it hard to drink. Children may also be limited in the amount they may drink. In addition, poor heart function can cause gut problems such as vomiting, gagging, and retching in some children.

Patients with cardiomyopathy (weak heart muscles) often develop heart failure quickly. Usually these patients need more calories as their heart is working harder, but they may be unable to take them if their appetite is small and they are having medical therapies. The dietitian will use various methods to help your child stay nourished before and after transplant.

### **Boosting nutrition for children of different ages**

For infants and young children with heart disease, breast milk or formula may be “concentrated” to provide more calories and nutrients in less volume. This usually involves adding some infant formula to your breast milk and/or following a recipe developed by the dietitian.

Many types and flavors of supplements are available to improve the weight of an older child on the waiting list. To help your child take supplements, try offering them in small quantities throughout the day rather than in a large portion. Also try offering cold rather than room temperature supplements and pour them into a glass or cup instead of leaving them in the can. Your dietitian can advise you about different supplements.

### **Feeding tubes**

Sometimes your child might need to be fed through a feeding tube. This tube can be placed through their nose or directly into their stomach. Feeding tubes are helpful if your child gets tired before they drink enough fluid or if there are strict limits on the fluids they can drink.

The dietitian will work with you and your child to develop a feeding schedule allowing your child to eat and drink if they wish and still get enough energy and nutrients to grow. For example, it may be possible to allow your child to eat and drink during the day and then top up the rest of the nutrition they need through the feeding tube overnight.

## **Medical tests**

By the time a child has completed the transplant assessment (see p. 12) and has been placed on the heart transplant wait list (see p. 18), they will already have undergone a lot of medical testing.

There is usually not much need for more medical tests from when a child is placed on the wait list to when they receive their heart transplant. Any medical tests during this time are generally intended to check that your child's condition remains the same and that they still need and are ready for a new heart.

### **Waiting at home**

A child waiting at home for a heart transplant will have relatively few medical tests once the transplant assessment is done. Any tests will be limited to:

- occasional blood tests to check for any antibodies against potential donor hearts,
- tests to monitor how their other organs are working, and
- occasional echocardiograms to look for any changes in how the heart is working.

If a child has a history of heart rhythm problems, an ECG or Holter monitor testing may also be performed before heart transplant.

### **Waiting in the hospital**

A child waiting in the hospital for a heart transplant will have the same tests as a child waiting at home but may also have additional blood work, x-rays or other testing. This depends on the health problems they have while they are waiting.

Sometimes a child may need to have repeat heart catheterization to measure the pressure in their heart and lungs. This usually happens if the child has been waiting for a long time or if there has been a major change in their health.

## **What happens if my child gets sicker while waiting for a heart?**

Once your child is placed on the transplant waiting list, the cardiologist and/or transplant team will review their health regularly. If your child's heart becomes sicker and your child needs more medical care, they may be moved to a more urgent listing status. This can mean:

- being admitted to the hospital to wait for a heart,
- taking intravenous (IV) medications (medications through a vein),
- getting help with breathing from oxygen or a ventilator machine, and/or
- getting support from machines called ventricular assist devices, which take over the work of the heart.

If a change in your child's condition makes a successful heart transplant less likely, your child may be removed from the list either for a short time (for example, while they receive treatment for an infection) or permanently (for example, if there is major organ failure). If this happens, the transplant team will explain this to you and your child and give you a plan.

## How will a transplant change my child's life?

The impact of a heart transplant on your child's life largely depends on what your child's life was like before transplant. If your child previously had no known health problems and has never taken medicine before, a transplant will make a big difference. On the other hand, if your child has struggled with heart disease in the past, they may be familiar with medications, blood tests, and frequent visits to the doctor.

The biggest change in your child's life is that they now have a new heart and a chance for a full life. This gift of life is not without cost, however.

- Your child will have to take medicine every day for the rest of their life to make sure their body does not reject their new heart.
- They will need to have blood and other medical tests for the rest of their life to:
  - make sure their medicine is working well,
  - look for any medicine side effects, and
  - look for any signs of heart transplant rejection and infection.
- Your child will need to develop relationships with different healthcare professionals and learn to be responsible for their own heart health as they get older and move from pediatric (child) to adult care. Good communication with the transplant team is essential to their success.

# The heart transplant

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Original artwork by a young heart transplant recipient



## How do we prepare for the heart operation?

### Preparing for the hospital stay

Children coming to the hospital usually have many questions and concerns, even if they do not know how to express them. Before your child comes to the hospital, give them as much honest information about their condition as you think they can understand. You will find a list of recommended books in the resources section of this manual. Most are easily bought online. Your child might also find it helpful to read about the experiences of another child with a transplant.

Encourage your child to trust the medical staff. It is important that children believe they are on the same team as their doctors. A counselor can help if your child is very anxious about the surgery. Don't be afraid to ask your transplant team for help or for a referral to someone who might be able to provide extra support to your family.

Some transplant programs assess for stress, depression, and anxiety as part of the transplant evaluation and/or during the waiting time, and routinely have older children needing a transplant talk to a psychiatrist or a doctor in adolescent medicine.

### Tips for talking to your child about their transplant surgery

- Be honest and use age-appropriate language when talking to your child.
- Tell your child what their incision (opening for surgery) or scar will look like.
- Draw a picture of an incision on a doll or on your child's chest.
- Tell your child they may have some pain but that they can ask for medicine to make it feel better. A child often is anxious about surgery because of their fear of the pain involved.
- Tell your child that the doctors and nurses are on their side and helping to make them better.
- Check that your child understands what will happen by asking them to explain in their own words what they think will happen or what could happen.

Many hospitals prepare children for surgery using age-appropriate materials such as soft cloth dolls, puppets, medical equipment, photographs, books, and other materials. These materials not only help to teach your child about hospital stays and procedures but also give them a chance to express their feelings in a non-threatening way and clear up any misunderstandings. When children feel prepared, they are usually less afraid and feel more in control.

### Fears and concerns about surgery and recovery

It is normal to be overwhelmed by the thought of transplantation and its effect on your life, your family and your future. Some people become very emotional and experience confusing or overwhelming feelings. This is normal; these feelings should pass with time.

### Maintaining routine during hospital stays

The hospital stay can be very upsetting for children. Their daily routine and sleep patterns change. They will also face strange and sometimes painful tests and meet many new people. It is normal for them to be irritable and bad-tempered after this experience, especially if their stay in the hospital has been a long one.

The experience can be especially hard for younger children, who most benefit from a regular routine. Try to keep to familiar routines as much as possible during your child's treatment. Bedtime routines are especially important for good sleep.

When your child leaves the hospital after surgery, it may take some time for things to get back to "normal."

## What happens on the day of surgery?

When a donor organ becomes available for your child, it will be a day filled with overwhelming emotions. You and your child may feel nervous, anxious, excited, and/or scared. At this time it is very important for you and your child to ask any questions that you feel have not yet been answered.

In the next few pages, you will have a glimpse into what you and your child can expect on the day of transplant.

### Finding out about a donor heart

A member of the transplant team will call you to say a donor heart is available for your child. They will give you specific instructions about when to come to the hospital and where to go when you arrive. The transplant team member will also ask you some questions about any recent symptoms that would cause concern for infection.

**Note:** It is very important your child does not eat or drink anything once you have been called. Please follow any instructions carefully. Not following instructions could result in delayed or cancelled surgery.

### Arriving at the hospital

Once your child arrives at the hospital, a nurse will examine them and take vital signs (such as their heart rate, blood pressure and temperature). They will review the information they have on file about your child's allergies or medications and update your child's medical history with you.

To prepare for transplant, your child will need to have blood tests and have an IV inserted into their arm or back of their hand. Your child will also have an x-ray of their chest. All these tests help us make sure your child is ready and safe for transplant.

Many people will see you and your child before the surgery and can answer questions. A transplant surgeon will have you sign a consent form for the surgery and answer any other remaining questions. An anesthesiologist (the doctor who gives your child the anesthesia, or sleep medicine for surgery) will also meet you, examine your child, and have you sign a consent form.

Your child is now ready to go to the operating room (OR). A member of the OR team will tell your child's nurse they are ready, and the nurse will then escort you and your child to the OR waiting area. The nurse or a member of the surgical team will discuss how and when they will give you medical updates during your child's surgery. You will be told where to wait to receive these updates.

## **If my child is called for transplant, is the surgery definitely going ahead?**

When a suitable heart is offered for your child, the doctors will accept it, let you know about the quality of the heart, and prepare your child for the transplant.

The doctors accepting the heart for your child usually have enough information to know the heart is healthy, including donor history, donor laboratory results, and studies of the donor heart, such as echocardiograms. However, donors are often very sick and their medical condition may get worse before the surgeon removes and prepares the heart for transplantation (see p. 27). In addition, the surgeon will inspect the donor heart in the operating room; sometimes it is too damaged to be used.

In these uncommon situations, the transplant must be called off. Usually this happens when you and your child are already at the hospital but before the operation has started. If this happens, the team will tell you to wait for another organ to become available.

This can be very disappointing, but it is more important to make sure your child receives a healthy donor heart than to take risks using a heart that may not work well.

## **What happens in the operating room?**

Assuming the donor heart is healthy, the transplant operation involves removing the failing heart from your child's body and attaching the new heart to your child's major blood vessels. This takes about four to eight hours. For children with complex congenital heart disease, the operation is more complicated.

Several members from the surgical team (nurse, surgeon, and other doctors and staff) will be with your child during surgery. The surgical team will describe your child's operation to you in detail.

## **Preparing for surgery**

When your child enters the operating room, they lie on the special operating room bed while the nurse attaches ECG stickers to their chest, an oxygen saturation probe to their finger and forehead, and a blood pressure cuff to one of their arms. These devices all help the team monitor your child's condition during the surgery.

Your child may be given medication to keep them calm. Then, within a few minutes of entering the OR, they will have anesthesia to send them completely to sleep. To manage your child's bodily functions during and after surgery, the team will then insert:

- a breathing tube,
- an intravenous catheter or a central line (a special IV placed in a large vein to deliver medicines, fluids, and nutrition),
- an arterial line (a special catheter, or thin tube, placed in an artery to monitor blood pressure),
- a bladder catheter, to drain urine,
- a nasogastric tube to drain the stomach and/or give medications
- a chest tube to drain fluid from around the lungs, and/or
- a peripheral IV to administer medications or fluids.

## **Removing your child's heart**

The surgical team will open up your child's chest and place them on a heart and lung bypass machine, which does the work of the heart and lungs during the operation. The surgical, nursing, anesthesia and perfusion

(blood circulation) teams monitor your child carefully during the surgery.

## **Transplanting the new heart**

When the new heart arrives, the surgical team works to implant it safely in your child. When this is done, the heart and lung bypass machine is stopped, and the new heart begins to take over.

After the bypass machine is stopped, the teams in the operating room watch the new heart to make sure it is working properly. Often an echocardiogram is done to see how the new heart is working and make sure there is no narrowing where the new heart is attached to your child's blood vessels.

When the surgical team is sure that everything is working as it should, your child will be prepared for transfer to the intensive care unit (ICU) for recovery.

## **Where do I wait during my child's surgery?**

You and your family members will be shown to the surgical waiting room or intensive care waiting room.

## **What happens in the intensive care unit (ICU)?**

When your child first arrives in the intensive care unit, or ICU, they will need time to "settle in." This usually takes at least one to two hours. Your child's nurse will tell you when you can visit.

## **What to expect when you first see your child**

Your child will be attached to many tubes and monitors, which can be an overwhelming sight at first. Your child's team will explain all the monitors, tubes, and IVs to you in detail.

### **Monitors**

Your child will be on a ventilator (breathing machine) until they are ready to breathe on their own. Your child will remain sedated while they are on the breathing machine so they are relaxed and comfortable. This usually takes a day or two for older children and teenagers, but it can sometimes take a bit longer for babies.

In addition to the ventilator, several monitors in the room will be used to check your child's heart rhythm, blood pressure, blood oxygen level, and possibly other signs, depending on your child's specific situation.

### **Devices and tubes**

Most children return from the operating room with a temporary pacemaker in place. This is an electrical device to control the heart rate. The pacemaker wires will be attached to your child's heart and come out through their skin.

Your child will have a bladder catheter (a soft plastic tube), which will continuously drain urine. This tube is inserted during surgery.

A nasogastric tube will also be in place, which will make sure the stomach stays empty of air and secretions. This tube is inserted through a nostril and then passed down into the stomach. The tube is placed during the surgery.

Your child will also have chest tubes to drain fluids that collect around the heart and lungs during and after surgery. These tubes will come out through the skin just under your child's ribs. The tubes are placed during the surgery.

As your child will still be asleep or very drowsy at this time, they will get fluid, medications, and nutrition through central and peripheral catheters.

Your child's nurse will be able to explain all monitors and tubes to you. Feel free to ask any questions.

### **Your child's incision**

Your child will have an incision (cut) along the length of their sternum (breastbone). This is called a "sternotomy" and will be covered with a dressing. After two or three days, the dressing will be removed and left off to let the incision continue healing.

Depending on their surgeon's preference, your child may have staples (wire) or a suture (thread stitches) to close the incision. Sometimes, a child returns from the OR with the "chest open" because they may be more stable that way. In this case, the incision is covered with a cloth or dressing and is then closed in the ICU or OR after a few days, as long as your child is recovering from the operation as expected. During this time period your child will be sedated and unaware.

As your child recovers from the surgery, the medical team will reduce their medications and begin to remove the invasive lines and monitors. The breathing machine will do less work as your child is woken up from sedation. When your child is finally disconnected from the breathing machine, they will be able to speak and, in time, be able to drink.

### **When does my child leave the ICU?**

Depending on their condition, a child can stay in the ICU for a few hours, a few days, or even a few weeks. When your child no longer needs intensive care, they will be moved to the cardiology floor.

Although most of the monitoring equipment will be removed, your child may still have chest drains, pacing wires, or intravenous infusions. Over the following days, these will be gradually removed as your child's condition improves.

### **Working with your child's healthcare team**

Once your child is in a ward, the nurse who looks after them regularly will also have other patients to care for, unlike in the ICU. Because of this, you will be encouraged to play a greater role in your child's care.

At this point, too, other transplant team members, such as the physiotherapist, occupational therapist, and dietitian, become involved again in your child's care. It is important that you and your child follow their recommendations and instructions so your child can begin adapting to life with their new heart.

This is also a time when the transplant coordinators and pharmacists work closely with you to make sure you are getting ready to care for your child at home.

## Your child's emotional and psychological recovery

The physical recovery from a heart transplant operation is only one part of your child's transplant journey. A heart transplant can be an emotionally challenging experience for your child, and for the rest of your family.

Children who have received a transplant can experience depression, self-esteem and self-image issues, and/or attention disorders after their surgery. Being aware of the warning signs and providing support and counseling for new issues will help to reduce their impact on your child's life.

The transplant team is prepared to support your or your child's emotional concerns and needs at this time. You can get support from the transplant psychologists, psychiatrists, doctor in adolescent medicine, social workers, and child life specialists.

A heart transplant generally improves the overall quality of life for a child and their family. It allows seriously ill children to feel well and take part in age-appropriate activities. It has helped many children get back to the normal routines and tasks involved in growing up.

However, a heart transplant is not a cure. Children and their families are trading a life-limiting heart disease for lifelong medications and their side effects, close medical follow-up, and invasive procedures.

## Going home after the transplant

Before you and your child are discharged from the hospital, you will start to learn about life after transplant. The transplant nurse coordinator, dietician, pharmacist and other team members will teach you how to keep your child healthy at home.

The next section of this manual has information about things that are important after a heart transplant.

It is important to remember each child's situation is different, and your child may not experience everything mentioned.

Your transplant team will give you much more information after your child has the heart transplant and they have time to observe your child's recovery.



**Original artwork by  
Adrianna, age 12**



## Life after the heart transplant

Right after your child is discharged from hospital, there will be frequent follow-up appointments at the heart transplant center. This close follow-up is very important to catch any problems or concerns early.

These appointments can be emotionally and financially draining, but the transplant team will work with you to help your child's follow-up care go as smoothly as possible.

After the first few months, and especially after the first year, your child's appointments will be less frequent. Eventually, the appointments will more easily fit into a normal family schedule.

**As you read this section, please remember that every child is different.** Also, different transplant centers have their own routines for follow-up after a heart transplant. Your transplant center will share their schedule with you.

Note, too, that schedules and tests may change for many different reasons. For instance, some tests are only done in patients of a certain age, weight, or height. Your heart transplant team members will explain why they are doing a certain test or procedure in your child at a specific time.

## Clinic visits and routine testing

Clinic visits and routine tests help the transplant team make sure the transplanted heart is healthy and working well. Your child's health and development will also be closely followed after heart transplant to identify any problems as early as possible.

This section outlines some tests heart transplant patients may undergo, but remember every patient and every transplant program is different. Your transplant team will explain the routine in your center and the plan for your child's specific situation and health concerns.

### Clinic visits

Immediately after their transplant, your child will usually visit the clinic once or twice a week. These visits will become less frequent once your child's body adjusts to the transplanted heart. Many centers eventually cut down appointments to once every three to six months for patients who are doing well.

### Laboratory (lab) tests

Your child will have regular blood, urine, or other lab tests. Common tests include:

- white blood cell count, to show any possible infection or side effects from transplant medications,
- level of waste products such as creatinine and blood urea nitrogen in the blood, to show how well the kidneys and liver are working,
- amount of glucose (sugar) or lipids (cholesterol and other fats) in the blood (some transplant medications can make them too high),
- specific tests to look for evidence of recent viral infections,
- level of HLA antibodies in the blood, to check if there is a risk that the body might start rejecting the donor heart, and
- immunosuppressant medication "levels," to see if there is a safe and effective amount of immunosuppressant medication in the bloodstream. High levels could be toxic or suppress the immune

system too much, and low levels may cause a patient to reject the new heart.

## Heart tests

### Echocardiogram (Echo)

Your child will have routine echocardiograms. This test is an ultrasound of the heart. It uses sound waves to:

- check the size, shape and movement of the heart and its valves,
- see how well the heart pumps blood,
- identify if there is any fluid in the sac around the heart (known as pericardial effusion).

Sometimes your child will have a special type of echocardiogram called a stress echo. This involves making the heart “stressed” or excited by having the person do exercise or take special medication. Afterwards, an echo is done to see how the heart functions when it is working vigorously (hard). The results are compared to the heart’s function when it is resting.

### Right heart cath (RHC)

This term is often used for right heart catheterization. The test checks the pressure in the right side of the heart and the lungs and is often done at the same time as a biopsy (see p. 71).

The test involves guiding a catheter (a thin, hollow tube) through the chambers of the heart and into the blood vessels of the lungs. Different centers have different schedules for this procedure.

### Left heart cath (LHC)

A left heart catheterization is usually done to check for any narrowing or blocks in the coronary arteries. The arteries are blood vessels that feed oxygen-rich blood to the heart muscle (see coronary allograft vasculopathy, p. 74). The test also measures pressures in the left side of the heart.

During the test, a catheter will be inserted into the artery in the groin or arm and passed up to the aorta and the left side of the heart. Dye will be injected to outline the coronary arteries and look for any abnormalities. Different centers have different schedules for this procedure.

### Electrocardiogram (EKG or ECG)

This test involves placing 12 electrodes on the chest to assess the electric activity or rhythm of the heart.

## Other tests and procedures

Your transplant team will explain any other routine tests that are done in your center. These tests may include:

- exercise stress testing,
- glomerular filtration rate (GFR), to see how well the kidneys are working,
- bone mineral density, to assess bone strength,
- constant (24-hour) ambulatory blood pressure monitoring, to check blood pressure at regular intervals during your child’s everyday routine, and/or
- developmental assessments, to check your child’s cognitive (thinking), communication, and movement skills as they grow.

## Transplant medications

The key to maintaining a successful heart transplant is following medication instructions correctly for the rest of your child's life. Skipping medications will lead to rejection of the heart or to decreased life of the heart.

It is important to give your child their medications exactly as prescribed by the transplant team.

It is completely natural to feel overwhelmed with the new medications and the information about them at first. You and your child will find it easier to follow the medication instructions once they become part of your routine. Over time, there will be fewer medications, making it even easier to stick to the transplant team's instructions.

Your transplant team's goal is to make sure you are familiar with all of the medications your child will be taking before they leave the hospital. We want you to become responsible for giving the medications. Over time, your child will become more involved in taking the medicines on their own.

### Types of transplant medications

Most transplant patients take three types of medications:

- immunosuppressants,
- anti-infection medications, and
- other medications.

#### Immunosuppressants

The immune system's job is to fight infection and try to destroy anything that should not be in the body. Immunosuppressants (also known as anti-rejection medications) suppress, or weaken, the immune system. This helps to prevent the body from attacking the newly transplanted heart.

Your child will take immunosuppressant medication for the rest of their lives, but, over time, the medical team may prescribe a lower dose.

#### Anti-infection medications

Your child has a higher risk of developing certain infections because of their immunosuppressant medicines. Anti-infection medications work to prevent or fight these infections. Your child must take these medications to help them stay as healthy as possible while their body gets used to their new heart.

Anti-infection medications are mostly taken during the first year after transplant. Sometimes they may also be prescribed if a person has a rejection episode and needs to be treated with more immunosuppressants, which increase the risk for an infection.

#### Other medications

Other medications are usually used to control side effects caused by the transplant medications or the surgery itself. Side effects from the medications can include; high blood pressure, stomach pains, and blood clots.

If your child does well, without side effects, the team will likely stop these medications.

## Understanding your child's medications

Because you are responsible for giving your child's medicine, it is very important you talk with your pharmacist or your child's doctor or nurse to understand:

- the name of each medicine and why your child needs it,
- when to give each medicine,
- how each medicine is given,
- how long your child will be on each medicine,
- the possible side-effects of each medicine,
- what to do if a dose is missed, and
- how and when to order medications to prevent missed doses.

## Guidelines for taking medications

Below is a list of basic guidelines that apply to many medications.

Please refer to the specific medication page in this manual, and ask the pharmacist, doctor, or nurse for information about each medicine.

### Giving medications and reporting side effects

- Always give medication at the same time every day and in the same way (with or without food), including weekends.
- Never skip a dose! Skipping doses increases the chance the heart may stop working properly.
- Do not stop or change any dose of your child's medications without speaking to the transplant team.
- Never give your child over-the-counter, herbal (natural) or homeopathic medications or any medications prescribed by another doctor without talking to your transplant team first. Many medications interact with transplant medications, leading to dangerous side effects or prevent the transplant medications from working properly.
- Call your transplant team right away if your child has side effects from any medications.

### Storing medications

- Store transplant medications out of reach of small children or animals.
- Store medications in a cool and dry place, but make sure to check the label first to see if you should keep them at room temperature or put them in the refrigerator.
- Never keep transplant medications above a stove or oven or in the bathroom. The heat or humidity in these places can damage them.

### Refilling prescriptions

- Always call your pharmacy for refills **a week before** the medications will run out.
- If your child misses doses of medicine, there is a greater chance that the heart will stop working properly.

### Travel

- If traveling by plane, keep your child's transplant medications in the cabin with you. If you put the medications in checked baggage, you risk being without them if the baggage is lost or delayed. Medication can also be damaged from being stored at freezing temperatures in the baggage storage area.

### **Eating and drinking**

- Grapefruit juice can interact with some transplant medications and raise the levels of immunosuppressant medicine in the blood.
- Check all labels carefully.
- Never let your child eat grapefruit or any fruit related to it, such as pomelo.
- Have your child avoid grapefruit juice and any mixed fruit juices containing grapefruit juice.

### **Hygiene**

- Always wash your hands before and after giving your child medications.

### **Why it is important to stick to one brand of medicine**

Medications always have two names: the chemical name and the brand name from the manufacturer. The same medications can be made by different manufacturers. The transplant team will discuss with you the need for a specific brand medication if necessary. Some brand may have a slightly different potency.

Make sure you tell your transplant center if the brand name or strength of the medicine changes, as your child's blood levels may need to be re-checked.

**The following pages in this section are meant as a guide and contain the most important and common information you may need about transplant medications.**

**Every child is different. Your child may need medications not listed here.**

**Be assured your child's transplant team will only choose medications they feel will be the best for your child.**

**If you have any questions, always call your transplant team to discuss them.**

## Immunosuppressant medications

### Induction immunosuppression

These are strong medications used to suppress, or weaken, the immune system at the time of the operation and for the first few days afterwards. They help to prevent rejection for days to weeks until your child recovers from the surgery and can start taking by mouth enough of the medications they will need for the rest of their life.

Not every transplant center uses induction immunosuppression medications.

Generic name	Alemtuzumab
Brand name	Campath®
What it does	Prevents the body from rejecting the transplanted heart
What it looks like	Prepared in a syringe (needle) or intravenous (IV) bag
How it is given	Injected into your child's vein
Most common side effects	<ul style="list-style-type: none"> <li>• Fever, chills, aches (during the infusion)</li> <li>• Blood pressure and heart rate (during the infusion)</li> <li>• Lower platelet counts</li> <li>• Lower white blood cell counts</li> </ul>
Other important information	Most children will take some medications, such as acetaminophen (Tylenol®) or diphenhydramine (Benadryl®), before the dose to prevent or reduce reactions during the infusion.

Generic name	Anti-thymocyte globulin (rabbit)
Brand name	Thymoglobulin®
What it does	<ul style="list-style-type: none"> <li>• Prevents your child's body from rejecting the transplanted heart at the time of transplant</li> <li>• Treats serious rejection at any time after transplant</li> </ul>
What it looks like	Prepared in a syringe (needle) or an intravenous (IV) bag
How it is given	Injected into your child's vein over several hours for 1 to 14 days
Most common side effects	<ul style="list-style-type: none"> <li>• Fever, chills or aches (during the infusion)</li> <li>• Changes in blood pressure and heart rate (during the infusion)</li> <li>• Difficulty breathing (during the infusion)</li> <li>• Rash</li> <li>• Lower platelet counts [platelets help stop bleeding]</li> <li>• Lower white blood cell counts [white blood cells help fight infection]</li> </ul>
Other important information	Most children will take some medications, such as acetaminophen (Tylenol <sup>→</sup> ) or diphenhydramine (Benadryl <sup>→</sup> ), before the dose to prevent or lessen reactions during the infusion.

Generic name	Basiliximab
Brand name	Simulect®
What it does	Prevents the body from rejecting the transplanted heart
What it looks like	Prepared in a syringe (needle)
How it is given	Injected into your child's vein on the day of transplant and for four days after the transplant
Most common side effects	<ul style="list-style-type: none"> <li>• Fever or chills (while the dose is being given)</li> <li>• Changes in blood pressure and heart rate (while the dose is being given)</li> <li>• Allergic reaction (rare)</li> </ul>



Generic name	Methylprednisolone (a corticosteroid)
Brand name	Solumedrol®
What it does	<ul style="list-style-type: none"> <li>• Prevents your child's body from rejecting the transplanted heart at the time of transplant</li> <li>• Treats rejection at any time after the transplant</li> </ul>
What it looks like	Supplied in vials (small bottles) and prepared in a syringe (needle) or intravenous (IV) bag
How it is given	<p>Injected into your child's vein</p> <p>Once your child is taking food by mouth, they may continue with it in a tablet or liquid form</p>
Most common side effects	<ul style="list-style-type: none"> <li>• Increased blood pressure</li> <li>• Higher blood sugar levels</li> <li>• More appetite (hunger)</li> <li>• Weight gain</li> <li>• Edema (puffiness)</li> <li>• Higher cholesterol</li> <li>• Mood swings, irritability</li> <li>• Difficulty sleeping</li> <li>• More sweating (more often at night)</li> <li>• Mild headache</li> <li>• Slow wound healing</li> </ul>
Other important information	High doses of methylprednisolone are usually given over a few days at the time of transplant or if your child has a rejection episode

## Maintenance immunosuppression

These are the medications that your child will take every day for the rest of their life to prevent rejection of the donor heart (see p. 70).

There are different types of maintenance immunosuppressants. Your transplant doctor will choose the ones that are best for your child. Below is an abbreviated list of medications in alphabetical order and not order of importance.

Generic name	Azathioprine
Brand name	Imuran®
What it does	Prevents the body from rejecting the transplanted heart
How it is given	<ul style="list-style-type: none"> <li>• Give once a day, at the same time, every day.</li> <li>• Give with food or without food, but give it the same way every day.</li> <li>• Giving with food can lessen stomach upset (such as nausea).</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Nausea (upset stomach), vomiting (throwing up)</li> <li>• Reduced appetite</li> <li>• Low platelet counts [platelets help stop bleeding]</li> <li>• Low white blood cell counts [white blood cells help fight infection]</li> <li>• Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]</li> <li>• Mild headache</li> <li>• Dizziness</li> <li>• Hair loss</li> <li>• Rash</li> </ul>

Generic name	Bortezomib
Brand name	Velcade®
What it does	Treats antibody mediated rejection (See p. 72) by targeting the plasma cells that form antibodies
How it is given	Injected into a vein or under the skin* *Schedule varies
Most common side effects	Increased risk of bleeding Peripheral neuropathy/numbness Increased risk of infection Nausea (upset stomach), vomiting (throwing up), diarrhea (watery stools), and constipation Headache Insomnia (inability to sleep) Thrombocytopenia or low blood platelet count
Other important information	Dose adjusted for liver function test abnormalities Dose adjusted for low platelets

Generic name	Eculizumab
Brand name	Soliris®
What it does	Treats antibody mediated rejection (See p. 72) in cases with complement fixation
How it is given	<ul style="list-style-type: none"> <li>• Injected into vein</li> </ul> Number of doses and course vary by transplant center
Most common side effects	<ul style="list-style-type: none"> <li>• Insomnia</li> <li>• Increased risk of infection</li> </ul>
Other important information	<ul style="list-style-type: none"> <li>• Transplant team will discuss need for additional vaccines or antibiotics during the course.</li> <li>• Allergic reaction can occur.</li> </ul>

Generic name	Cyclosporine
Brand name	Gengraf®, Neoral®, Sandimmune®
What it does	Prevents the body from rejecting the transplanted heart
How it is given	<ul style="list-style-type: none"> <li>• Give at the same times every day, usually 12* hours apart (*8 hours apart for some children).</li> <li>• Give either with food or without food. Give it the same way every day, as changes in food intake can affect how much cyclosporine passes from your child's stomach into their bloodstream.</li> <li>• Neoral® and Sandimmune® are different drugs. <b>Never</b> swap one for the other.</li> <li>• Make sure that you always have the same brand of cyclosporine.</li> <li>• Call your transplant team if you notice that the capsules or liquid cyclosporine look different from what your child normally takes.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Decreased magnesium in the blood</li> <li>• Increased potassium in the blood</li> <li>• Increased blood pressure</li> <li>• Increased blood sugar (some children develop diabetes)</li> <li>• Damage to the kidneys (usually if blood levels of cyclosporine are too high)</li> <li>• Tremors (shakiness of the hands or feet)</li> <li>• Upset stomach, vomiting (throwing up) or diarrhea (watery stools)</li> <li>• Increased fine body hair growth</li> <li>• Tender or enlarged gums</li> </ul>
Other important information	<ul style="list-style-type: none"> <li>• <b>Never</b> give your child grapefruit juice or any juices containing grapefruit. These products raise the cyclosporine level in your child's blood, which can lead to more side effects. Read the labels of mixed fruit juices (front and back!) carefully.</li> <li>• <b>Never</b> let your child eat grapefruit (even when mixed in a fruit salad) or any fruit grown from grapefruit, such as pomelos or tangelos.</li> </ul>

Generic name	Everolimus
Brand name	Zortress®
What it does	Prevents the body from rejecting the transplanted heart
How it is given	<ul style="list-style-type: none"> <li>• Give at the same times every day, usually 12* hours apart (*8 hours apart for some children).</li> <li>• Medication is not currently available in liquid; follow instructions from pharmacist on how to prepare.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Mouth sores</li> <li>• High lipid levels</li> <li>• High blood pressure</li> <li>• Protein in urine</li> <li>• Delayed wound healing</li> </ul>
Other important information	<ul style="list-style-type: none"> <li>• Avoid grapefruit juice or any juices that contain grapefruit. These products raise the sirolimus level in your child's blood, which can lead to more side effects. Read the front and back labels of mixed fruit juices carefully.</li> <li>• Avoid all grapefruit products (by itself or mixed in a salad) and any fruit grown from grapefruit such as pomelos or tangelos.</li> </ul>

Generic name	Mycophenolate
Brand name	Cellcept® (mycophenolate mofetil), Myfortic® (mycophenolate sodium) Several generic products are also available.
What it does	Prevents the body from rejecting the transplanted heart.
What it looks like	<p>Mycophenolate mofetil (Cellcept®) and mycophenolate sodium (Myfortic®) are different drugs with different dosing instructions. <b>Never</b> swap one for the other.</p> <p>Mycophenolate mofetil comes in:</p> <ul style="list-style-type: none"> <li>• 250mg capsules (usually orange and blue),</li> <li>• 500mg tablets (usually purple), and</li> <li>• suspension (liquid).</li> </ul> <p>Mycophenolate sodium (Myfortic®) comes in:</p> <ul style="list-style-type: none"> <li>• 180mg tablets (light green), and</li> <li>• 360mg tablets (light orange).</li> </ul> <p>Other brands of mycophenolate can look different. Always use the same brand. Call your transplant team if you notice the mycophenolate looks different from what you normally give your child.</p>
How it is given	<ul style="list-style-type: none"> <li>• Give mycophenolate at the same times every day, 12 hours apart.</li> <li>• Give mycophenolate with food or without food. Give it the same way every day, since changes in food intake can affect how much mycophenolate passes from your child's stomach into their bloodstream.</li> <li>• Giving mycophenolate with food may lessen stomach upset (such as cramps or diarrhea).</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Stomach cramps, diarrhea (watery stools)</li> <li>• Nausea (upset stomach), heartburn or vomiting (throwing up)</li> <li>• Low platelet counts [platelets help stop bleeding]</li> <li>• Low white blood cell counts [white blood cells help fight infection]</li> <li>• Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]</li> <li>• Mild headache</li> <li>• Risk of malformations in an unborn fetus (teenage girls should take precautions to avoid getting pregnant while taking)</li> </ul>

Generic name	Prednisone / Prednisolone
Brand name	Deltasone®, Orapred®, Pediapred®
What it does	Prevents the body from rejecting the transplanted heart
How is it given	By mouth
Most common side effects	<ul style="list-style-type: none"> <li>• Increased blood pressure</li> <li>• Higher blood sugar levels</li> <li>• Upset stomach, vomiting (throwing up) or diarrhea (watery stools)</li> <li>• Increased appetite (hunger)</li> <li>• Weight gain</li> <li>• Edema (puffiness)</li> <li>• Mood swings, irritability</li> <li>• Difficulty sleeping</li> <li>• More sweating (more often at night)</li> <li>• Mild headache</li> <li>• Acne (pimples)</li> <li>• Slow wound healing</li> <li>• Stretch marks</li> </ul> <p>Side effects of <b>long-term use</b></p> <ul style="list-style-type: none"> <li>• Weaker bones</li> <li>• Slower growth (height)</li> <li>• Cataracts (a gel-like glaze over the eye(s))</li> </ul>



Generic name	Sirolimus
Brand name	Rapamune®
What it does	<ul style="list-style-type: none"> <li>• Prevents the body from rejecting the transplanted heart</li> <li>• May slow down the progress of a heart condition (called cardiac allograft vasculopathy) that can occur over time after the transplant</li> </ul>
How it is given	<ul style="list-style-type: none"> <li>• Give once a day, at the same time, every day. Some children take it twice a day if they are on a high dose.</li> <li>• Give with food or without food, but give it the same way every day. Food does not have a big effect on how much sirolimus passes from your child's stomach into their bloodstream.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Upset stomach, vomiting (throwing up) or diarrhea (watery stools)</li> <li>• Mild headache</li> <li>• Mouth sores or ulcers</li> <li>• High cholesterol and/or triglyceride levels</li> <li>• Low white blood cell counts [white blood cells help fight infection]</li> <li>• Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]</li> <li>• Low platelet counts [platelets help stop bleeding]</li> <li>• High blood pressure</li> <li>• Delayed wound healing</li> <li>• Acne</li> <li>• Increase in liver function (transaminases) tests</li> <li>• Leg cramps</li> <li>• Lung inflammation (swelling)</li> </ul>
Other important information	<ul style="list-style-type: none"> <li>• Avoid grapefruit juice or any juices that contain grapefruit. These products raise the sirolimus level in your child's blood, which can lead to more side effects. Read the front and back labels of mixed fruit juices carefully.</li> <li>• Avoid all grapefruit products (by itself or mixed in a salad) and any fruit grown from grapefruit such as pomelos or tangelos.</li> <li>• Sirolimus may cause reversible sterility in males.</li> <li>• Precautions should be taken to prevent pregnancy while taking sirolimus.</li> </ul>

Generic name	Tacrolimus
Brand name	Prograf® Several generic products are also available
What it does	Prevents the body from rejecting the transplanted heart
How it is given	<ul style="list-style-type: none"> <li>• Give at the same times every day, usually 12* hours apart (*eight hours apart for some children).</li> <li>• Give either with food or without food. Give it the same way every day, as changes in food intake can affect how much tacrolimus passes from your child's stomach into their bloodstream.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Decreased magnesium in the blood</li> <li>• Increased potassium in the blood</li> <li>• Increased blood sugar (some children develop diabetes)</li> <li>• Increased blood pressure</li> <li>• Damage to the kidneys (if blood levels of tacrolimus are too high, but long term damage is also possible)</li> <li>• Tremor (shakiness of the hands/feet)</li> <li>• Upset stomach, vomiting (throwing up) or diarrhea (watery stools)</li> <li>• Mild headache</li> <li>• Seizures (if blood levels of tacrolimus are too high)</li> <li>• Leg cramps</li> <li>• Hair loss</li> </ul>
Other important information	<ul style="list-style-type: none"> <li>• Avoid grapefruit juice or any juices containing grapefruit. These products raise the tacrolimus level in your child's blood, which can lead to more side effects. Read the front and back labels of mixed fruit juices carefully.</li> <li>• Avoid all grapefruit products (by itself or mixed in a salad) and any fruit grown from grapefruit such as pomelos or tangelos.</li> <li>• Discuss with the transplant team if you always need the same brand. Call your transplant team if you notice the tacrolimus looks different from what you normally give your child.</li> </ul>

## Other immunosuppressants

Generic name	Cyclophosphamide
Brand name	Cytosan®
What it does	Treats certain cases of post-transplant lymphoproliferative disorder (PTLD) (see p. 80)
How it is given	<ul style="list-style-type: none"> <li>• Injected into your child's veins over several hours</li> <li>• Depending on the situation, your child may receive only one dose of cyclophosphamide or one dose every few weeks.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Changes in blood pressure and heart rate (during the infusion)</li> <li>• Nausea (upset stomach), vomiting (throwing up), cramping, or diarrhea (watery stools)</li> <li>• Bladder problems</li> <li>• Lower white blood cell counts [white blood cells help fight infection]</li> <li>• Lower platelet counts [platelets help stop bleeding]</li> <li>• Rash</li> <li>• Hair loss</li> </ul>
Other important information	Your child will receive extra IV fluids before, during, and after cyclophosphamide doses to protect their kidney and bladder.

Generic name	Rituximab
Brand name	Rituxan®
What it does	<ul style="list-style-type: none"> <li>• Treats certain types of post-transplant lymphoproliferative disorder (PTLD) (see p. 80)</li> <li>• Treats antibody-mediated rejection (see p. 72)</li> </ul>
How it is given	<ul style="list-style-type: none"> <li>• Injected into your child's veins over several hours</li> <li>• Depending on the situation, your child may receive only one dose of rituximab or one dose every few weeks.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Fever, chills, muscle aches (during the infusion)</li> <li>• Changes in blood pressure and heart rate (during the infusion)</li> <li>• Difficulty breathing (during the infusion)</li> <li>• Headache, dizziness</li> <li>• Change in blood sugar</li> <li>• Rash</li> <li>• Lower platelet counts [platelets help stop bleeding]</li> <li>• Lower white blood cell counts [white blood cells help fight infection]</li> </ul>
Other important information	Most children will also take some medications, such as acetaminophen (Tylenol <sup>(R)</sup> ) or diphenhydramine (Benadryl <sup>(R)</sup> ), before the rituximab dose to prevent or ease reactions during the infusion.

## Medications to prevent and treat infections

Generic name	Acyclovir
Brand name	Zovirax®
What it does	Prevents and treats infections caused by certain types of viruses
How it is given	Given by mouth as liquid or pills
Most common side effects	<ul style="list-style-type: none"> <li>• Nausea (upset stomach)</li> <li>• Vomiting (throwing up) or diarrhea (watery stools)</li> <li>• Mild headache</li> <li>• Dizziness</li> <li>• Temporary or permanent kidney damage (see below)</li> </ul>
Other important information	To prevent kidney problems, your child should drink plenty of water or other fluid (unless the doctor has told your child to drink less).

Generic name	Atovaquone
Brand name	Mepron®
What it does	Prevents a certain type of lung infection called pneumocystis jiroveci pneumonia (PJP)
How it is given	Given by mouth as a liquid
Most common side effects	<ul style="list-style-type: none"> <li>• Fever</li> <li>• Headache, dizziness</li> <li>• Insomnia (inability to sleep)</li> <li>• Nausea (upset stomach), vomiting (throwing up), stomach cramping, diarrhea (watery stools)</li> </ul>
Other important information	Can be mixed in small amounts of orange juice or milk if your child cannot tolerate the taste or texture by itself

Generic name	Clotrimazole
Brand name	Mycelex <sup>→</sup>
What it does	Prevents and treats a type of fungus that grows in the mouth; also known as “thrush”
How it is given	Given by mouth, usually as a lozenge
Most common side effects	Nausea (upset stomach) or vomiting (throwing up)

Generic name	Cytomegalovirus immune globulin (CMV-IVIG)
Brand name	Cytogam <sup>®</sup>
What it does	Prevents and treats a virus called CMV (cytomegalovirus)
How it is given	Injected into the vein
Most common side effects	<ul style="list-style-type: none"> <li>• Change in heart rate, blood pressure or breathing rate (during the infusion)</li> <li>• Muscle aches</li> <li>• Nausea (upset stomach) or vomiting (throwing up)</li> </ul>

Generic name	Dapsone
Brand name	Avlosulfon <sup>®</sup> ; DDS
What it does	Prevents a lung infection called pneumocystis jiroveci pneumonia (PJP)
How it is given	Given by mouth as a pill
Most common side effects	<ul style="list-style-type: none"> <li>• Nausea (upset stomach) or vomiting (throwing up)</li> <li>• Loss of appetite</li> <li>• Insomnia (difficulty sleeping)</li> <li>• Headache</li> </ul>

Generic name	Fluconazole
Brand name	Diflucan®
What it does	Prevents and treats infections caused by yeast, a type of fungus
How it is given	Given by mouth as a liquid or pill Sometimes given as an injection (short)
Most common side effects	<ul style="list-style-type: none"> <li>• Upset stomach</li> <li>• Vomiting (throwing up)</li> <li>• Diarrhea (watery stools)</li> <li>• Mild headache</li> <li>• Dizziness</li> <li>• Liver problems</li> </ul>

Generic name	Gancyclovir
Brand name	Cytovene®
What it does	Treats infections by two types of viruses: <ul style="list-style-type: none"> <li>• cytomegalovirus (CMV), and</li> <li>• Epstein Barr virus (EBV).</li> </ul>
How it is given	Given by mouth or injected into your child's vein (IV)
Most common side effects	<ul style="list-style-type: none"> <li>• Mild headache</li> <li>• Lower platelets, which can cause bleeding</li> <li>• Lower white blood cell counts, which can cause infection</li> <li>• Lower red blood cell (hemoglobin) counts ; also known as "anemia"</li> <li>• Temporary or permanent damage to the kidney</li> <li>• Upset stomach, vomiting (throwing up), or diarrhea (watery stools)</li> </ul>



Generic name	Nystatin
Brand name	Mycostatin®
What it does	<p>Prevents infection caused by yeast, a type of fungus, also known as “thrush”</p> <p>Thrush can occur in the mouth and throat. If not treated, it can spread to other parts of the body.</p> <p>Thrush often looks like a white, sometimes furry coating on your child’s tongue or white spots on the inside of the mouth. Your child’s voice may also be hoarse.</p>
How it is given	<ul style="list-style-type: none"> <li>• By mouth - your child swishes it around their mouth for a minute before swallowing it</li> <li>• Your child should not eat anything for 20 minutes after taking the dose.</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Upset stomach</li> <li>• Vomiting (throwing up)</li> <li>• Diarrhea (watery stools)</li> <li>• Cavities (if teeth are not brushed regularly – see below)</li> </ul>
Other important information	<ul style="list-style-type: none"> <li>• Nystatin contains sugar. To prevent cavities, your child should brush their teeth regularly.</li> <li>• If your child does not like the taste of nystatin, your pharmacist can flavor it.</li> </ul>

Generic name	Pentamidine
Brand name	Nebupent®, Pentam®
What it does	Prevents and treats a certain type of lung infection called pneumocystis jiroveci pneumonia (PJP)
How it is given	Inhaled through a mask or given through a vein (IV)
Most common side effects	<p>When inhaled:</p> <ul style="list-style-type: none"> <li>• cough, tightness in the chest, and/or</li> <li>• bitter taste in the mouth</li> </ul> <p>Both forms:</p> <ul style="list-style-type: none"> <li>• low white blood cell counts [white blood cells help fight infection],</li> <li>• low platelets [platelets help stop bleeding], and/or</li> <li>• low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body].</li> </ul>
Other important information	If your child is receiving inhaled pentamidine, they may also inhale a medication called ‘albuterol’ or ‘salbutamol’ before the pentamidine to prevent coughing and chest tightness.

Generic name	Sulfamethoxazole-Trimethoprim (SMX-TMP)
Brand name	Bactrim®, Septra®, Cotrimoxazole®
What it does	<p>Prevents a certain type of lung infection called pneumocystis jiroveci pneumonia (PJP)</p> <p>Your child cannot take this medication if they have an allergy to Sulfonamides or “sulfa” drugs or Trimethoprim.</p>
How it is given	By mouth as a liquid or pill
Most common side effects	<ul style="list-style-type: none"> <li>• Upset stomach, vomiting (throwing up) or diarrhea (watery stools)</li> <li>• Mild headache</li> <li>• Rash</li> <li>• Increased sensitivity to the sun</li> <li>• Low white blood cell counts [white blood cells help fight infection]</li> <li>• Low platelets [platelets help stop bleeding]</li> <li>• Low red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]</li> </ul>
Other important information	<p>Your child cannot take this medication if they have an allergy to sulfonamides or “sulfa” drugs or trimethoprim.</p> <p>Because SMX-TMP makes your child’s skin more sensitive to the sun, your child needs to wear sunscreen regularly when outside.</p>

Generic name	Valgancyclovir
Brand name	Valcyte®
What it does	Prevents and treats two viral infections in transplant patients: <ul style="list-style-type: none"><li>• cytomegalovirus (CMV), and</li><li>• Epstein Barr virus (EBV).</li></ul>
How it is given	<ul style="list-style-type: none"><li>• Give once or twice a day at the same time each day</li><li>• Give with plenty of fluids</li><li>• Give with food to help more of the medication pass from your child's stomach into their bloodstream</li></ul>
Most common side effects	<ul style="list-style-type: none"><li>• Mild headache</li><li>• Lower platelets, which can cause bleeding</li><li>• Lower white blood cell counts, which can cause infection</li><li>• Lower red blood cell (hemoglobin) counts [hemoglobin provides energy to the body]</li><li>• Temporary or permanent kidney damage</li><li>• Upset stomach, vomiting (throwing up) or diarrhea (watery stools)</li></ul>

## Vitamins and supplements

Generic name	Multi-vitamin
Brand name	Once-A-Day®, Centrum®, AquaDEKs®, Poly-Vi-Sol®, Tri-Vi-Sol® (many other brands)
What it does	Helps to prevent low vitamin levels that can be caused by some medications or a diet low in vitamins and minerals
Most common side effects	<ul style="list-style-type: none"> <li>• Upset stomach</li> <li>• Nausea and vomiting</li> </ul>

Generic name	Calcium
Brand name	Oscal®, Tums® (calcium carbonate), Citracal® (calcium citrate), NeoCalGlucon® (calcium glubionate)
What it does	Helps to build strong bones and teeth
Most common side effects	<ul style="list-style-type: none"> <li>• Stomach pain</li> <li>• Constipation</li> <li>• Gas</li> <li>• Nausea and vomiting (throwing up)</li> </ul>

Generic name	Iron
Brand name	Femiron®, Ferretts®, Palafer® (ferrous fumarate), Ferate®, Fergon® (ferrous gluconate), Feosol®, Fer-In-Sol® (ferrous sulfate)
What it does	Helps to correct blood anemia (low red blood cell counts)
Most common side effects	<ul style="list-style-type: none"> <li>• Constipation (hard stools)</li> <li>• Dark-colored stools</li> <li>• Stomach pain and cramping</li> <li>• Nausea and vomiting</li> </ul>
Other important information	Iron supplements may turn your child's stools very dark. Do not be alarmed if this happens.

Generic name	Magnesium
Brand name	Mag-Ox <sup>®</sup> (magnesium oxide), Magonate <sup>®</sup> (magnesium gluconate), Milk of Magnesia <sup>®</sup> (magnesium hydroxide), magnesium sulfate
What it does	Increases low magnesium levels that can be caused by some medications or a diet low in vitamins and minerals
Most common side effects	<ul style="list-style-type: none"> <li>• Stomach upset</li> <li>• Cramping</li> <li>• Diarrhea (watery stools)</li> </ul>

Generic name	Potassium
Brand name	K-Effervescent <sup>®</sup> (potassium bicarbonate), Klor-Con <sup>®</sup> (potassium chloride), Phos-K <sup>®</sup> (potassium gluconate, potassium phosphate)
What it does	Increases low potassium levels that can be caused by some medications or a diet low in vitamins and minerals
Most common side effects	<ul style="list-style-type: none"> <li>• Stomach pain</li> <li>• Diarrhea</li> <li>• Gas</li> <li>• Nausea and vomiting (throwing up)</li> </ul>

## Other common medications

### Infection-control

Generic name	Intravenous immunoglobulin (IVIG)
Brand name	Many brand names
What it does	<ul style="list-style-type: none"> <li>• Gives your child immunoglobulins, which are important in fighting infection</li> <li>• Treats a special type of rejection called antibody-mediated rejection (see p. 72)</li> </ul>
How it is given	Injected into your child's vein; infusion lasts several hours
Most common side effects	<ul style="list-style-type: none"> <li>• Fever, chills, aches (during the infusion)</li> <li>• Blood pressure and heart rate (during the infusion)</li> <li>• Difficulty breathing (during the infusion)</li> <li>• Rash</li> </ul>

### Diuretics

Class	Loop diuretics ("water pills")
Brand (and generic) names	Lasix® (furosemide), Bumex®, Burinex® (bumetadine), Demadex® (torsemide)
What they do	<ul style="list-style-type: none"> <li>• Help to decrease body swelling by removing extra fluid from the body</li> <li>• Increases the amount you urinate</li> <li>• Can also lower blood pressure</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>• Increased amount of urine (pee)</li> <li>• Dizziness</li> <li>• Low blood pressure</li> <li>• Headache</li> <li>• Low electrolyte and mineral levels in the blood</li> <li>• Decreased hearing (rare)</li> <li>• Temporary or permanent damage to the kidney</li> </ul>

Class	Potassium-sparing diuretics
Brand (and generic) names	Aldactone® (spironolactone), Dyrenium® (triamterene)
What they do	<ul style="list-style-type: none"> <li>Removes extra fluid from the body by increasing urine output, but does not reduce potassium levels</li> <li>Can also lower blood pressure</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>Increased amount of urine (pee)</li> <li>Increased potassium levels in the blood</li> <li>Breast development in boys</li> <li>Diarrhea</li> <li>Nausea and vomiting</li> <li>Low blood pressure</li> </ul>
Class	Thiazide diuretics
Brand (and generic) names	HCTZ (hydrochlorothiazide), Diuril® (chlorothiazide)
What they do	<ul style="list-style-type: none"> <li>Removes extra fluid from the body by increasing urine output</li> <li>Can also lower blood pressure</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>Increased amount of urine (pee)</li> <li>Dizziness</li> <li>Low blood pressure</li> <li>Low electrolyte and mineral levels in the blood</li> </ul>
Class	Thiazide-like diuretics
Brand (and generic) name	Zaroxolyn® (metolazone)
What it does	<ul style="list-style-type: none"> <li>Removes extra fluid from the body by increasing urine output</li> <li>Can also lower blood pressure</li> </ul>
Most common side effects	<ul style="list-style-type: none"> <li>Increased amount of urine (pee)</li> <li>Dizziness</li> <li>Low blood pressure</li> <li>Low vitamin and electrolyte levels in the blood</li> </ul>



## Anti-hypertensives (blood pressure medications)

Class	Angiotensin converting enzyme (ACE)-inhibitors
Brand (and generic) names	Lotensin® (benazepril), Vasotec® (enalapril), Prinivil®, Zestril® (lisinopril), Capoten® (captopril), Monopril® (fosinopril), Accupril® (quinapril), Altace® (ramipril)
What they do	Lower blood pressure and treat symptoms of heart failure
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Low blood pressure</li> <li>• Cough</li> <li>• Increased potassium levels in the blood</li> <li>• Face, tongue or neck swelling</li> <li>• Risk of malformations in an unborn fetus (teenage girls should use precautions to prevent pregnancy)</li> </ul>
Other important information	<p>Call your doctor if your child develops:</p> <ul style="list-style-type: none"> <li>• face, tongue or neck swelling, or</li> <li>• an irritating cough that does not go away.</li> </ul>

Class	Angiotensin receptor blockers (ARBs)
Brand (and generic) names	Cozaar® (losartan), Atacand® (candesartan), Diovan® (valsartan), Benicar®, Olmetec® (olmesartan)
What they do	Lower blood pressure and treat symptoms of heart failure
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Low blood pressure</li> <li>• Increased potassium levels in the blood</li> </ul>
Other important information	Avoid diets high in potassium (salts, bananas, tomatoes, potatoes, nuts and fruit juices)

Class	Dihydropyridine calcium channel blockers (CCBs)
Brand (and generic) names	Norvasc® (amlodipine), Procardia® (nifedipine), Plendil® (felodipine), Nimotop® (nimodipine), DynaCirc® (isradipine)
What they do	Lower blood pressure
Most common side effects	<ul style="list-style-type: none"> <li>• Lower leg swelling</li> <li>• Dizziness</li> <li>• Tiredness</li> <li>• Low blood pressure</li> <li>• Anxiety</li> </ul>

Class	Non-dihydropyridine calcium channel blockers (CCBs)
Brand (and generic) names	Cardizem® (diltiazem), Verelan® (verapamil)
What they do	Lower blood pressure and may help regulate abnormal heart rhythms
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Headache</li> <li>• Low blood pressure</li> <li>• Lower leg swelling</li> <li>• Abnormal heart beats (extra beats or skipped beats)</li> <li>• NOTE: will increase tacrolimus levels</li> </ul>

Class	Vasodilators
Brand (and generic) name	Apresoline® (hydralazine)
What they do	Lower blood pressure and treat symptoms of heart failure
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Low blood pressure</li> <li>• Increased heart rate</li> <li>• Leg swelling</li> <li>• Flushing</li> <li>• Mood changes</li> </ul>

Brand (and generic) name	Catapres® (clonidine)
What it does	Lowers blood pressure and can help attention disorders
How it is given	By mouth or as a patch you wear on your skin
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Low blood pressure</li> <li>• Abnormal heart beats</li> <li>• Mood changes</li> <li>• Skin irritation where the patch is applied</li> <li>• Nausea and vomiting</li> </ul>
Class	Beta-Adrenergic Blocking Agent (beta-blockers)
Brand (and generic) names	Tenormin® (atenolol), Toprol®, Lopressor®, Betaloc® (metoprolol), Trandate® (labetalol), Inderal® (propranolol), Coreg® (carvedilol), Betapace® (sotalol), Corgard® (nadolol)
What they do	Lower blood pressure and help control abnormal heart beats
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Low blood pressure</li> <li>• Slow heart beat</li> <li>• Lower leg swelling</li> <li>• Mood changes</li> <li>• Fatigue</li> <li>• Blurred vision</li> </ul>

## Statins (cholesterol and lipid-lowering medications)

Class	HMG-CoA reductase inhibitors “statins”
Brand (and generic) names	Lipitor® (atorvastatin), Zocor® (simvastatin), Lescol® (fluvastatin), Mevacor® (lovastatin), Pravachol® (pravastatin)
What it does	<ul style="list-style-type: none"> <li>Decreases the amount of bad cholesterol and lipids in the blood</li> <li>Can also help prevent and slow down the progress of cardiac allograft vasculopathy (see p. 74)</li> </ul>
How it is given	By mouth, as a liquid or pill
Most common side effects	<ul style="list-style-type: none"> <li>Abdominal (belly) discomfort</li> <li>Increases in liver function tests</li> <li>Muscle pain and fatigue</li> </ul>
Other important information	Call your doctor if your child develops any severe muscle pain or if your child’s urine becomes dark brown.

## Anti-arrhythmics (medications to control heart rhythm)

Class	Anti-arrhythmics
Brand (and generic) names	Lanoxin® (digoxin), Pacerone®, Cordarone® (amiodarone), Rythmol® (mexiletine, propafenone), Tambocor® (flecainide), Tikosyn® (dofetilide)
How it is given	By mouth, as a liquid or a pill; sometimes in the vein (IV)
What it does	Treats abnormal heart rhythms
Most common side effects	<ul style="list-style-type: none"> <li>Dizziness</li> <li>Abnormal heart rhythm, including slow heart rate</li> <li>Low blood pressure</li> <li>Nausea and vomiting</li> <li>Blue/gray skin appearance (amiodarone)</li> <li>Abnormal liver function (amiodarone)</li> <li>Lung scarring (amiodarone)</li> <li>Abnormal thyroid function (amiodarone)</li> <li>Blurred or yellow/green vision (digoxin)</li> </ul>

## Anti-ulcer medications

Class	Proton pump inhibitors (PPIs)
Brand (and generic) names	Nexium® (esomeprazole), Losec®, Prilosec® (omeprazole), Prevacid® (lansoprazole), Pantoloc®, Protonix® (pantoprazole)
What it does	Prevent and treat heartburn, indigestion and stomach ulcers
How it is given	By mouth, as a liquid or a pill
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Diarrhea</li> <li>• Nausea and vomiting</li> </ul>

Class	Histamine antagonists
Brand (and generic) names	Zantac® (ranitidine), Pepcid® (famotidine), Axid® (nizatidine)
What they do	Prevent and treat heartburn, indigestion and stomach ulcers
How it is given	By mouth, as a liquid or a pill
Most common side effects	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Nausea and vomiting</li> <li>• Low platelet counts, which can cause bleeding</li> <li>• Abnormal heart beats</li> <li>• Mood changes</li> </ul>

Brand (and generic) names	Carafate® (sucralfate), Mylicon®, Gas-X® (simethicone)
What it does	<ul style="list-style-type: none"> <li>• Coats the throat and stomach to treat and prevent ulcers</li> <li>• Simethicone helps to control gas.</li> </ul>
How it is given	By mouth as a liquid or a pill
Most common side effects	<ul style="list-style-type: none"> <li>• Dry mouth</li> <li>• Stomach pain</li> <li>• Constipation</li> </ul>

## Anti-platelet medications

Generic name	Acetylsalicylic acid (ASA)
Brand name	Aspirin®
What it does	Thins the blood and prevents blood clots
Most common side effects	<ul style="list-style-type: none"> <li>• Easy bleeding</li> <li>• Easy bruising</li> <li>• Stomach upset</li> </ul>

Generic name	Dipyridamole
Brand name	Persantine®
What it does	Prevents blood from clotting
How it is given	By mouth, as a liquid or a pill, sometimes in the vein (IV)
Most common side effects	<ul style="list-style-type: none"> <li>• Easy bleeding</li> <li>• Easy bruising</li> </ul>

## Medications to prevent and treat blood clots

Generic name	Enoxaparin
Brand name	Lovenox®
What it does	Prevents and treats blood clots
How it is given	Given as a subcutaneous injection (a 'needle' just below the skin) once or twice a day
Most common side effects	<ul style="list-style-type: none"> <li>• Easy bleeding</li> <li>• Easy bruising</li> </ul>

Generic name	Warfarin
Brand name	Coumadin®
What it does	Prevents and treats blood clots.
Most common side effects	<ul style="list-style-type: none"> <li>• Easy bleeding</li> <li>• Easy bruising</li> </ul>

## Immunizations

### When will my child get their immunizations after transplant?

It is very important that your child get their immunizations (vaccines or “shots”) after a heart transplant to prevent infection.

Children with heart transplants can usually start or continue their routine vaccines four to six months after their transplant. It is best to wait until then because the vaccines might not work properly if your child receives them soon after the transplant, when their immune system is much weaker.

Every child’s situation is unique, however, and some children may need to wait more than six months after transplant before they get their shots. The transplant team will work with your pediatrician or family doctor to make sure your child is immunized properly and tell you the best time to start or continue your child’s vaccines.

#### Different vaccine doses or schedules

Your child may need different doses or schedules of some vaccines depending on their health after their transplant. Some school and community vaccination programs may not be able to provide a different vaccine dose. In this case, your family doctor or pediatrician will need to give these to you instead. Talk to your transplant team about what your child needs.

#### Live vaccines

Your child **should not have** “live vaccines” after transplant. A live vaccine poses the risk that your child will get the illness that the vaccine is supposed to prevent.

Common live vaccines are:

- chickenpox (varicella),
- rotavirus,
- measles/mumps/rubella (MMR), and
- influenza drops into the nose (influenza nasal mist).

Other family members and your child’s classmates can safely get the chickenpox, rotavirus and MMR vaccines. Neither the patient nor the family members should receive the influenza nasal mist, the killed version (injection form) is recommended.

You can read more about chickenpox and other common infections in the infection section of this book.

#### Flu shots

Most transplant teams recommend influenza vaccine, also called the “flu shot,” for transplant patients and their families every year. After heart transplant, children and household members should get the injectable (needle) flu vaccine and not the nasal spray.

#### Vaccines and travel

Traveling away from home may mean your child needs extra immunizations. It is best to get specific advice about this from the transplant team or a travel clinic.

## Rejection

Rejection is the immune system's normal reaction to something it thinks is the enemy. Your child's immune system works by protecting their body from attack by foreign things such as germs (bacteria or viruses) and cancer cells. This keeps your child healthy.

Your child's immune system will try to reject their new heart because it recognizes that it is different from the rest of your child's body. Your child will be taking immunosuppressant medications (see p. 39) for the rest of their life to prevent rejection of their heart.

Different types of rejection are possible, including acute cellular rejection (caused by the white blood cells in your body) and antibody-mediated rejection (caused by proteins called antibodies that recognize "foreign" things in your body). Your transplant team will explain these to you.

### Can rejection happen anytime?

Yes it can, but it is most common during the first year after transplant. It will happen if your child misses medications, so it is very important to take medication as prescribed by your child's transplant team. Most of the time, rejection is treated by giving extra medication by mouth.

Many children have some rejection soon after a heart transplant, but rejection is less common after the first year. In time, as your child's body gets more used to the new heart, the signs of rejection are generally fewer or milder. As long as your child takes their immunosuppressant medications as instructed, rejection is much less likely.

### What are the common signs and symptoms of rejection?

Rejection symptoms can often be described as heart failure combined with the flu, but it is unlikely you will be the first to notice the signs of rejection in your child.

However, the following are some signs of rejection. Tell the transplant team immediately if you notice or if your child complains of:

- fever,
- fatigue,
- shortness of breath,
- stomach upset,
- irritability,
- palpitations (faster/irregular heart beat),
- dizziness,
- swelling or significant weight gain, and/or
- changes in your child's usual heart rate or blood pressure.

Most rejection events are mild and will be noticed by the transplant team before your child has any symptoms or visible signs.



## How can the transplant team identify rejection without any visible signs?

There are different types of rejection, and some can be difficult to diagnose. The transplant team will monitor your child for signs of rejection by doing certain tests regularly (see below).

The tests will depend on your child's age and risk factors for rejection. Different things can affect your child's risk of rejection. The heart transplant team will identify the risks for your child and explain them to you. The risk of rejection can change over time.

## How can I help to prevent rejection?

- Give your child's medications exactly as directed by the heart transplant team.
- Do not miss any doses of medications.
- Bring your child to all clinic appointments, follow-up tests and blood tests.
- Check with the heart transplant team before giving your child any over-the-counter medications, including herbal (natural) medications. These medications can sometimes interfere with the immunosuppressant medications.
- Check with the heart transplant team before giving medications prescribed by another doctor.
- Call the transplant team about any concerning changes in your child's health.

## What types of tests diagnose rejection?

One of the best tests to diagnose rejection in your child's new heart is a heart biopsy (see description below). This is also known as an endomyocardial biopsy, or EMB.

Sometimes other, less invasive, tests give us clues about rejection. These include echocardiograms (echos), electrocardiograms (ECGs), 24-hour Holter monitor testing and a blood test called BNP.

The results of these tests help the heart transplant team decide if there is any sign of rejection. Some centers will use these tests first before doing a biopsy.

### Heart biopsy

A heart biopsy can find signs of rejection even though your child does not experience any symptoms or show any outward (visible) signs. The heart biopsy is the most effective test for diagnosing rejection in a heart transplant patient and identifying the effectiveness of rejection treatment.

Biopsies are usually done in the cardiac catheterization lab ("cath lab"), though some are done in the echo lab under echocardiography guidance.

In the lab, a pathologist looks at a small sample of heart tissue under a microscope for signs of rejection. The results from this study are reported back as a number under the **heart biopsy grading scale**.

## Heart biopsy grading scale

Grade 0 (No acute rejection)	No features of acute rejection or cell damage on the biopsy tissue (heart tissue samples) There is no need to change your child's medications.
Grade 1 R (Focal, mild acute rejection)	A mild immune system response usually without much cell damage, often described to families as "no or mild rejection" At least one piece of the biopsy tissue is involved, but there is usually no need to change your child's medications.
Grade 2 R (Moderate acute rejection)	A greater immune system response, with more cell damage At least one piece of biopsy tissue is involved. Grade 2 R usually requires treatment, which can include: <ul style="list-style-type: none"> <li>• increasing your child's maintenance immunosuppressant medications,</li> <li>• switching to different maintenance immunosuppressant medications,</li> <li>• giving a steroid "bolus" over three days (by mouth or through an IV ), and/or</li> <li>• using stronger immunosuppressant medications.</li> </ul>
Grade 3 R (Diffuse, borderline severe acute rejection)	An even greater immune system response and inflammation usually within multiple pieces of biopsy tissue This means the cells of the child's heart are damaged. Swelling, hemorrhage (bleeding) and vasculitis (inflammation of blood vessels) can also be present. Usually a 3 R result requires your child be admitted to hospital, where they will receive steroids through an IV. Your child may also receive other anti-rejection medications if the rejection is not responding to the steroids or is causing your child to be unstable.

### *Antibody-mediated rejection*

Other features on a biopsy may lead the team to suspect or diagnose antibody-mediated rejection. Although rare, some children, before transplant, have antibodies in their blood that could attack the new heart. Heart tissue and blood are tested for the presence of these antibodies.

Antibody-mediated rejection is treated differently than cellular rejection. If your child has antibody-mediated rejection, the team will treat them with medications and procedures to reduce the production of antibodies or wash the antibodies from your child's system. If your child needs either of these treatments, your transplant team will explain them to you.

### *How often are heart biopsies done?*

Routine biopsies begin one to four weeks after transplant and will often be more frequent in the first year after transplant. Ask your transplant center for their biopsy schedule. Typically, biopsies become less frequent as time goes on, as long as your child does not have frequent episodes of rejection.

Some centers do biopsies less frequently, based on your child's health status. For example, infants sometimes have a heart biopsy only if other tests show there are signs of rejection. Your child might have additional biopsies if they are clinically unwell (show physical signs of being unwell) or if the team suspects rejection.

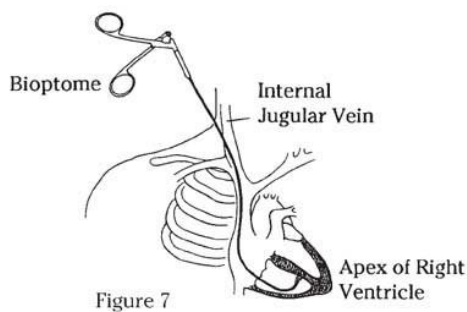
### *What happens during the biopsy?*

Most biopsies take about an hour and are done while your child is an outpatient (they do not stay in the hospital overnight). Your child usually has two to four hours of recovery time before they may go home.

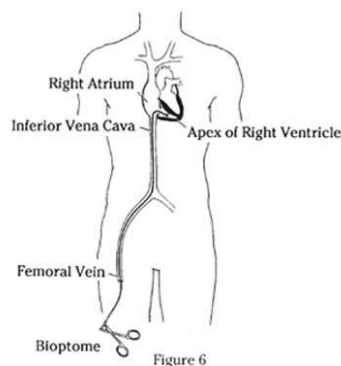
A heart biopsy will involve the following steps.

1. Your child is taken to the cardiac catheterization lab. They are given different levels of sedation or anesthesia (medicine to calm them or send them to sleep) based on your center's protocol (rules) and your child. You can discuss this with your transplant team.
2. A catheter, or tube, is threaded through a large vein in the neck or groin into the right chamber of the heart (see illustrations below). Through this tube, a wire with a pincher on the end is threaded into the heart, where it removes five to eight pieces of heart muscle, each no bigger than a pin point. Removing these pieces does not usually damage the heart.

Catheter inserted through the neck



Catheter inserted through the groin



3. After the tissue samples are taken, the doctor removes the catheter and applies pressure to control any potential bleeding. A Band-Aid® is then put on the insertion site.
4. The biopsy samples are sent to a pathologist (see p. 15), who examines them under a microscope and decides if the transplanted heart has any signs of rejection (see p. 70).

### *Possible complications of heart biopsy*

Complications from a heart biopsy are rare but can include:

- bruising or bleeding at the site where the catheter was inserted into the body,
- damage to the blood vessel used for the biopsy or to nearby nerves,
- damage to a valve in the heart,
- abnormal rhythms (heart beats), and/or
- perforation (tearing) of the heart, with collection of blood around the heart.

## **Transplant cardiac allograft vasculopathy (CAV)**

One type of rejection is cardiac allograft vasculopathy (CAV). This happens when the coronary arteries (small blood vessels that carry blood) thicken and narrow, making it harder for blood to get to the heart. Parts of the heart muscle die when they do not get enough oxygen.

This problem can happen at any time after transplant, but the exact cause is not known. It is typically a long-term complication and continues to be the major reason people eventually die or need another heart transplant.

### **How is CAV diagnosed?**

CAV is often difficult to diagnose. Adult patients with blocked coronary arteries have chest pain, but this often does not happen to patients after transplant because the heart does not have any nerve signals.

There are, however, other signs or symptoms that may make your transplant team wonder if your child has developed CAV. A number of tests, described below, can give some clues. (Remember every transplant program has its own standards for routine testing. Your transplant team will explain their standards to you.)

### *Coronary angiography*

Most children will have a coronary angiography to look at the size and shape of their coronary arteries at various times after transplant. This involves injecting a dye into the heart through cardiac catheterization (see p. 73) to make the arteries easier to see. This test is good at looking for bigger coronary vessels, but it does not always show changes in the smaller blood vessels.

### *Intravascular ultrasonography (IVUS)*

In some centers and in bigger children, an ultrasound probe going through the blood vessels in the leg can look at the coronary arteries. This technique can sometimes detect changes in the blood vessels earlier than coronary angiography.

### *Exercise testing (stress test)*

Children may have some form of exercise testing after transplant. This usually requires the child to ride a bike or walk or run on a treadmill. While the child exercises, their heart is connected to an ECG monitor to monitor their heart rate and rhythm. Sometimes your child might also have a breathing test to see how well they use oxygen during exercise.

If certain changes are picked up by the ECG during the exercise test, they may draw attention to the possibility of CAV and prompt the transplant team to arrange more tests.

### *Non-invasive studies*

Other screening tests that may be done at your center include exercise echocardiography, dobutamine stress echocardiography or stress MIBI.

These studies look for changes in how the heart works or how the walls of the heart move. They can help the transplant team decide if enough blood is getting to the heart muscle during exercise.

### **Can anything be done to prevent CAV?**

CAV can happen at any time after transplant, even into adulthood. In some cases, nothing can be done to stop CAV from developing.

However, routines and habits that helpful include:

- regular exercise,
- following a healthy diet,
- taking medication regularly and not missing any doses,
- maintaining a normal body weight,
- going for regular tests for high blood pressure, high cholesterol, and diabetes (high blood sugar), and treating them if they happen, and
- not smoking.

### **How is CAV treated?**

At the moment, despite efforts by many researchers, there is no cure for CAV. If your child develops CAV, there are a number of medications that will be started to:

- try and slow down the narrowing in the coronary arteries, and/or
- prevent blood clots from forming in the small coronary arteries.

In some cases, your child may have surgery to open up the blocked arteries. Your child will be closely monitored and in more severe cases may need to limit their activity. In very severe cases, your child may need another heart transplant.

## **Infections and diseases**

Infections are a concern because of the immunosuppressant medications your child is taking to prevent rejection.

Your child will get normal childhood infections (runny noses and coughs, ear infections, sore throats, vomiting, and diarrhea) and they will usually get better. In general, you can take care of these infections as you would for a child who has not had a heart transplant. If you have any concerns, see your family doctor or pediatrician.

Some infections are more serious in a child who is on immunosuppressant medications after a heart transplant. Your child's transplant team will teach you about these infections after your child's surgery. Your child's blood tests will check for some of these infections a few times every year.

## How do I help prevent my child from getting infections?

- Practice good hand-washing for everyone who lives at home. Hand-washing is especially important before preparing food and after diaper changes or going to the bathroom.
- Ask friends and relatives who are sick to avoid visiting until they are better.
- Wash hands well after contact with animal body waste (for example after cleaning up after a family pet).
- **If you have been told to do so**, tell the heart transplant team if your child is in contact with someone who has chickenpox. We will explain how and when to do this.
- Maintain general wellbeing by getting enough rest, eating healthy food, drinking enough fluids, and keeping active.

## What signs of infection should I watch for?

Contact your pediatrician or family doctor if your child is sick with any of these signs or symptoms:

- fever,
- runny nose and cough,
- sore throat or sore ears,
- pains in the stomach,
- vomiting,
- diarrhea,
- feeling of burning or pain when peeing,
- sores on the lips and around the mouth, and/or
- rashes.

As in all children, your child will likely get many of the colds and flus caused by viruses “going around” every year. We expect that your child will recover well from these infections.

## Serious viral infections

Some kinds of viral infections may put children with heart transplants at risk. These include:

- chickenpox (varicella),
- herpes simplex virus (HSV),
- cytomegalovirus (CMV), and
- Epstein-Barr virus (EBV).

If your child gets one of these viruses, they will likely be monitored more closely and they may be treated for them.

### Chickenpox (varicella)

Chickenpox is a disease caused by the varicella virus. People with chickenpox develop an itchy rash that looks like insect bites at first before developing into fluid-filled blisters that may break open and crust over.

Chickenpox can also cause fevers, headache, abdominal (belly) pain, muscle aches and a general feeling of “unwellness” or irritability.

Chickenpox used to be very common, with most people getting the disease in childhood. A vaccine has made chickenpox much less common in many countries, including the United States and Canada, but it is still possible for children in these countries to catch the disease.

A child with a heart transplant is at risk for getting chickenpox if they did not have the infection before their surgery or have not received the varicella vaccine. A child has a blood test before they are listed for heart transplant to see if they are protected against chickenpox. If they are, the blood test will show antibodies in the blood.

*What happens if my child is at risk for chickenpox?*

If your child is not protected from chickenpox through a previous infection or a vaccine, you will need to make sure that you instruct relatives, friends, teachers, and caregivers to tell you if your child has been exposed to chickenpox while in their care.

You will also need to avoid contact with people who have shingles. This is a painful rash that is also caused by the varicella virus. Contact with someone with shingles can cause chickenpox in a child.

Being exposed to chicken pox is not an emergency. There are normally a few days before the virus takes hold. During this time, your child's doctors can arrange for your child to get medication if they need it (see information below). You can contact your heart transplant team during regular working hours to discuss the exposure.

*What medications may my child get if they were exposed to chickenpox or shingles?*

If your child is exposed to someone with chickenpox or shingles, they may need an infusion of varicella antibodies to help prevent them from developing chickenpox. This infusion (medication through a vein) must be given within four days of your child's exposure to chickenpox to have the best chance of helping. Note this medication is not readily available in all areas.

Some programs recommend giving an antiviral medication to reduce the potential severity of the disease in certain patients who are exposed to chickenpox or shingles.

Even if a child receives medications, it is still possible they may catch the virus. Chickenpox can develop between **10 and 21 days after exposure to the disease**.

*What if my child develops chickenpox after being exposed to it?*

If your child develops spots you think may be chickenpox, they will need to see the family doctor or pediatrician and inform the heart transplant team. Your child may need to receive the antiviral medication acyclovir (see p. 52). If there are signs that the chickenpox rash is quite severe or the virus appears to be affecting other organs, your child may need treatment in hospital.

*If my child has chickenpox after transplant, will their symptoms be more severe?*

In general, even in a transplant patient, chickenpox usually causes the same signs and symptoms as it does in other children: mostly fever and a skin rash. Rarely, chickenpox can affect other body organs and potentially make a patient very sick.

*Can my child have the chickenpox vaccine after their heart transplant?*

Health experts review and update vaccine recommendations every year. In 2018, the answer is it is **not recommended**. The chickenpox (varicella) vaccine is a live vaccine, meaning it could actually give your child chickenpox instead of protecting them from it. If this recommendation changes over time, or if a new vaccine option becomes available, your transplant team will discuss it with you.

*Can my other children get the chickenpox vaccine?*

It is safe for brothers and sisters to get the chickenpox vaccine. Adult family members who have not had chickenpox may also want to discuss vaccination with their family doctor.

**Herpes simplex virus (HSV)**

Herpes simplex virus types 1 and 2 are a family of viruses that can cause blisters and sores in different areas of the body.

- Herpes simplex virus type 1 (HSV-1) generally causes cold sores in the mouth or on the lips. It can be passed from one person to another through saliva or sores on the skin of an infected individual.
- Herpes simplex virus type 2 (HSV-2) is linked with genital sores. It is usually passed during sexual contact with an infected individual.

Children who have had a heart transplant can acquire both types of herpes virus, but cold sores due to HSV-1 are more common. The sores may be painful and filled with fluid. In more serious cases, they can be linked with symptoms such as fatigue, fever, or body aches.

*How can HSV be treated?*

There is no cure for HSV, but treatment can relieve HSV symptoms. Painful cold sores can be treated with a topical ointment (a lotion or gel applied directly to the sores) or, in more severe cases, a medicine called acyclovir (see p. 52).

If children experience a lot of pain from the cold sores, and the pain affects their ability to eat and drink normally, they may need further treatment in hospital.

**Cytomegalovirus (CMV)**

Cytomegalovirus (CMV) is another member of the herpes virus family. Like Epstein-Barr virus (see below), it is very common; between 50 and 90 percent of adults have been infected with CMV.

Usually, CMV infection causes no symptoms in healthy children and adults. However, even then, CMV can stay in the body for a very long time after the initial infection.

Due to the effects of your child's immunosuppressants, CMV is an important cause of disease after heart transplant. CMV that might already be present in your child (without any symptoms) may become active or CMV may be passed to your child as a new infection through the transplanted heart or in other ways.

CMV infection after transplant may cause a wide range of symptoms, including:

- fever,
- joint pain,
- reduced white blood cell counts,
- pneumonia, and/or
- gastritis (severe stomach upset).

Because of the wide variety of symptoms, this virus must be considered as a possible cause for any unexplained infection in someone who receives a transplant.



### *How is CMV diagnosed?*

CMV is most commonly diagnosed through blood tests that can detect even very tiny quantities of CMV in the blood. Occasionally, blood tests may be “negative” (no CMV is found) if the body has limited the infection to one region of the body. In these cases, the transplant team may need to order tests of specific tissue (such as an intestinal biopsy) to confirm a diagnosis of CMV.

### *How is CMV treated?*

CMV is treated differently before and after symptoms appear.

To prevent symptoms, CMV is often treated for several months after transplant surgery with:

- immunoglobulins through an IV, and
- anti-infection medications such as gancyclovir (see p. 54) or valgancyclovir (see p. 58).

If your child already has symptoms of CMV, they usually need higher doses of anti-infection medications over a specific time.

### **Epstein-Barr virus (EBV)**

Epstein-Barr virus (EBV) is a member of the herpes virus family. It is very common, and most adults in the United States have been exposed to it by the time they turn 40.

In most people, EBV causes a viral illness that is either asymptomatic (has no symptoms) or mild. At most, the infected person may have a sore throat or flu-like symptoms. EBV also causes mononucleosis or “mono” in teens and young adults. Once a person has an EBV infection, the virus stays in their body for the rest of their life, although usually with no problems.

For transplant patients, EBV infection increases the chance of developing post-transplant lymphoproliferative disorder (PTLD) (see below), a condition that can lead to cancer. This can occur after a new infection or if a dormant virus (one that has remained in the body after a previous infection) becomes active again.

The link between EBV and PTLD means that transplant doctors often check their patients’ EBV status over time, usually through blood tests. The tests look for the virus itself or check if the body is making antibodies to EBV (a sign of a new or previous EBV infection depending on the type of antibody detected).

### *How is EBV treated?*

Treatment of EBV depends on the results of the tests.

- A patient does not need treatment if there are no signs of EBV or EBV antibodies in their blood.
- If there are antibodies but no EBV, a patient is usually monitored over time.
- If there is evidence of EBV in the patient’s blood, transplant teams may sometimes lower the dose of immunosuppressants to allow the body to clear the virus on its own.
- Drugs to treat EBV are available, but often they have side effects or are not effective.

## Post-transplant lymphoproliferative disorder (PTLD)

Post-transplant lymphoproliferative disorder (PTLD) is a complication occurring in about 10-15 percent of heart transplant patients.

PTLD is usually linked with a virus that occurs after transplant. The virus can make a person's lymph glands larger. A normal immune system can get rid of these cells, but in someone with a transplant, immunosuppressants prevent the immune system from clearing these cells. Over time, there is a risk that the enlarged lymph glands will turn into lymphoma (a malignant tumor, or cancer).

PTLD can cause flu-like symptoms, pneumonia, vomiting, and/or diarrhea. Many non-PTLD illnesses cause similar symptoms. If your child develops these symptoms, the transplant team will usually monitor them and decide if more tests are needed to check for PTLD.

*What type of viral infections can lead to PTLD?*

The most common virus associated with PTLD is Epstein Barr virus (EBV) (see above).

Most transplant teams will routinely check the amount of EBV or other viruses in the blood to see if there has been an infection. If the test shows a new infection or the return of an old one, the team may reduce the patient's dose of immunosuppressant medications for a short time to allow the immune system clear the virus on its own.

*How is PTLD diagnosed?*

The diagnosis of PTLD is often made in several steps. If the transplant team suspects PTLD after reviewing a patient's symptoms and doing a physical exam, they may order other studies, such as x-rays, CT scans, or PET scans, to look for other evidence. If enlarged lymph nodes are seen in these scans or x-rays, a doctor will take a biopsy of the lymph nodes to make a diagnosis.

If PTLD is diagnosed, the transplant team will usually decrease the immunosuppressant medications and may begin giving anti-viral medications.

Some children who have a new PTLD diagnosis need to be assessed by an oncology team and may have chemotherapy.

Fortunately, when it is identified in time, PTLD can be treated successfully. However, children who are treated will need to have follow-up appointments for the rest of their lives to check for the return or relapse of PTLD.

## Kidney issues

Immediately after a heart transplant, the kidneys can often take a while to start working properly. Some patients even need dialysis for the first few days. Usually, however, their kidney function returns to normal.

Some transplant medications have the unfortunate side effect of causing kidney damage, usually over many years. This may create the need for a special diet, more medications, or, in rare cases, dialysis or a kidney transplant. Other medications can make the kidneys work harder. The transplant team will give you

recommendations with any new medications for your child.

Because of the concern about kidney function, it is very important that your child drink enough water after a heart transplant, especially in the heat. Drinking enough water helps the kidneys remove waste through urine.

## **Hypertension**

Hypertension (high blood pressure) is a common issue after a heart transplant. It is important to treat high blood pressure promptly to prevent further kidney disease and heart disease.

Many children need medication to lower high blood pressure soon after a transplant, but they can often cut down or stop taking it after some time. However, high blood pressure can come back later in life. This is often related to the patient's immunosuppressant medications and their effect on the kidneys.

# **Following a healthy lifestyle after transplant**

## **Physical activity and exercise**

Exercise and physical activities are part of a heart-healthy lifestyle and we encourage regular activity in all transplant patients.

Regular exercise is crucial for keeping your child strong and healthy, as it:

- helps them develop socially,
- develops their motor skills (such as hand-eye co-ordination and movement), and
- boosts their overall fitness.

We encourage you to enroll your younger child in developmental play groups and community activities. Older children can take part in recreational and organized sports and join school or community teams. Encourage your child to try new activities so they can find things they really enjoy.

## **Exercise training**

For the first several weeks (your transplant team will give you the exact weeks) after transplant, your child should avoid strenuous activities, such as high-intensity aerobics, lifting or climbing.

After this time, your child can take part in exercise training. A physical therapist (see p. 16) can help your child regain the muscle strength they lost while waiting for and recovering from surgery. This therapist can also help increase your child's endurance (their ability to exercise for longer without increasing their heart rate).

Exercise training after a transplant is not geared at reaching a certain heart rate as a measure of exercise intensity. Instead, your child's transplant team will focus on a range of good exercise practices and checks, for example by:

- having your child work towards an extended warm-up and cool-down (see below),
- monitoring intensity using an RPE (rating of perceived exertion – how hard your child feels they are working), and
- teaching your child a range of stretching and ROM (heart rate, oxygen uptake and metabolic equivalents) exercises.

### **Exercising safely after transplant**

After transplant, your child should spend at 5-10 minutes warming up and cooling down before and after any physical activity. Their heart rate is now controlled by hormones (such as adrenaline) because the nerves connected to their heart were cut when their old heart was removed.

During exercise, the body produces adrenaline, but the new heart may take a few minutes to detect this. A warm-up period allows the heart to beat faster in response to increased levels of adrenaline. A cool-down period allows the heart rate to slow down and the body to return to normal gradually.

During exercise, your child's heart rate may be limited by their medications or by the ability of adrenaline to stimulate it. The best way to work out the intensity of the exercise is to assess your child's breathing. For exercise to be effective and safe, a transplant patient should be breathing faster than normal but should not be gasping for air or even short of breath.

Your child should only exercise and do physical activity at a level they can tolerate. Neither your child nor their coaches should push your child beyond their abilities. Remember, too, that your child must take plenty of fluids during exercise to stay hydrated and take breaks when needed.

### **Taking part in organized sports**

Most children who receive a heart transplant return to a relatively normal and age-appropriate lifestyle after six months. They are able to take part in team sports and other active pursuits if they wish.

Children who want to take part in *competitive* sports, however, should talk to their transplant team, especially their cardiologist. The team may recommend further tests, including exercise testing (see below). Your child will also need to follow a number of post-transplant exercise recommendations.

In general, a child with a heart transplant can take part in all competitive sports that are suitable for their exercise ability if:

- their tolerance for exercise is normal for their age, and
- there is no evidence of CAV (narrowing of the heart's blood vessels, see p. 74).

The special issues involved with managing transplant patients make it very important you consult with your child's transplant team, especially their cardiologist, before deciding if your child can start, or continue, competitive sports after surgery. Your transplant team can explain things to you.

### **Exercise testing**

If your child is aged six or older, they will often have an exercise stress test in the first six to 12 months after their transplant. If they are aged five or under, exercise testing will start around the age of six.

An exercise test involves having the patient walk on a treadmill or ride a stationary (not moving) bicycle for as long as they are able while they are connected to machines and devices to monitor their heart rate and rhythm and their blood pressure.

The results of the stress test can help the transplant team to monitor for CAV (see p. 74) and assess your child's physical fitness, especially for taking part in competitive sports. If there are problems or concerns during the stress test, the transplant team may follow up with other tests.

## **Heart-healthy eating**

### **Eating well after transplant**

After a heart transplant, your child's appetite will be different than before. They may have more energy to eat and should tolerate meals better.

The dietitian on your child's transplant team will assess and monitor your child to develop a nutritional plan. Each child's plan is different, but, in general, children should learn to choose healthy foods and appropriate portions and minimize "junk" foods. In addition, food should be cooked and stored properly to prevent food-borne illness.

### **Supports to gain weight and feed by mouth**

For children who are very underweight before their heart transplant, the first 12 to 18 months after transplant are the most important time for them to "catch up" in weight and height.

Underweight infants and very young children often need fortified (strengthened) breast milk or formula with extra calories. Older children may need calorie-rich foods or extra tube feedings. As these children develop normally, they will no longer need extra calories. Their nutrition plans will be adjusted to reflect a more age-appropriate food intake and feeding pattern.

Some young children who were very sick before transplant might find it difficult to take food by mouth. If this applies to your child, a feeding therapist or, in some hospitals, an occupational therapist can assess them and recommend treatments to improve their feeding and swallowing so they can eat safely and efficiently. Often the dietitian and occupational therapist will work together to enhance your child's feeding, growth, and development.

### **Following a heart-healthy diet**

Following transplant, children should follow heart-healthy food guidelines. These include:

- eating fruits and vegetables,
- choosing whole grains, lean meats and alternatives, low-fat dairy products, and unsaturated oils, and
- limiting foods that are high in salt, sugar and saturated fat and low in nutrients.

Some immunosuppressant medications, especially steroids, can make children very hungry, increase their cholesterol levels, and cause them to gain weight. To reduce the risk of high cholesterol and excess weight gain, have healthy foods and snacks available for your child. Consider options such as fruit, chopped vegetables, low-fat yogurt, or milk and cereal. Your child's dietician can offer more advice.

### **Handling food safely**

Transplant patients are at higher risk for developing infections, including those that come from incorrectly prepared or stored food. As a result, it is important to make sure that the food your child eats is safe. You can reduce foodborne illness following four easy steps.

1. Clean
  - Wash your hands and all surfaces, utensils, and cutting boards:
    - before you prepare food, and
    - after touching pets, coughing or sneezing, changing diapers, touching the phone, touching garbage, or using the washroom.
2. Chill
  - Refrigerate or freeze all perishable food within two hours of buying it.
  - Set your fridge to 4°C (40°F).
  - Marinate and defrost food in the fridge, not on the kitchen counter top.
3. Separate
  - Keep raw foods and their juices separate from other food in the fridge and when preparing them.
4. Cook
  - Use a food thermometer to tell if food is cooked properly.
  - Reheat leftovers to 74°C (165°F).

### **Drinking enough fluids**

Drinking plenty of fluids, especially water, is also very important after your child's heart transplant, especially to protect the kidneys. The heart transplant team will tell you how much water your child should drink every day to keep their kidneys healthy.

Remember, your child must avoid anything related to grapefruit. Grapefruit and grapefruit products raise the levels of tacrolimus, cyclosporine, or sirolimus in your child's blood (see pp. 44). This can lead to more side effects.

Your child needs to avoid all of the following:

- grapefruit juice or any juices that contain grapefruit,
- grapefruits or any fruits grown from them, such as pomelos and tangelos, and
- fruit salads or mixed fruit juices containing grapefruit or grapefruit juice.

Read the front and back labels of mixed fruit juices carefully to make sure they do not contain grapefruit.

Your child's dietitian will be happy to answer any questions or concerns you have about your child's nutrition, feeding, or growth.

## Your child's wellbeing and school performance

If you, your family, or a member of your child's school or transplant team expresses any concerns about your child's mood, behavior, or school performance, your child may be referred to a psychologist, psychiatrist or neurodevelopmental specialist.

A psychologist/psychiatrist is a professional who works with children and teens to understand how their brain works and how an illness can affect their behavior. They can also help young people deal with some of the stresses of living with end-stage heart disease and transplant.

A neurodevelopmental specialist is a professional who works with children and teens to assess and make recommendations for learning and school specific needs.

A child is usually referred if:

- your family or the transplant team are concerned about your child's development,
- your child is struggling at school (for example with reading, spelling, or math),
- there are concerns about your child's language skills, attention, or memory,
- there are changes in your child's thinking abilities or brain imaging scans,
- your child has missed a lot of school, and/or
- your family or the transplant team is concerned about anxiety, depression, or coping.

### Assessment for emotional support

If your child is being assessed for emotional support and therapy, they will be seen alone (if they are old enough) and with you. Depending on the child's age, they, or you, will be asked about how they have been feeling and about their mood, relationships, involvement in school, social and recreational activities, sleep, appetite, and any other worries or changes in their life.

The psychologist, psychiatrist or neurodevelopmental specialist may also ask your child, your family, or your child's teachers to fill out some questionnaires to find out how everyone thinks your child is doing.

Sometimes, the psychologist or psychiatrist may diagnose a specific difficulty such as depression or anxiety. It may then be helpful for your child to see a psychologist or a mental health therapist (or counselor) for a number of sessions. They can listen to your child, help them understand why they feel this way, and give ideas about things your child can do, or say, to help change how they feel. They may also discuss these ideas with you or with other important people in your child's life (such as their teacher) so everyone can help your child.

Sometimes medication might be recommended for older children and teens. Those in this age group may also need to see a psychiatrist or adolescent medicine doctor for assessment and monitoring.

## Assessment in relation to school performance

If your child is being assessed because of their school performance, the neurodevelopmental specialist will look at your child's thinking skills, academic performance, memory, language, visual processing, speed and dexterity, attention, and emotional control.

If there is any condition that could affect your child's education (such as a learning disability), the neurodevelopmental specialist will diagnose it and/or recommend different forms of treatment.

With your family's consent, the neuropsychologist can also talk to your child's school to co-ordinate learning and health needs and recommend educational supports that could help your child.

## Commonly asked questions

### How long will the new heart last?

It is not clear how long a new heart will function well in a child. Survival has improved greatly over the last 20 years, with most children have a good chance of surviving into adulthood. This depends on the age of your child when they have a transplant. In 2018:

- More than half (1/2) of infants survive with their transplanted heart until 22 years after their transplant.
- More than half (1/2) of children aged between 1 and 5 survive with their transplanted heart until 18 years after their transplant.
- More than half (1/2) of children aged between 6 and 10 survive with their transplanted heart until 14 years after their transplant.
- More than half (1/2) of children between 11 and 17 survive with their transplanted heart until 13 years after their transplant.

However, it is difficult to know exactly how long a transplanted heart will last. This uncertainty can be a source of stress for parents and older children.

There are many reasons a child can develop heart failure after a heart transplant. The most common ones include rejection (see p. 70) and transplant coronary artery vasculopathy (CAV) (see p. 74). Other reasons include non-specific allograft failure, which means the new heart fails to work properly without any clear reason why. This is a type of rejection that still needs to be better understood.

To give your child the best chance of success with a new heart, make sure:

- they take their medications as prescribed.
- they follow a heart-healthy lifestyle (see p. 81), and
- they keep all your follow up appointments at the transplant center.

But even if you and your child follow these recommendations, a new heart might still unexpectedly fail. If the reason for this is known, the heart transplant team will explain it to you.

In cases of heart failure, your child may need to be treated for rejection or put on heart failure or heart rhythm medications. They may even need to be assessed or relisted for another heart transplant. Your transplant team will explain these things if they apply to your child.



## **When can my child return to daily activities, including school?**

There is no specific time children are expected to stay home after their transplant; each child's situation is unique. Please talk to your transplant team about what is best for your child.

As your child recovers from their transplant operation and gains more energy, encourage them to take part in all normal family activities. Children can also play outside, go for walks, and see friends.

If relatives or friends are sick, it is best to ask them to visit once they are well. Other ways to keep your child healthy include regular hand-washing, which will help to prevent spread of infections. Children returning to school (or work if they are in their teens) might find it useful to carry hand sanitizer and anti-bacterial wipes with them to clean any work surfaces.

Before your child returns to school, talk to the school about the best way to continue class work. Your child's teacher may provide some work. In most cases, the school district will arrange for a tutor.

It is very important that your child's teachers (or co-workers) realize that a transplant patient is healthy and no longer ill when they receive their new heart. As such, they should treat your child as normally as possible. The transplant team will help with your child's return to school or work once your child is ready.

## **Does my child need a special skin care routine?**

Transplant patients generally don't need special skin care, unless they develop an unusual skin condition or rash (see below). Showering and bathing with regular soap is generally okay, but mild soap and lotion after bathing are recommended if the skin is dry.

A number of children will have dry skin or eczema after their transplant. This can be cared for by having regular baths with hydrating oil, using Vaseline® on damp skin and, if necessary, using cortisone cream from your family doctor or pediatrician. The eczema can sometimes be so severe that your child may need to see a dermatologist or take medications.

Immunosuppressants prescribed after transplant can increase the risk of certain viral skin conditions, such as warts or herpes. Teens who have had a transplant may also be at increased risk of acne, which is already common in teenagers, due to steroids.

## **Will medications affect my child's hair?**

If your child is on prednisone, their hair is likely to become dryer or coarser. Your child's hairdresser will probably suggest a good conditioner to help with this. Until your child's prednisone dosage is lowered, they should avoid chemical treatments like highlights, hair dye, permanents, and straightening. These can all make the hair more likely to break.

Medications may also cause more facial hair. You or your child can use a hair-removal cream, but be sure to follow the instructions carefully to avoid skin irritation. Teens may also try bleaching, waxing, or electrolysis.

## What type of dental care should my child have after transplant?

Regular dental care and check-ups are important for transplant patients.

- Right after transplant, your child's teeth and gums should continue to be cleaned every day. Preventative care is more important than ever.
- Tell your child's dentist that your child has had a transplant.
- Encourage your child or teen to tell you about any pain or discomfort.
  - Since your child's immune system is weaker after their transplant, problems such as abscesses or mouth pain can lead to or be signs of serious infection.
  - Some transplant medications can cause gum problems.

The American Heart Association currently recommends that most heart transplant patients only need antibiotics before dental procedures for six months after their heart transplant. Some children will need these for longer, usually due to leakiness of one of the heart valves. Ask your child's transplant team for the specific recommendations for your child.

## Can my child go out in the sun as usual?

Transplant patients are more likely to develop skin cancer, so it is extremely important that you protect your child's skin.

- Avoid the sun between 10 am and 2 pm; this is when ultraviolet rays are the strongest.
- Have your child wear protective clothing outdoors, including a hat.
- Encourage your child to sit or play in shaded areas.
- Apply sunscreen and lip balm daily to uncovered areas of your child's body.
- Remember to re-apply sunscreen every few hours—more often if your child is swimming or sweating—because it wears off.
- Use skin products with at least SPF 30.
- Check your child's skin for abnormal spots (irregular moles or growths) and report them to their doctor.

## What if my teen wants to get a tattoo or piercing?

**There are differences in what programs recommend about tattoos and piercings.** Please talk to your own transplant team to find out what they recommend for their own patients.

Programs that are open to tattoos and piercings have the following recommendations.

### Piercings

- Make sure that the site being pierced is cleaned very well and that the piercer uses only a new, sterile, stud (or other piercing ring).
- Follow the cleaning instructions from the piercer for the first four to six weeks.
- If the site turns red, is painful, or has any discharge, your child should see their doctor as soon as possible to check for any infection.

### Tattoos

- Make sure the tattoo artist uses a new, sterile, needle.
- If possible, ask the artist to use new (never opened) bottles of ink.
- Follow the instructions from the tattoo artist for keeping the site clean.
- If the site turns red, is painful, or has any discharge, your child should see their doctor as soon as possible.

to check for any infection.

## **Can my child have a pet?**

Most animals are safe from a transplant perspective. You can safely have a pet in your home if your family follows a few simple guidelines.

- Have your child wash their hands well after handling pets, cleaning cages or litter boxes, or picking up feces (stool or “poo”). Some transplant programs may prefer that patients do not clean litter boxes.
- Make sure you take your pet to the vet regularly and that your pet is up-to-date with all vaccinations.
- If you have any questions about a specific species, please talk with your transplant team.

## **Can my child travel?**

Your child can travel after transplant if they have been well, without medical complications. Please talk with your transplant team before you make any travel plans, especially if traveling abroad.

### **Tips for safe travel**

- Always carry your child’s medications with you. Never pack them in your checked-in or stowed luggage in case it gets lost.
- Keep medications in their original containers (bottles or pill packages) with the pharmacy labels on them.
- Consider buying travel health insurance if you are planning international travel. Check if it covers pre-existing conditions.
- Well before your trip, talk with your transplant team and a travel clinic about any vaccines your child needs for traveling abroad.
- Ask your transplant center for a letter about your child’s condition and how to contact the transplant team in case your child needs medical attention while away.
- Know the location of the nearest hospital at your destination and ask your transplant team if they can recommend doctors in the area.

## **My child still has trouble sleeping. Is this normal?**

Many children who have a heart operation have trouble sleeping and concentrating afterwards and may show signs of hyperactivity. This is also true of transplant children, who have been found to have more schooling and behavioral issues than healthy children. Help is available through psychological counseling and/or medication. Tell the heart transplant team if you have any concerns about your child’s sleep habits. They can help with recommendations.

## **My child has started wetting the bed at night. Why is this?**

Bedwetting is common after transplant surgery. It may be due to the trauma of being in hospital, but it can also result from urinary infections. Another reason for bedwetting is that the heart beats quickly, even during sleep. This means, even at night, the kidneys get a lot of blood and so produce more urine.

Helpful treatments for bedwetting can include behavioral training and/or medications. Your transplant team may ask your family doctor or pediatrician to manage this issue.

## Adolescence

Adolescence, or “the teenage years,” is challenging even for children without health problems. Children with a chronic illness can have even greater difficulties when they become teenagers. In addition, behaviors that are a “normal” or “expected” part of the teenage years can put heart transplant patients at risk for rejection or other medical problems.

The teen years are a struggle for most people, but they can be even more difficult if someone receives a transplant during this period. There might be delays in some of the normal teen milestones such as driving, exploring sexuality, and questioning or resisting family rules (or what some might call “rebellious”). Separation from their peers, isolation, and loss are all part of the teen transplant experience.

The heart transplant team is very aware of these challenges. When your child visits the team, they will assess your child and provide support and guidance to foster healthy teenage development, coping skills, and discipline to follow the treatment plan.

When your teen meets the transplant team, they will have a chance to discuss issues such as:

- their capacity to consent or assent to treatment,
- their home situation,
- education,
- their body image,
- any substance use,
- their history of following their treatment plan,
- how puberty is going,
- their sexual history,
- their mood, including any suicidal thoughts,
- their coping skills, and/or
- any questions about death and dying.

Not following medical treatment and recommendations is the leading cause of death in the teenage years. It is very important to maintain communication with your teen and get them preventative support if they need it.

## Transition from pediatric to adult care

As your child moves through the teen years, your transplant team will work with you and your child to ensure a smooth transition to an adult transplant team for future care.

Transition is the gradual, planned movement of teenagers and young adults with chronic (long-term) physical and medical conditions from a child-centered to an adult-centered healthcare system. While transition varies between transplant programs, it often begins between age 10 and 14 and finishes by age 18 to 24.

Planning for transition begins at an early age and focuses on helping patients become independent and confident young adults who can care for their chronic condition. Caregivers also receive support as their roles change with their child's evolving needs.

Transition planning involves good communication between the patient and family and the pediatric and adult transplant providers. The goal is to help patients develop the knowledge and skills they need to manage their own care and make good personal and medical decisions. This includes taking their medications as prescribed or following up with clinic and test appointments as recommended. During this time, the doctors and nurses will talk about different topics, from signs and symptoms of infection and rejection to insurance and pharmacy issues.

Successful transition planning helps to ensure coordinated care that is culturally sensitive, appropriate for your child's age and development, and family focused.

### Early transition (10-13 years)

- Healthcare providers raise the concept of transition with the family.
- Healthcare providers may begin to see the patient alone for part of the visit.
- Healthcare providers discuss medical health with patients and caregivers.
- Caregivers manage medical appointments and medication refills and oversee patients' taking of medications.

### Middle transition (15-17 years)

- Healthcare providers continue to see the patient alone for part of the visit.
- Patients receive a binder of information designed to teach them about their condition and prepare them for eventual transfer to an adult transplant program.
- Patients learn the names of their medications, doses, and schedule.
- Caregivers help patients manage their healthcare (for example by helping to remind them to take their medications).
- Patients and caregivers develop a calendar for appointments together.
- Patients and caregivers discuss their concerns, goals, and questions with the pediatric transplant team.

## **Late transition (18-23 years)**

- Healthcare providers continue to see the patient alone for part of the visit.
- Patients can explain their health history, current conditions, and importance of short- and long-term problems.
- Patients know their medications and are responsible for taking and ordering them.
- Patients make their own appointments and can explain their follow-up care plan.
- Patients understand their medical history and any problems (for example hypertension, acne, lack of kidney function).
- Patients know the contact information for their primary care provider, transplant team, social worker, insurance provider, and pharmacy.
- Caregivers prepare to be consulted by the child about health decisions.
- Patients choose a health care proxy, complete advance directives, and provide consent to transfer their information to the adult transplant program.
- The pediatric program schedules a transition visit about six months before the transfer of care to the adult program. The visit includes meeting the new team of providers and touring the facilities in the adult care center.
- If possible, the patient is connected with another person who has already transitioned to adult care.

## **Research**

### **Why do research in children?**

Many studies have been done to evaluate treatment in adult heart transplant patients, but more needs to be done in pediatric heart transplant patients. In addition, medications, devices and treatments are often not as well tested in children, especially children with heart transplants.

Most of the medications and treatments we will use in your child are not officially approved by Health Canada or the Food and Drug Administration (FDA) in the United States for use in children with heart transplants. However, they are used all over the world every day.

In sum, children are not little adults. We need to think about how a child's brain and body are developing, as well as the way a child's body handles medications and other treatments over time.

### **Why are children different than adults?**

Children are growing; they are changing and maturing all the time. For instance, when thinking about the right dose for a child, we look at their stage of growth.

An eight-month-old is completely different than an eight-year-old who, in turn, is completely different than an 18-year-old. So even among children, everyone is different. And at each of these stages of growth, they may need different doses of medicine, different sizes of devices, or different types of therapy.

Many medications are filtered out of the body and handled differently by a child's developing liver or kidneys. Because research has been so limited, we don't know how the medications will affect these organs in the long-term. We need to study them to find out.

## Why are clinical studies important?

They can help us:

- understand differences in children as they grow and develop,
- identify the best dose of medications to prevent rejection but reduce other long-term side effects,
- produce chewables, liquids, or tablets that are easier for children to take,
- find treatments for problems that occur only in children with heart transplants, and
- find treatments for new or existing diseases to improve the health of children in the future.

Past studies in heart transplant patients have helped us provide the current treatments given to your children.

## How can my family help?

Your family may be approached by the transplant team doctor, clinical research nurse, or another member of the heart transplant team to take part in one or more research projects. The team member will explain the project and answer any questions about the study.

All medical information collected in a research study remains confidential, and all information identifying your child, such as name or birth date, will be removed. There are very strict rules about research in children, and all studies, no matter how big or small, are approved by a research ethics board.

While your child may not directly benefit from the results of a research study, we believe the heart transplant research we are doing today will greatly benefit our patients of tomorrow.

Whether your child will take part will always be your decision. If you choose not to participate, your child will not receive different treatment. If you choose to participate in any of the studies, you have the right to withdraw at any point if you change your mind. This will not affect your child's treatment.



## Additional resources



Original artwork by  
Aaron, age 7





# Glossary

**Acute cellular rejection**

Activation of recipient's white blood cells (lymphocytes) to the donor heart

**Advance directive**

A legal document allowing older teens and adults to state their wishes about end-of-life care ahead of time

**Ambulatory blood pressure monitoring**

Monitoring a person's blood pressure at set intervals while they do everyday activities as part of their normal routine

**Anesthesiologist**

A doctor who specializes in giving sleep and pain medicine before an operation

**Antibodies**

Proteins in the body that fight "foreign" objects

**Antibody-mediated rejection**

Activation of antibodies to the donor heart

**Biopsy**

A test to take tiny samples of tissue and examine them under a microscope

**Bone mineral density test**

A test, usually involving a type of x-ray, to check the strength of bones

**B-type natriuretic peptide (BNP)**

A hormone measured in the blood that reaches high levels in cases of heart failure

**Cardiac allograft vasculopathy**

A gradual, long-term rejection of a transplanted heart causing blood vessels on the outside of the heart to narrow

**Cardiac catheterization**

A test using a thin tube to check the pressure in a person's heart and blood vessels

**Cardiologist**

A doctor who specializes in the heart

**Cardiomyopathy**

A condition of weak heart muscle

**Catheter**

A thin hollow tube

**Chemotherapy**

Literally, treatment with chemicals; usually refers to medications to treat cancer

**Cognitive difficulties**

Difficulties understanding, learning, remembering, or sharing information

**Compatible blood groups**

Blood groups enabling a transplant or blood transfusion from one person to another; the blood groups do not need to be exactly the same

**Congenital heart disease**

Heart issues that exist when a person is born

**Coronary angiography**

A test using dye and an x-ray machine to look at the size and shape of the coronary arteries at different times after transplant

**Creatinine**

A waste product removed by the kidneys before it is released in urine; high creatinine levels in the blood can be a sign that the kidneys are not working properly

**Cytomegalovirus**

A type of herpes virus that can cause fever, joint pains, pneumonia, severe stomach upset; and reduced white blood cells after transplant

**Developmental assessment**

A test to see how well a child is developing, for instance how well they can walk, speak, hear, engage with other people, and understand what is happening around them

**Developmental play**

Activities such as drawing or games aiming to develop social or cognitive skills

**Dexterity**

Having good control over the muscles of the hands and fingers (also known as fine motor skills)

**Echocardiogram (echo)**

A test using sound waves to check the size and shape of the heart and see how well it pumps blood

**Electrocardiogram (ECG or EKG)**

A test measuring the strength and frequency of a person's heart beat

**Endomyocardial biopsy (EMB)**

A type of heart biopsy

**Epstein-Barr virus**

A type of herpes virus that usually carries no or very mild symptoms but, in transplant patients can increase the chance of developing post-transplant lymphoproliferative disorder (PTLD)

**Glomerular filtration rate (GFR) test**

A test to see how well a person's kidneys filter waste and function

**Health care proxy**

A document allowing a patient to appoint someone to make healthcare decisions for them if they can no longer decide for themselves, for example if they become too ill

**Hepatologist**

A doctor who specializes in the liver

**Hypertension**

High blood pressure

**Immunosuppressant**

Medication intended to weaken the immune system so it will not reject a new heart

**Incision**

A cut or an opening made during surgery

**Inpatient**

A person staying in a hospital overnight for tests or treatment

**Interdisciplinary team**

A team including people with different disciplines or professions, for example, social workers, dietitians, doctors, nurses, and psychologists

**Magnetic resonance imaging (MRI)**

A type of x-ray showing detailed pictures of the inside structures of the body, such as the chambers of the heart and blood vessels

**Nephrologist**

A doctor who specializes in the kidneys

**Neurologist**

A doctor who specializes in the nervous system (the brain, spinal cord, and nerves around the body)

**Neuropsychologist**

A person trained to work with children and teens to understand how the brain works and how an illness can affect their behavior

**Non-specific allograft failure**

Poor functioning of a transplanted heart without any clear reason

**Oncology team**

A team specializing in cancer treatment

**Outpatient**

A person who has tests or treatment in hospital but goes home later the same day

**Palliative care**

Also known as end-of-life care or hospice care; helps patients and families maintain a good quality of life and as normal a routine as possible in times of very serious illness

**Pediatrics**

A branch of medicine involving the care of babies, children, and adolescents

**Pediatrician**

A doctor specializing in care to babies, children, and adolescents

**Post-transplant lymphoproliferative disorder (PTLD)**

A disease after transplant that causes a person's lymph nodes to become larger after a viral infection; over time the enlarged lymph nodes could become cancerous

**Pulmonary function test**

A test to see how the lungs are working

**Pulmonologist**

A doctor who specializes in the lungs

**Rating of perceived exertion (RPE)**

A scale to measure how hard the heart works to pump blood around the body during exercise

**Transition**

In medical terms, the gradual, planned movement of teenagers and young adults to an adult-centered healthcare system

**Ultrasound**

A test using sound waves to create images of organs or tissue inside the body

**Ventricular assist device (VAD)**

A small machine that pumps blood around the body

**Ventilator**

A machine to help a person breathe

**Visual processing**

A person's ability to see and understand information in words or pictures



## Helpful websites and resources

**Note:** All website information and links were up-to-date at the time of printing.

### Transplant-related organizations and websites

**American Heart Association**      [www.americanheart.org/children](http://www.americanheart.org/children)

Offers easy-to-read medical information and pictures on congenital heart defects and children

**Canadian Transplant Association (CTA)**      [www.organ-donation-works.org](http://www.organ-donation-works.org)

A registered charity that includes transplant recipients and others who are committed to identifying and removing barriers to organ donation and supporting athletic and other awareness events to motivate transplant recipients to maintain a healthy lifestyle

**Children's Organ Transplant Association**      [www.cota.org](http://www.cota.org) or 1-800-366-2682

An organization that works with individuals of all ages to arrange the necessary funding for organ transplant expenses

**David Foster Foundation**      [www.davidfosterfoundation.com](http://www.davidfosterfoundation.com)

Dedicated to providing financial support to Canadian families with children in need of life-saving organ transplants and increasing organ donor awareness in Canada and the United States

**National Foundation for Transplants**      [www.transplants.org](http://www.transplants.org) or 1-800-489-3863

National, non-profit organization that offers a program of healthcare and financial support services and patient advocacy for transplant candidates, recipients and their families

**Trillium Gift of Life Network**      [www.giftoflife.on.ca](http://www.giftoflife.on.ca)

Created to help save and enhance lives by maximizing organ and tissue donations for transplantation

**Trio**      [www.trioweb.org](http://www.trioweb.org) or 1-800-TRIO-386

A non-profit organization committed to providing support, awareness, education and advocacy to those involved with organ transplants

**United Network for Organ Sharing (UNOS)**      [www.unos.org](http://www.unos.org) or 1-800-TXINFO-1

A non-profit membership organization that manages the National Organ Procurement and Transplant Network (OPTN) and US Scientific Registry under contracts with the US Department of Health and Human Services

**World Transplant Games Federation**      [www.wtgf.org](http://www.wtgf.org)

The organizing body of the World Transplant Games with the purpose to “visibly demonstrate the benefits of successful organ transplantation, work to increase public awareness of its success, and thereby increase organ donation rates, as well as promote the full rehabilitation and wellbeing of our participants”

## Adjustment and coping websites

**Band Aids and Blackboards**     [www.lehman.cuny.edu/faculty/jfleitas/bandaides/](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/)

Designed for children with medical challenges of all types, this site is highly interactive, with information for kids, teens and adults

**Experience Journal**     [www.experiencejournal.com](http://www.experiencejournal.com)

Provides stories and videos of families and clinicians facing pediatric heart disease along with a hospital preparation manual titled *Helping Your Child with a Medical Experience, A Practical Parent Guide*

**Mind Your Mind**     [www.mindyourmind.ca](http://www.mindyourmind.ca)

Award-winning site for youth by youth, offering information, resources, and tools to help manage stress, crisis, and mental health

**Sibling Support**     [www.siblingsupport.org/sibshops/index\\_html](http://www.siblingsupport.org/sibshops/index_html)

Support to individuals who have siblings with special needs

## Transition

**MyHealthPassport**     [www.sickkids.ca/myhealthpassport/](http://www.sickkids.ca/myhealthpassport/)

## Food safety

**Canadian Food Inspection Agency**     [www.inspection.gc.ca](http://www.inspection.gc.ca)

Up-to-date information on food recalls and allergy alerts from the Government of Canada

**Canadian Partnership for Consumer Food Safety Education**     [www.fightbac.org/tag/canada](http://www.fightbac.org/tag/canada)

Consumer education to help people enjoy food safely

**FoodSafety.gov (FDA/USDA/CDC)**     [www.foodsafety.gov](http://www.foodsafety.gov)

Up-to-date information on food recalls and allergy alerts from the FDA, USDA and CDC in the United States

**Partnership for Food Safety Education**     <http://www.fightbac.org>

Consumer education to prevent food poisoning



# Appendix 1: Contributors and affiliations

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Pediatric Heart Transplant Society Foundation

Our mission is to raise and administer funds to advance the science and treatment of children while listed for and following heart transplantation.

Visit us at [www.phtsfoundation.org](http://www.phtsfoundation.org)