



# Pediatric Heart Transplants

A Guide for Patients and Families

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# Endorsements

The following organizations have reviewed and endorsed these educational guidelines in January 2013 for five years.



*"Improving Human Life by Advancing the Field of Transplantation"*

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

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



*"Advancing the practice and science of transplantation for the benefit of Canadians and society."*

[www.cst-transplant.ca](http://www.cst-transplant.ca)



International Pediatric  
Transplant Association

*"Dedicated to promoting the advancement of the science and practice of transplantation in children worldwide."*

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



*"Dedicated to the advancement of the science and treatment of end-stage heart and lung diseases."*

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



# What is the Pediatric Heart Transplant Study Foundation?

The PHTS Foundation was established in 2010 as a 501(c) (3) non-profit organization dedicated to raise and administer funds to advance the science and treatment of children while listed for and following heart transplantation. The PHTS Foundation supports the good works of the Pediatric Heart Transplant Study (PHTS).

The Pediatric Heart Transplant Study (PHTS) is dedicated to the advancement of the science and treatment of children during listing for and following heart transplantation. Although there are 500 transplants a year worldwide, any individual center may only do a few and even the largest centers rarely do more than 20. It is essential that each center's experience and information is collected together, analyzed and the lessons learned passed on to everyone to advance the knowledge and improve the treatment of children's transplants. The purposes of the PHTS are to establish and maintain an international database for heart transplantation, to use the database to encourage and stimulate basic and clinical research in the field of pediatric heart transplantation, and to promote new therapeutic strategies.

We trust that you will find the information in this manual useful. Please do not hesitate to send feedback through our website at <http://www.phtsfoundation.org/>



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## 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 ensure your child recovers quickly and remains healthy and happy after the 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>Introduction.....</b>	<b>9</b>
<b>Before Your Child’s Heart Transplant .....</b>	<b>10</b>
How Is Someone Referred for a Heart Transplant?.....	11
Assessing Your Child for a Transplant .....	12
The Transplant Team.....	14
What Happens After the Assessment?.....	17
How Does My Child Get on the Heart Transplant Waiting List?.....	17
How Does the Transplant Team Find a Heart? .....	19
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.....	23
Nutrition.....	23
Medical Tests.....	24
What Happens if My Child Gets Sicker While Waiting for a Heart? .....	25
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
What Happens on the Day of Surgery? .....	29
What Happens in the Intensive Care Unit? .....	32
What to Expect When You First See Your Child.....	32
When Does My Child Leave the ICU?.....	33
Working With Your Child’s Healthcare Team .....	33
Your Child’s Emotional and Psychological Recovery .....	34
Going Home after the Transplant .....	34
<b>After the Heart Transplant .....</b>	<b>35</b>
Life After the Heart Transplant.....	36
Clinic Visits and Routine Testing.....	37
Clinic Visits.....	37
Heart Tests .....	37
Other Tests and Procedures.....	38
Transplant Medications.....	39
Types of Transplant Medications.....	39
Understanding Your Child’s Medications.....	40
Guidelines for Taking Medications .....	40
Why It Is Important to Stick to One Brand of Medicine .....	41
Immunosuppressant Medications .....	43
Medications to Prevent and Treat Infections .....	54
Vitamins and Supplements.....	61

Other Common Medications .....	63
Infection-control.....	63
Diuretics .....	63
Anti-Hypertensives (Blood Pressure Medications).....	65
Statins (Cholesterol and Lipid-Lowering Medications).....	68
Anti-Arrhythmics (Medications to Regulate Heart Beat).....	68
Anti-Ulcer Medications .....	69
Anti-Platelet Medications.....	70
Medications to Prevent and Treat Blood Clots .....	70
Immunizations .....	71
Rejection .....	73
Transplant Cardiac Allograft Vasculopathy (CAV).....	77
Infections and Diseases.....	79
Serious Viral Infections.....	80
Kidney Issues .....	85
Following a Healthy Lifestyle After Transplant.....	86
Physical Activity and Exercise.....	86
Heart-Healthy Eating .....	88
Your Child’s Behavior, Emotional Well-Being and School Performance.....	90
Commonly Asked Questions.....	92
How Long Will the New Heart Last?.....	92
When Can My Child Return to School or Other Daily Activities? .....	92
Does My Child Need a Special Skin Care Routine?.....	93
Will Medications Affect My Child’s Hair?.....	93
What Type of Dental Care Should My Child Have After Transplant? .....	93
Can My Child Go Out in the Sun as Usual? .....	94
What if My Teen Wants to Get a Tattoo or Piercing?.....	94
Can My Child Have a Pet?.....	95
Can My Child Travel?.....	95
My Child Still Has Trouble Sleeping. Is This Normal? .....	95
My Child Has Started Wetting the Bed at Night. Why Is This?.....	95
Adolescence .....	96
Transition From Pediatric to Adult Care.....	97
Research.....	99
Why Do Research in Children?.....	99
Why Are Children Different Than Adults? .....	99
Why Are Clinical Studies Important?.....	100
How Can My Family Help?.....	100
<b>Additional Resources .....</b>	<b>101</b>
Glossary .....	102
Helpful Websites and Resources.....	105
Transplant-Related Organizations and Websites.....	105
Adjustment and Coping Websites .....	106
Transition.....	106
Food Safety .....	106
Appendix 1: Contributors and Affiliations.....	107





# Introduction

If your child needs or might need a heart transplant, you will feel a lot of emotions all at once — anger, sadness, confusion, frustration and fear. These feelings can become overwhelming, especially if your child is very sick. Fortunately, many children who have a heart transplant go on to live normal, happy, healthy lives once they recover from the surgery.

This manual is designed to provide information about heart transplantation in children for parents and family members. During this difficult time, the best way to care for your child (and yourselves) is to stay informed and talk openly with your child’s transplant team. It is also important to communicate with your child to make sure they understand what is going on and are prepared for the challenges ahead.

We hope that you find this information helpful, but please remember it does not replace the important guidelines and information you and your child will get from the heart transplant team.

# Before Your Child's Heart Transplant



Original Artwork by  
Asiya, Age 10  
Heart transplant 6 years ago

## 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.
- 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. They will consider if your child:

- Needs, or qualifies for, a heart transplant.
- Needs a transplant right at that moment.
- Is able to have a heart transplant.

These issues are explained in the next few pages of this manual.

## 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.
- 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 the 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 are often 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 ensure your child is physically ready and emotionally prepared for a heart transplant.

The results of the tests will give an idea of your child's overall health. 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.
- Whether they have been seen at the transplant center before.

Tests also may vary according to your healthcare system or country.

## 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, see p. 19.)
- Levels of B-type natriuretic peptide (BNP), a type of 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 work out if your child has a higher risk of rejection (see p. 74). 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, a test allowing the team to check the pressure in your child's heart and blood vessels using a thin tube (see p. 38.)
- An exercise test or a six-minute walk.
- 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*

- 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.
- 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 different infections, such as these (but there could be others):

- Hepatitis A, B and C.
- HIV.
- Cytomegalovirus (CMV, see p. 82.)
- Epstein-Barr virus (EBV, see p. 83.)
- Herpes simplex virus.
- Tuberculosis (TB).

### **Interdisciplinary Team Assessments**

These involve meetings and tests with different healthcare professionals, including:

- A physiotherapist.
- An occupational therapist.
- A dietician.
- A social worker.
- A doctor in adolescent medicine.
- A psychologist.
- A psychiatrist.

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 anesthetist (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).
- 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. This team helps you make the best decisions for your child and your family.

## **The 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 and 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 performs the surgery to give your child the new heart. You and your child will meet the surgeon when you are called in for the transplant surgery.

### **Pathologist**

A pathologist is a doctor specializing in examining tissue. After a transplant, they will evaluate heart biopsies for rejection (see p. 73). Pathologists are also commonly involved before transplantation 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 about managing and storing 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 Co-ordinator (US only)**

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

### **Physiotherapist**

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.

### **Dietician**

A clinical dietician or nutritionist is specially 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**

A psychologist assesses how your child thinks, behaves and processes their emotions. If your child has any special learning or health needs, the psychologist will help to coordinate responses within your child's school. They can also make recommendations about any education diagnosis, for example, a learning disability.

### **Psychiatrist**

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

- 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, end-of-life care or hospice care. Palliative care is about helping children and families maintain a good quality of life. This team will help you explore how to maintain a "normal" life for your child.

### **Chaplains or Pastoral Care**

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



## What Happens After the Assessment?

After the consultations and tests, the whole transplant team (see p. 14) meets to decide if your child is a suitable candidate for a heart transplant. The team approach to care makes sure every treatment option for your child's case will be discussed.

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.
- Height.

Sometimes the waiting list will include information about what type of donor is acceptable for your child. If this 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.
- 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, most countries have a system meeting the needs of the sickest children first and makes 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**

A child meets *at least one* of the following conditions:

- Needs help breathing with a ventilator.
- Needs support with a mechanical device such as ECMO or ventricular assist device (VAD).
- Is less than six months old with heart disease and needs continuous prostaglandins (PGE).
- Needs certain IV medications, known as inotropes, at a high dose or more than one.
- Is expected to live less than 14 days without a heart transplant.

### **Status 1B**

A child meets *at least one* of the following conditions:

- Needs IV medicine, known as inotropes, at a low dose.
- Is less than six months old and does not meet status 1A criteria.
- Cannot grow at a certain rate.

### **Status 2**

A child is due a heart transplant but does not meet the criteria for Status 1A or 1B.

### **Status 7**

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

In Canada, there are four status levels on the national transplant waiting list. 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, there are 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).
- If your child has any antibodies that could attack the donor heart.

Hearts are then matched to the person according to their wait list status, with the sickest patients getting 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 matches (or is compatible) with 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 bear in mind that this information is confidential. The members of the transplant team only know the information they need to carry out the transplant safely. For example, they cannot tell you 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 putting in any identifying information. Your transplant coordinator 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 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 (see p. 17).

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) so they can reach you. 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 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 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 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 to find out how they will look and feel after a transplant and give you the chance to ask questions about their past 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 decide 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.

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 you can manage this risk if a vacation is needed to maintain a certain quality of life for the whole family. Your transplant team will help you to 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 are allowed to 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 dietician 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 is usually done by adding some infant formula to your breast milk and/or following a recipe developed by the dietician.

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 them cold rather than at room temperature and pour them into a glass or cup instead of leaving them in the can. Your dietician 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 in 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 dietician 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 (p. 13) and has been placed on the heart transplant wait list (p. 17), they will already have undergone a lot of medical testing.

There is usually not much need for extra medical testing from when a child is placed on the wait list to the time they receive their heart transplant. Any medical tests that do happen 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.
- 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, they will be reviewed regularly by the cardiologist and/or the transplant team. 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.
- Taking intravenous (IV) medications.
- Getting help with breathing from oxygen or a ventilator machine.
- 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?

A lot depends on what your child's life was like before transplant. If they are a "normal" kid and have never taken medicine a day in their life, a transplant will make a big difference. On the other hand, if they have 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 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 the 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, to look for any side effects and to look for any signs of rejection and infection.
- They 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 to adult care. Good communication with the transplant team is essential to their success.