



# Mended *Little* HeartGuide

A Parent and Caregiver **Resource Guide**  
for Families Living with Congenital Heart Disease

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## Dear Friend,

If your child was diagnosed with a heart problem either before or after birth — even if he or she is older and has already undergone surgery and/or a heart procedure — you may feel like you have been thrust into a world of unknowns. There are very few guides on how to be the parent or caregiver of a child with a heart defect or heart disease. In fact, odds are, you had never heard of a congenital heart defect or congenital heart disease before your child was diagnosed. The good news is that this Mended *Little* HeartGuide will provide you with the information you need and help guide you to additional resources.

Medical professionals and parents worked together to create the Mended *Little* HeartGuide, so it not only has accurate information but also empowers families to cope — and even thrive — in a world that can be frightening and difficult. This guide is a companion to the medical information you'll receive from your child's physicians. It provides answers to many questions you may have about caring for your child, yourself and the rest of your family.

The Mended *Little* HeartGuide has five sections to help you, regardless of where you are in your child's heart journey:

**Part 1:** General information for parents and caregivers

**Part 2:** Information to help parents and primary caregivers after their child's prenatal CHD diagnosis

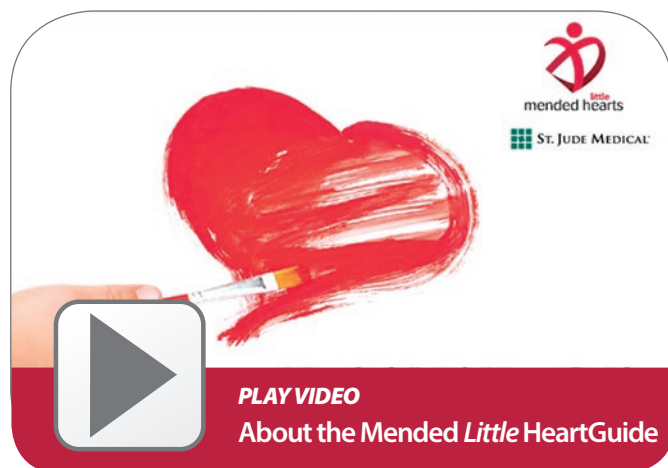
**Part 3:** Information to help parents and caregivers while their child is in the hospital

**Part 4:** Information to help parents and caregivers after their child comes home from the hospital

**Part 5:** Forms to help parents keep track of information

Please know that Mended *Little* Hearts is here for you if you need support. You are not alone. On behalf of everyone at Mended *Little* Hearts, we extend our heartfelt wishes to you and your family.

Mended Little Hearts



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**Note to Reader:** There is often discussion and confusion about the terms “congenital heart defect” and “congenital heart disease” because they are used interchangeably, and some people strongly prefer one over the other. For the purposes of this Mended *Little HeartGuide*, “congenital heart defect” is used when referring to the birth defect and “congenital heart disease” is used when referring to the lifelong condition of a child who was born with a congenital heart defect. Both are abbreviated CHD, so when reading this educational material, please use the version that best fits the context.

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

# About My Child's Heart

Print a PDF of  
this list



Please review this information with your child's cardiologist.

My child's diagnosis: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Date of diagnosis: \_\_\_\_\_

In my own words, this means: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Surgeries my child will need/has had, if any: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Procedures my child will need/has had, if any: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

In my own words, this is what will be/was done during my child's surgeries and/or procedures: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I can find more reliable medical information about my child's heart condition here: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Diagram of My Child's Heart

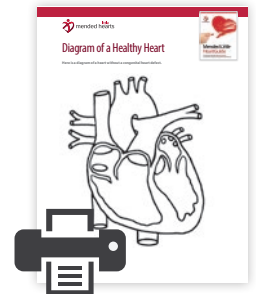
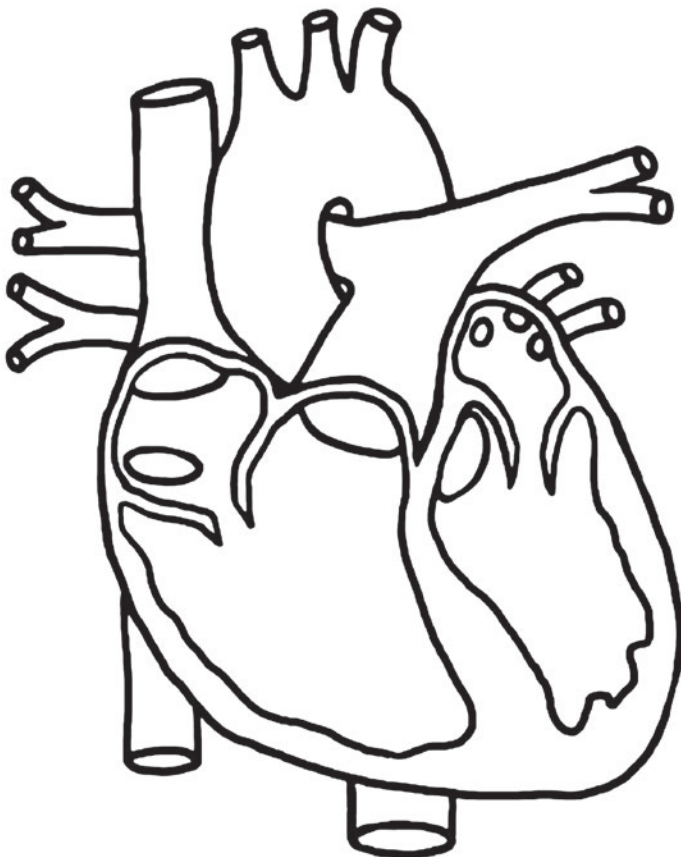
Print this page and ask your child's cardiologist to draw a picture of your child's heart here.



Print a PDF of this sheet

## Diagram of a Healthy Heart

Here is a diagram of a heart without a congenital heart defect.



Print a PDF of this sheet



# Part 1: General Information



- ▶ Connecting With Others
- ▶ Taking Care of Yourself
- ▶ Things You May Be Feeling
  - ◇ Grief
  - ◇ Fear
  - ◇ Guilt
  - ◇ Anger
  - ◇ Confusion
  - ◇ A Note About Post-Traumatic Stress Disorder
- ▶ Empowering Parents to Make Health Care Choices
- ▶ Navigating Insurance
- ▶ Common Tests and Procedures
- ▶ Valves and Devices for CHD Patients
- ▶ Glossary of Common CHD Terms and Abbreviations



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**Part 1: General Information**



# Connecting With Others

Many parents and caregivers feel very alone when they find out that their child has a congenital heart defect or congenital heart disease. Mended *Little Hearts* can help you join a caring support network of other parents and caregivers who have had similar experiences. Here are some ways to get started:

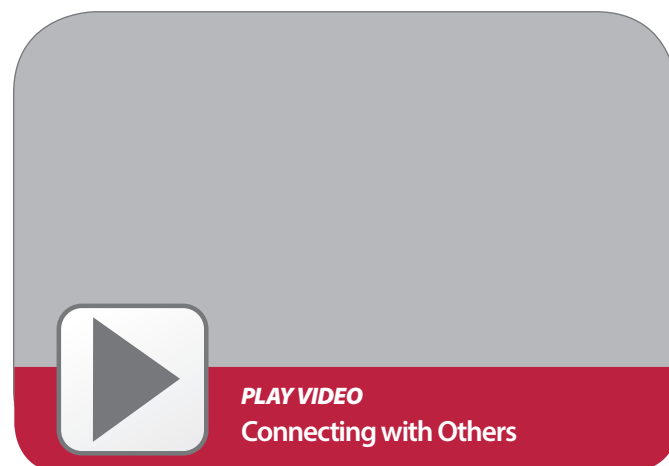
## Find a local support group.

Mended *Little Hearts* has local support groups across the nation for parents and caregivers of children with CHD. Please visit our website at [MendedLittleHearts.org](http://MendedLittleHearts.org) and click "[Find A Group](#)" for information about groups near you. You can also call 1-888-HEART99 (1-888-432-7899) between 8 a.m. and 5 p.m. CST and someone will be happy to help connect you. Local groups provide support meetings and educational programs, conduct CHD awareness events and work with local hospitals to help families who need support.

## Join our closed Facebook group and follow us on social media.

Mended *Little Hearts* has a closed Facebook group, [MLH CHD Chat](#), where parents, caregivers and people directly affected by congenital heart disease can talk with others who have had similar experiences. There, you can feel safe asking questions, expressing concerns and talking about your family's experiences. Simply request to be added to the group on Facebook.

Mended *Little Hearts* also has a public [Facebook page](#), [Mended Little Hearts National Organization](#), where followers can learn about new groups across the nation, national and local activities and new technology, research and treatments for CHD. We are also on [Twitter@MLH\\_CHD](#).



## Take part in our Parent Matching program.

Mended *Little Hearts* has a [Parent Matching program](#) that connects parents via email to other parents who have a child with the same or a similar heart defect. Parent Matching participants receive email messages of support from other parents. If they choose, participants also have the opportunity to complete a short training program that allows them to send emails of support to new Parent Matching participants whose child has a heart defect similar to their child's. You can sign up for [Parent Matching](#) on the MLH website.

## Become a member of Mended *Little Hearts*.

If you do not have a [Mended Little Hearts group](#) near you, you can still join Mended *Little Hearts* as a Member At Large to receive emails and news about Mended *Little Hearts* activities, webinars, educational materials and resources for families. There is no cost to join and the information you share is always kept private. You can join by visiting the [Mended Little Hearts website](#) or calling 1-888-HEART99 (1-888-432-7899).

# Taking Care of Yourself (Do Not Skip This!)

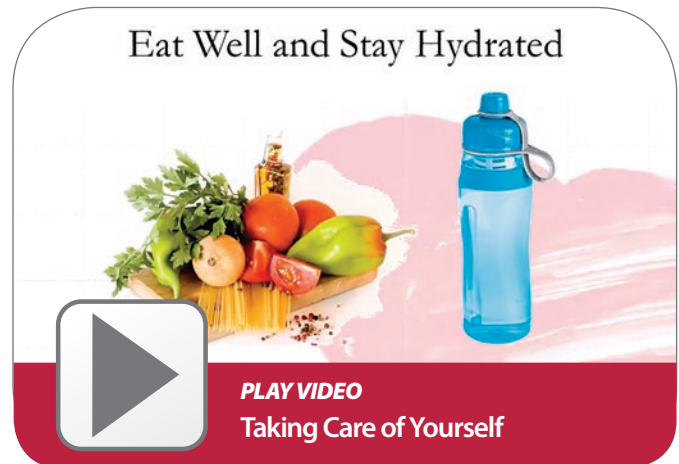
Parents and caregivers of children with CHD often think that taking care of their child comes first. Wrong! You must take care of yourself so that you can effectively care for your child. (We understand that this is easier said than done.) You will be faced with making important choices about your child's care, and you can't make the best decisions if you're too tired, physically unwell or overwhelmed with very high levels of stress or anxiety. That's why it's vital for you to follow these tips and take care of yourself first:

## Ask for and accept help.

Acknowledging and accepting that you need help can be difficult. Remember, your family and friends want to help you and support you during this stressful time, so allow them to do so. Make a list of things that need to be done to keep your life running, and be realistic about what you have the time and energy to accomplish. Keep the list handy, and next time a friend or family member asks how they can help, pick something from the list.

## Give yourself a break.

You do not need to have all the answers or to be with your child every second of every day. Please, give yourself a break! We know it is scary to leave your child's side, particularly after surgery or when he or she is in the hospital, but you do really need to get away — even for just a little while. For your own mental health, it is essential to schedule time away from the responsibilities of parenting and caregiving. Make plans for a friend, family member or health care provider to spend time with your child while you read a book, go shopping, dine out, nap ... anything that is truly relaxing.



## Connect with your care team, support network and other families.

Being the caregiver of a child with medical needs can be an isolating experience. It is important that you reach out and connect with others who can help you feel less alone during the journey. Ask your medical provider or social worker to refer you to community support groups or put you in touch with another family that has experienced a similar situation. Use the internet to keep distant family and friends updated on your child's condition and care plan. Take advantage of your hospital's support services such as social workers, child life services, pastoral care or parent navigators.

## Take care of your own health.

When you are caring for your child, it's easy for your health to become secondary. But if you aren't healthy, it will be more difficult to meet your child's needs. Make the time to see your physician regularly. If you have recently given birth, it is important to follow your doctor's recommendations regarding activity restrictions and to keep follow-up appointments.



Pay attention to your emotional state as well, and contact your physician or social worker if you are concerned about depression.

## Eat well and stay hydrated.

Living on coffee and hospital cafeteria food is no way to treat your body, and it won't give you the energy you need to continue to be your child's best advocate. It is important that you eat nutritious foods and drink plenty of water during your child's hospitalization. It is easy to lose track of time and miss meals when you are on "hospital time." Combat this by carrying snacks such as granola bars, fruit or nuts.

## Exercise.

Whether your child is in the hospital or at home, regular exercise is important for both your physical and emotional well-being. Try to schedule at least 20 minutes of exercise a day — even a brisk walk around the hospital counts! Studies have shown that regular exercise clears the mind, encourages better sleep and is a great stress reducer — things that are even more vital during difficult times.

## Distract, distract, distract!

Keeping up with your favorite hobbies or developing new ones is a good way to take a mental vacation. Knitting, reading, drawing and blogging are easy ways to busy your hands and quiet your mind.

## Educate yourself.

Knowledge is power! Learn about and understand your child's diagnosis, medications and treatment plan. (Ask your doctor to recommend reputable websites where you can learn more and **ONLY** get information from those.) If your hospital allows, participate in medical rounds for your child, and request family meetings to get updates or discuss care plan changes. Ask questions if you don't understand something. Keep a notebook nearby to write down questions as they come to mind.

## Get organized.

Keep all of the information you've received about your child's diagnosis in one place. The **forms** in this Mended *Little HeartGuide* will help you record important information. Get a binder to store and organize papers given to you by the hospital or doctors. **Directions on creating a binder** are also included in this Mended *Little HeartGuide*.

## Take back your family.

Don't let your child's diagnosis define your family. Recognize that your son or daughter's illness places every member of the family under increased stress and makes it more difficult for you to support each other. This is especially true for other children, who may have fears and anxiety that they aren't voicing. It is important for your family to spend time together that is not focused on your child's diagnosis. Plan family game nights, share special meals or attend a sporting event as a family.



# Things You May Be Feeling

You will experience many emotions when your son or daughter is initially diagnosed with CHD, and these will continue throughout your child's life, especially if he or she needs surgery or other heart procedures. After diagnosis, you must suddenly learn how to care for a child with special medical needs in addition to learning basic parenting skills. You have been thrust into a world of surgeries, procedures, specialists, medications, devices and medical jargon. You must also learn to accept that congenital heart disease is not only present at birth but is a lifelong condition requiring specialized care. Understandably, feelings of sadness, anger, fear, guilt and confusion are common.

Although it may seem hard to imagine at times, many parents and caregivers report that raising a child with CHD has made them stronger and that they became kinder and more compassionate people after recovering from the trauma of a CHD diagnosis and/or surgeries. Many even say that having a child with CHD was a positive event in their lives.

This section details some common thoughts and feelings that you may be experiencing as a parent or caregiver of a child with CHD and provides tips on the best ways to cope with those feelings.



# Grief

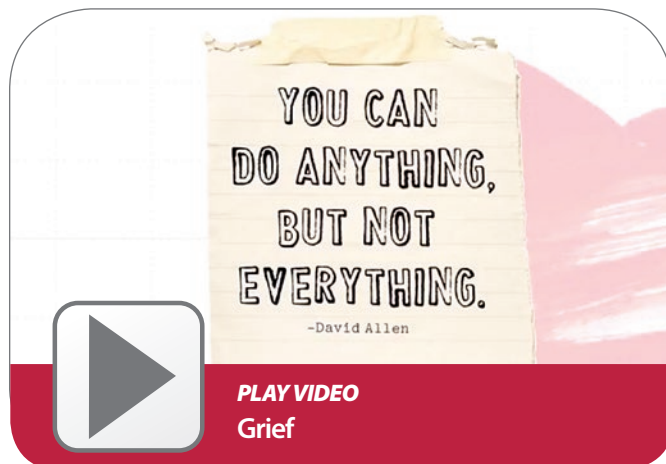
It is completely normal for parents and caregivers to feel grief, and even intense sadness, when their child is diagnosed with CHD, hospitalized or told that they need surgery. Grief is often strongest in times of crisis but can pop up — sometimes unexpectedly — at other times during a child's life as well.

When you get home from the hospital, the grief that you didn't allow yourself to feel while you were there may catch up to you. Grief may be stronger on milestones like birthdays or the anniversary of a surgery or diagnosis. Cardiology appointments, hospital visits or heart procedures may bring grief back as well. This grief takes many parents and caregivers by surprise because they thought that they had already worked through the sadness.

Sometimes parents and caregivers don't even understand why they are sad. Here are some common reasons for grief that can be hard to identify until you learn about them from another parent:

## Loss

When discussing the gender of a child before birth, many parents say, "I don't care if it's a boy or a girl, as long as the baby is healthy." After the diagnosis of a congenital heart defect, it is normal for parents to mourn the "healthy baby" they had hoped to have. This doesn't mean that you don't love your child with CHD. You are simply adjusting to having a child who may face unexpected challenges and limitations. You may feel grief because your child might not be able to participate in sports or some other activities that children without CHD can. The feelings of loss might extend to siblings, who are likely to lose time with and attention from their parents because of their brother or sister's needs. Parents often face this mourning process without the support of family members and friends



because there was no actual loss of a child. It is a true loss, nevertheless. Other parents and caregivers who have gone through the experience understand these emotions. "Welcome to Holland" by Emily Perl Kingsley captures these feelings in a poem.

## Lifetime Condition

When you get home from the hospital, you may continue to experience sadness. It can be very difficult to acknowledge that CHD is a lifelong condition that requires specialized care. Even after a successful surgery, you may feel sad that your child's condition is not "fixed" and that other surgeries and procedures may be ahead. It just doesn't seem fair, and it is very hard to watch our sweet, innocent children endure so much.

## Limitations

You might also feel sad about limitations — either physical or developmental — that your child may have. Parents and caregivers want their children to have, do and be anything they want, and it is hard to accept that this might not be possible for your child. Before having children, many parents visualize what their children will be and do, but when a child is born with CHD, those plans may need to change, sometimes drastically.

It's important to remember that even children without CHD often grow up to be very different from the image that parents had for them before birth.

## Guilt

Guilt can worsen grief. Many parents believe they should feel grateful that their child is alive or that their child's situation is not worse, so their sadness makes them feel guilty. These guilty feelings are normal, but they also increase feelings of grief.

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## HELPFUL TIPS FOR MANAGING GRIEF

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While it may seem that sadness is here to stay, it will get better. Be patient with yourself because healing will take time. Here are some specific things you can do to help manage your feelings of grief:

### Acknowledge your grief.

Sometimes just being aware of your feelings helps. Trying to fight, avoid or deny your sadness or feeling guilty about your grief may only make things worse. Know that it is okay to feel sad and disappointed. It does not mean that you don't love your child. You **DO** have a loss to mourn, and you should allow yourself to experience the feelings that come along with that. Just remember that your goal is to move out of grief rather than to stay in it.

### Keep a journal.

Writing your feelings out on paper can help lessen their impact. Keep a grief journal that's separate from your everyday journal, if you have one. Don't go back and read what you wrote; just get your emotions out as a means of letting them go.

## Make a list of things that you are grateful for.

We know it can be very, very hard to feel grateful for anything when you have a child with a serious illness, especially during a difficult hospital stay. Start simple: Each day, list one thing in your life that you are grateful for — even something small like the sunshine outside or a kind gesture from a stranger. Gratitude helps the healing process and turns your focus toward something positive.

## Change your thoughts.

Do not deny your sadness, but when you find yourself feeling sad for an extended period of time, try to think of something that you are happy about, even if it seems minor — a beloved pet, a favorite food or a kind word from a friend. Sadness needs to come and go so that you can enjoy life with your child. Sometimes you will have to fake it 'til you make it, but even the simple act of smiling causes changes in your body that will help you start feeling better. Eventually, you'll begin to feel true happiness again.

## Connect with others who understand what you are going through.

If you can, join a support group or system. Be sure they provide positive support, even though you may be discussing negative feelings and emotions. See the **Connecting With Others** section of this Mended *Little HeartGuide* for tips on how to find support.



## Talk to a grief counselor.

You may think you don't need a grief counselor because you didn't lose a child, but as discussed above, the feelings are similar because in one way, you did lose the healthy child you had planned to have. People who specialize in grief can help you work through the process.

## Focus on what your child can do.

If your child will have limitations, asking what he or she can do and focusing on that instead will help create an attitude that will help both you and your child in the long run.

## Give yourself time.

The saying "Time heals all wounds" is true. That doesn't mean you'll completely eliminate sadness from your life, but you will begin to feel better with time. Every person heals differently. Sometimes people will expect you to "get over it" long before you feel ready. Go at your own pace. You have been through a trauma and need to recover. Keep in mind that "this, too, shall pass" and that the grief will not last forever.



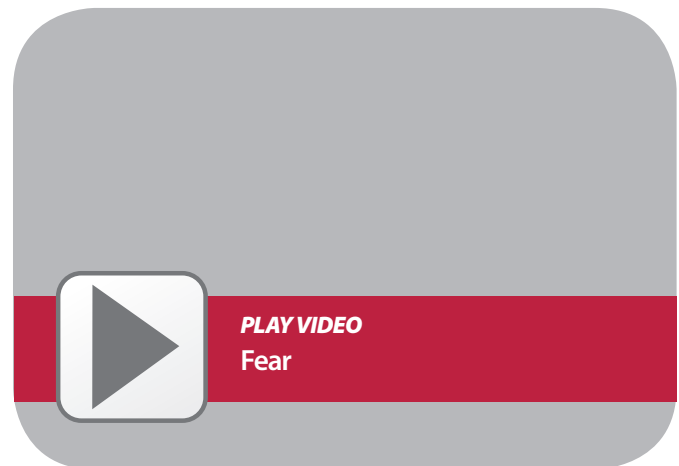


# Fear

Having a child with CHD means having fear — sometimes, a LOT of it. It's all too easy to fill your head with frightening "what if ...?" scenarios. Fear can rear its head in a variety of situations: Heading into heart surgery with a child is one of the most terrifying things you will ever do. Coming home from the hospital with your child after surgery is also incredibly scary, particularly if you have been in the hospital for a long period of time. Taking your son or daughter to the cardiologist or doctor can induce fear and worry because you don't know what kind of news you'll receive.

One of the biggest fears of parents and caregivers of children with CHD is that their child will not survive. For many of our children, there are no clear solutions. Treatments that completely fix their hearts have not yet been developed. We don't know what the future holds because many of the surgeries, procedures and devices used on CHD patients today have not been around long enough for us to understand their long-term effectiveness. The first successful heart surgeries were not done until the early 1900s, and the first one that used heart-lung bypass didn't happen until the early 1950s. If you are in a CHD support group or network, you are likely to hear about children who did not do well. You'll learn about some who lost their battle with CHD. Hearing these stories may increase your fear, but it may also encourage you to learn about the courageous families who endured the loss of a child and still found a way to help others and raise awareness.

Parents and caregivers sometimes fear that their child will be exposed to germs and illnesses. Some even end up quitting their job and staying home because they are afraid to leave the house with their son or daughter.



When cold and flu season comes around, these feelings can intensify. You have worked so hard to secure your child's health that you don't want to do anything that could jeopardize that, but unless a cardiologist has instructed you to limit contact, living in a bubble is not healthy for you or your family. There are many precautions you can take that still allow you to venture out with your child and have company in your home.

The day-to-day care of children with special medical needs — especially kids who require medications and/or the use of special equipment — can cause fear and stress. If you are a first-time parent, the normal concerns about learning to care for a new baby are compounded by the added responsibility of figuring out how to care for a newborn with medical issues. Some children with CHD will require a lot of specialized care, so parents may also worry about taking time off work and managing finances. Even if your child does well, you may worry about treating him or her like any other child, especially when it comes to exercise, sports and other physical activities.

## HELPFUL TIPS FOR MANAGING FEAR

Again, it is completely normal to feel afraid. There are still more questions than answers about children living with CHD, and not all children with CHD do well.

However, allowing fear to control your life will not only fail to change anything about your situation, it will also decrease the quality of life for your whole family. With that in mind, here are some specific ways to manage your fear:

### **Acknowledge your fears.**

Ask yourself, “What am I really afraid of?” Be specific. Writing your fears down helps you define and face them.

### **Take control, where possible.**

If you are afraid that your child will get sick, take steps to keep the whole family healthy. Eat nutritious foods, exercise, wash your hands frequently and avoid people who are sick. Ask your child’s cardiologist about exposure to others; you might be surprised by how much your child and family can do. If you have fears about your child’s medical condition, talk to your child’s doctor. Sometimes an honest conversation can reassure parents, or at least help them determine what is a true concern and what is not.

### **Let go of the things you cannot change.**

There are some things you will not be able to control. As much as you can, release your fears about those things. Getting trapped in the “what if ...?” cycle does nothing but rob you of quality time with your child. Schedule time during the day (no more than 15 minutes) to let your mind go and allow yourself to think about everything that you’re afraid of. When those fears come up during the rest of the day, remind yourself that you have a time scheduled to deal with them. Decide that you will not worry or think about them until that designated time. This will help increase your well-being throughout the rest of the day. Another technique is to write one fear down on a piece of paper. Fold it and place it inside a sealed jar or box.

Depending on your belief system, you can mentally hand the fear over to a higher power to handle, or simply decide to release it from your mind.

### **Stay in the present moment.**

The best way to manage fear and stress is to become present. When you find yourself thinking about tomorrow, focus on right here, right now instead. Become aware of your surroundings — who you are with, what you are doing, sounds, smells, etc. You can’t be in the future and present at the same time. Bringing yourself back to the present will help lessen your fear. The instant the “what if ...?” thoughts start, take some deep breaths and come back to the here and now. The truth is, we don’t know what the future holds for any of us, so don’t waste the time you have right now living in fear.

### **Find Quiet Time.**

Finding some quiet time — if only five minutes — every day is vital. Take time to let go and quiet your mind. Breathe deeply. This will allow you to stay calmer all day.

### **Join a support network.**

Support networks are important. Often, a group meeting will be the first opportunity that parents have to hear about other kids with the same condition as their child, adults living successfully with CHD and other parents and caregivers who are managing well. Meeting those people can help reduce your fear and give you hope that your child can have a bright future. Support groups also allow you to talk with others who understand what you’re going through. Sometimes just sharing your fears with someone who has walked your path can be very helpful. When you learn that others have the same fears, it can reassure you and make you feel less alone.

# Guilt

Many parents, especially mothers, feel like they did something wrong to cause their child's CHD. These feelings of guilt are real, and you should acknowledge them, but then let them go. There is no known cause for CHD. There are factors that may make it more likely for you to have a child with CHD, but that doesn't mean you caused your child's heart problem or that you should feel guilty. You might hear about things that mothers can do to help reduce the likelihood of having a child with CHD, and while this is good information for you in the future and for others who may be thinking about having a child, it does not mean that you did anything to cause your child's CHD.

There are plenty of moms and dads who do everything right — eating healthy foods, exercising, taking pre-natal vitamins, etc. — and still have a child with CHD. Conversely, there are moms and dads who do not do these things but still have healthy children without CHD. You do not know that anything you did or did not do directly caused your child's condition, so let the guilt go. If your child senses that you feel guilty, your son or daughter will believe that there is something wrong with him or her.

## HELPFUL TIPS FOR LETTING GO OF GUILT

### Talk to someone you trust.

Have a conversation about your feelings of guilt with someone who won't judge you. If you know another parent of a child with a birth defect who is doing well, try talking with him or her. It's likely he or she has worked through the same feelings you're experiencing now.



### Do NOT listen to anyone who blames you for your child's CHD.

Unfortunately, sometimes even well-meaning people place blame for a child's CHD on a parent. Again, there is no known cause of CHD; therefore it is not possible for someone to say that anything you did caused your child's heart problem.

### Treat yourself kindly.

Even if you had actually caused your child's CHD (and there is no evidence that you did!), feeling guilty about it would not help you or your child. Every time you start to feel guilty or to engage in negative self-talk, focus on something positive and beautiful about your child instead. Look at your son or daughter as a miracle that you played a part in creating — CHD and all. Treating yourself with kindness and loving yourself will help your child feel more positive about growing up with CHD.

# Anger

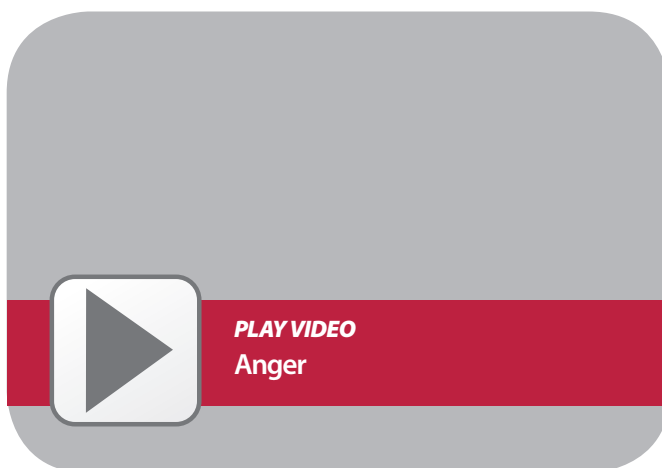
Most parents don't want to admit that they felt anger when their child was diagnosed with CHD, but it is a completely normal reaction. You may continue to feel angry after returning home from the hospital, or you may start to feel angry for the first time once you are at home and not under the daily stress of having a hospitalized child. You might feel like it isn't fair (it's not) and wonder why it had to happen to you. You might feel resentment toward others who have healthy children, especially if it seems like they don't appreciate how fortunate they are. Well-meaning people may say things that are offensive or hurtful, triggering additional anger. Depending on your beliefs, you may feel angry at God or feel as if CHD is a punishment. Most parents and caregivers of children with CHD experience feelings of anger at some point, and those feelings do not make you a bad person. (However, if your anger reaches a point where you feel violent toward yourself or others, seek help immediately.)

## HELPFUL TIPS FOR MANAGING ANGER

Even if you are justified in feeling angry, that anger is destructive to you and your family. The best way to handle it is to notice it, avoid resisting it, name it (why are you angry?) and breathe. If you can't seem to let extreme anger go, seek counseling. Sometimes talking to a professional is the only way to move through the anger. Here are a few other techniques that may help you manage these feelings:

### Breathe.

When you feel anger welling up, take deep, calming breaths and ground yourself. Focusing on your breathing can calm you down and bring you back to the present moment.



### Count to 10.

You may have been told as a child to count to 10 before reacting when you are angry. That's good advice for adults too. Counting to 10 in your mind can help you get to a better place and make better decisions about how to react.

### Assume good intentions.

Other parents who have a child with CHD are the only ones who know what it's like — and even those people have many different experiences. When people say or do something that offends you, don't automatically assume that they meant to be hurtful. Many people think they're being helpful and supportive ... even when they're not.

### Take 24 hours before reacting to anything online.

Giving yourself a day to calm down can really help when dealing with people via email or social media.

### Find others who understand.

Many parents feel resentful toward others — even friends and family — who just don't seem to understand what they are going through. Additional resentment can come when parents of perfectly healthy kids don't seem to appreciate how lucky they are. Join a support group in your community or online to find other parents who understand how you feel.

# Confusion

When your child was diagnosed with CHD, you may have received a huge amount of medical information that you didn't fully understand. You might have turned to the internet to learn more, adding to your confusion and fear. Other parents of children with CHD might provide you with additional advice, which could be helpful, but could also add to your confusion because each person's experience is different.

## HELPFUL TIPS FOR ELIMINATING CONFUSION

Fortunately, you can take steps to better understand your child's condition and eliminate confusion. Here are some ways to start:

### Ask questions.

Don't be afraid to keep asking doctors, nurses and other medical professionals questions until you truly understand what they are saying. When you think of a question, write it down so that you don't forget to ask it during your next visit to your child's doctor. This Mended *Little Heart*Guide has a [printable form](#) you can use to list your questions. Once you've asked, write down the answers so you can refer back to them as needed.

### Use reputable information.

Visit ONLY reputable websites. Mended *Little Hearts* provides a listing of trustworthy websites at [MendedLittleHearts.org](http://MendedLittleHearts.org) under the heading "[CHD Resources.](#)" Use these online resources to educate yourself about your child's condition. If you don't have internet access, there are written materials that can help you learn more. You can order a book



called [It's My Heart](#) from The Children's Heart Foundation or get a booklet called ["If Your Child Has a Congenital Heart Defect"](#) from your local affiliate of The American Heart Association. Your local children's hospital is also likely to have printed information for you.

### Trust yourself.

Learn to trust your intuition when making choices. You will often be able to tell when a decision is right for your family and when it is not by the way you feel. Many times, there are no "right" answers, so trust yourself to make the best decision you can with the information you have — but don't go back and second guess yourself.

### Connect with others.

Join a reputable support network that can help you find resources you may need to care for your child. If there is a Mended *Little Hearts* group near you, it can help connect you to resources in your area and to others who have been on a similar journey. While other parents and caregivers cannot answer your medical questions, they can give you tips on caring for your child in day-to-day life once you are home from the hospital.



# A Note About Post-Traumatic Stress Disorder (PTSD)

Some parents of children with CHD report that they feel like they have post-traumatic stress disorder (PTSD). These feelings sometimes occur more than a year after their child's diagnosis or heart surgery and can even surface years later as their child reaches adulthood. It is undoubtedly traumatic to have a child diagnosed with a heart defect, to watch a child go through surgery or other procedures and to wait on treatment to save your child, and many parents and caregivers may have symptoms of PTSD. However, it is important to note that PTSD is a medical diagnosis with specific criteria and symptoms.

PTSD can occur after experiencing a traumatic event, witnessing a traumatic event in person or even learning about a close family member or friend's traumatic event. Symptoms include re-experiencing the event, either in dreams or through memories and flashbacks; having distressing memories, thoughts, feelings or reminders of the event; blaming oneself or others; avoiding interaction with others, especially those associated with the trauma; and the inability to remember key pieces of the event. These symptoms must be continuous for at least one month for a PTSD diagnosis.

Treatment for PTSD depends on its severity. If you have had symptoms of PTSD continuously for at least a month or if you have severe symptoms that are impacting your life, seek counseling from someone who treats PTSD. If your symptoms are not impacting your daily life but are bothering you to some lesser degree, consider talking with others who have worked through similar symptoms to learn how they handled



them. Simply sharing experiences can be a helpful, healthy way to manage PTSD symptoms.

## Get help from a counselor or specialist if...

- You have suicidal thoughts. (Get help IMMEDIATELY!)
- You feel sad all the time.
- You can't get out of bed.
- You have thoughts of violence toward others.
- You can't eat or start overeating regularly.
- You can't sleep.
- You are turning to alcohol or drugs to cope.
- You have consistent headaches, aches, pains or other physical problems not associated with a disease or illness.

# Empowering Parents to Make Health Care Choices

Mended *Little* Hearts believes that parents and caregivers of children with CHD should have the right information to empower them to make the best possible choices when it comes to their child's care and treatment. Mended *Little* Hearts encourages transparency, information sharing and the education of parents and caregivers. Here are some tips for empowering yourself when making health care decisions for your child with CHD:

## Educate yourself via reliable sources.

To make good decisions about care, you need to understand your child's condition. Being exposed to a whole new world of medical terminology and information can be confusing and overwhelming, but taking the time to learn about your child's CHD will help you throughout your son or daughter's life.

There are many reliable sources of information. A few that MLH members recommend include [pted.org](http://pted.org) (which features moving diagrams), the Children's Heart Foundation book [It's My Heart](#) (available in both paperback and e-book), the [Centers for Disease Control and Prevention](#) website, the [American College of Cardiology's CardioSmart](#) site, the American Heart Association's booklet ["If Your Child Has a Congenital Heart Defect"](#) (available online and in print from many local affiliates) and [SCAI's Seconds Count](#) website. Your local children's hospital can also offer information on your child's condition. Please be aware that some other websites may not only be unreliable but also needlessly alarming for new CHD parents.



## Work with your child's doctor.

Ask your child's doctor to draw a **picture of your child's heart** and very clearly explain the condition. Don't be afraid to keep asking questions until you truly understand. No question is a stupid question. Health care providers would rather you understand your child's CHD than leave with unanswered questions. If you think of questions while you are away from your child's medical team, write them down so that you'll remember to get answers later. This Mended *Little* HeartGuide has a printable form you can use to **list your questions** as well as forms where you can record information about your child's heart defect and the surgeries or procedures he or she will need. ([About My Child's Heart](#)).

## Learn about your hospital.

Unless your child needs emergency surgery immediately after being diagnosed with CHD, you have time to learn about your hospital and surgeon and to make choices about care. It is your right to choose the hospital and surgeon that you feel is best for your child. Do not be afraid to ask questions to make sure your son or daughter is getting the best care possible for his or her condition.



## Ask questions such as:

- How often have you performed this procedure for this condition?
- What is your survival rate?
- What is the average recovery time at this hospital?
- What complications are likely to occur?
- How does the care team work together, and how well do they handle patients with this condition?
- Do you have a care unit dedicated to pediatric heart patients?
- What is the mortality rate at this hospital for CHD? (Note: Mortality rate may not be a good indicator because some hospitals take many higher-risk patients and may, therefore, have higher mortality rates.)
- What resources are available for families at this hospital?

*U.S. News & World Report* ranks children's hospitals, and those rankings are also worth reviewing as you make your selection. You need to feel comfortable with the hospital and surgeon you decide on and should feel empowered to choose the best option for your child. Don't be afraid to get a second opinion. Many parents and caregivers feel that their doctor will be offended or that getting a second opinion means that they don't like their doctor. That is not the case. CHD is complex, and second opinions can be helpful. In many cases, the second opinion simply confirms that the first doctor and hospital are the right choice, but it could also reveal new information that will help you get the best care for your child.

## You may have to travel.

Not every city has a hospital that performs surgery on children with CHD, so you may need to travel. You may also decide that a hospital in another city will provide better care for your child than your local hospital. If you do decide to travel to another area, consult with your insurance company prior to making arrangements to ensure that services will be covered.

Resources such as Ronald McDonald Houses are available for families who need to travel for medical procedures. Learn about these resources to help you decide if traveling is a feasible option for your family. (More information is available in the **Financial Considerations During the Hospital Stay** section of this Mended *Little HeartGuide*.) There are Mended *Little Hearts* groups in many areas that may be able to guide you to information for families from out of town. If you do decide to travel, get a realistic estimate of how long you will be away from home — understanding that no one can predict this with 100 percent certainty because children's recovery rates vary.

## Use caution when comparing experiences.

Parents often ask other parents about their experiences with a particular hospital, surgeon or doctor. While this can be helpful, it's important to remember that everyone's experience is unique. For a variety of reasons, including the severity and complexity of the child's CHD and even personality, two families can have vastly different experiences with the same hospital, surgeon or doctor. Parents who have a good experience tend to promote that facility. The best policy is to do additional research and investigation into recommendations you get from other families, blogs and social media.

# Navigating Insurance

The complexities of insurance can seem overwhelming, especially when you are already trying to manage your child's care and needs. Here is some useful information that may help you navigate the system:

## Insurance Cards

Have your insurance card with you for appointments and hospital admissions. This card, provided by your insurance company, has important details such as your policy number and insurance company's contact information. You may need to present it at the clinic or hospital to provide proof of coverage.

## Understanding Your Coverage

Your insurance company should have sent you a book explaining your coverage and benefits. It is your responsibility to know what your policy covers — and what it doesn't — because you may be accountable for the cost of services not covered by your policy. Your insurance card will have a phone number you can use to contact your insurance company if you have additional questions about your policy or coverage. If you don't understand your coverage, talk with someone who can explain it to you. Ask whether your child is eligible for complex case management services to help you with the insurance system and any pre-authorizations that may be needed.



## In-Network and Out-of-Network Providers

Some insurance policies specify which facilities and providers they consider to be in-network and out-of-network. You may receive less coverage (or no coverage at all) if you choose to go to an out-of-network provider. Ask your insurance company for a list of in-network providers and find out about your coverage at out-of-network providers. Some insurers require referrals from your child's primary care physician for specialty services or out-of-network providers. It's your responsibility to understand these requirements. If you choose to go out-of-network, you may need to work with the hospital to find out whether they will accept what the insurance company is willing to pay. If not, you could get stuck paying the difference between what the insurance company will pay and what the hospital charges. Keep asking until you get a clear idea of how much you might owe.

## Prior Authorization Requirements

Some policies require prior authorization for hospital admissions, specialty appointments or procedures. Most hospitals have staff members who will contact the insurance company on your behalf to get this authorization. Ask your child's health care providers if they will be making those calls or if you are expected to.

## Medication Coverage

Many insurance companies have a separate process for medication coverage. You may have a different card that you will need to show at the pharmacy. Pharmacists can assist you in figuring out which medications are covered, at what cost and whether any prior authorization is required. They may also be knowledgeable about drug assistance programs if your medication is not covered.



## Denial Appeals

If you find yourself with a bill that you did not expect or receive a notice of a denied insurance claim, contact your insurance company. Before calling, review your written policy information so that you understand your plan's coverage. Ask the insurance company to clarify the reason for denial. Your health care provider may need to re-submit the claim or you may need to file an appeal. Check your policy or call your insurance provider to find out what the appeals process is for your plan. You may need a letter of support from your health care provider. A resource for appeals, "Your Guide to the Appeals Process," is available at [PatientAdvocate.org](http://PatientAdvocate.org).

## Coverage After Age 18

If you are worried about having insurance coverage for your child once they turn 18, you should begin to explore options early. If you have a private insurance policy, call the number on the card and ask how long children can remain on their parents' policy. Current rules allow children to stay on parental policies until they are 26. This may change, however, and does not happen automatically. Most policies allow kids to stay on their parents' insurance while they are in school. Call your insurance company to find out what your plan allows.



## Disability Coverage

If you or your child has a condition that might qualify for disability coverage, visit the office of Social Security's website at [www.ssa.gov](http://www.ssa.gov). There, you can find out whether the diagnosis meets the qualifications for coverage and what information you need to apply. If disability coverage is a good option for your child, start the application process as soon as possible after birth. If you are applying for a child transitioning to adult care, be sure to get the application completed and turned in at least six months before his or her 18th birthday. Adult disability is called SSDI. Child disability is called SSI.

Also, you may qualify for coverage for infant formula for your baby through the Women, Infants and Children (WIC) program. Learn more about WIC at [www.fns.usda.gov](http://www.fns.usda.gov).

## Benefits for Adults With CHD

Adults with CHD may want to consider insurance benefits when deciding on employment opportunities. They may find that taking a lower-paying job with better medical benefits makes more financial sense in the long run. There is support available for these adults. Their doctors may be able to connect them with social workers who can assist. They can also call their local Social Security office about disability benefits, and their local human services office and state department of health may also be able to steer them toward resources.

## No Coverage

If you find yourself without health care coverage, look into low-cost or sliding-fee centers in your area.

You can research these online or ask a social worker at your local health center to help. These clinics are available for health care and dental care in most cities.

## Cost Estimates

Many hospitals now have a mechanism to provide cost estimates for procedures or appointments for people without insurance. Sometimes they are billed at a lesser rate and they may be eligible for charity care funding. If you are without insurance coverage, contact your hospital or clinic in advance to discuss costs and payment options to help you plan.



## Financial Assistance in Hospitals

Most hospitals have a community care program that offers financial assistance to patients with no or poor insurance. You may be asked to fill out a financial form and to explain your circumstances. The hospital might be willing to reduce your bill or work out a reasonable payment plan with you. It is important to do this in a timely manner, however, as unpaid bills will eventually be sent to collections, at which point they can affect your credit rating and may no longer be negotiable.

# Common Tests and Procedures

Many children born with congenital heart defects undergo medical tests and procedures to help with diagnosis, fix problems and provide physicians and nurses with more information before a surgery or treatment. Here are some of the most common tests children with CHD may encounter:

## Pulse Oximetry

Pulse oximetry or “pulse ox” is a common test that measures how much oxygen is circulating in the blood at any given time. Oxygen saturation for a healthy person without CHD is typically 95 to 100 percent, but this percentage is often lower in children with severe congenital heart defects. During testing, a small light-emitting monitor is usually placed on the child’s finger or toe. Pulse ox testing is painless; nothing goes into the child’s skin except for light.

This test is often used in screening for critical congenital heart defects but can be also used to monitor patients with CHD, to alter treatments and to plan future procedures. It is not uncommon for some patients with CHD to be sent home with a pulse oximeter so that they can measure the amount of oxygen in their blood as part of a home-monitoring program. In addition, many states have begun to adopt pulse oximetry measurements for all newborns. Implementing this inexpensive, painless test as part of every newborn’s routine screenings has allowed earlier detection of critical heart problems.

## Electrocardiogram

An electrocardiogram — often referred to as an EKG or an ECG — is specifically designed to look at the electrical activity of the heart. It was one of the first tests ever invented to monitor patients’ hearts. For



children with CHD, cardiologists use this test to check for abnormal heart rhythms and to see whether all chambers of the heart are beating together.

Like pulse oximetry, this test is painless. It involves placing wires with clips onto the child with sticky, round pads. Nothing goes into the skin or hurts the child. The heart rhythm is recorded for about 10 seconds. After recording the rhythm, the pads are removed. Sometimes, some adhesive stays on the child’s skin; baby oil may be helpful in removing it.

Children with severe CHD may be sent home for periods of time with electrocardiogram monitors that can measure the electrical activity of the heart during normal daily activities. A Holter monitor, for example, is worn for 24 hours. This can give physicians a better view of the heart rhythm during various parts of the day. For larger children, these monitors can be placed in a backpack to make them easier for the child to carry around. Another type of monitor children may be sent home with is an event monitor, which is similar to a Holter monitor but requires parents to recognize and record when their child has symptoms of an irregular rhythm.

## Echocardiogram

An echocardiogram (often called an “echo” by families) is a very useful tool in the diagnosis and management of CHD. Because echo technology keeps improving, medical professionals don’t need to use invasive tests as often. The echocardiogram is essentially a sophisticated ultrasound machine (like the ultrasound used on pregnant moms). A gel is put onto the child’s skin and then a probe is placed on top of the skin and moved around so that pictures of the heart can be seen on a computer monitor.

This test is not painful, but sometimes children can become uncomfortable, especially when the probe is placed on the neck area. Small children may become restless during the test. It can help to play a video or to read to them to keep them still during the test. In some cases, children are given medication to sedate them before an echo (called a “sedated echo”) so that they remain very still and allow doctors to get the clearest possible picture of the heart. Echocardiograms do not require any radiation.

The echocardiogram takes two-dimensional pictures of the heart to evaluate how it’s structured and how it’s functioning. Medical professionals can also look at pressures in various parts of the heart and the flow of

blood as it moves through the heart. This helps them figure out what the best treatment is for your child. This test is excellent for checking to see how patients are doing before and after surgery and has become an essential tool for cardiologists in both the diagnosis and management of CHD. Furthermore, improvements in this machine have led to the ability to take three-dimensional pictures that begin to assist with certain CHD procedures.

## MRI/CT Scans

MRI and CT scans are two other tests that help medical professionals get a good look at parts of the heart. MRI scans are being used more and more often because they involve no radiation and can provide significant amounts of information about how the heart is structured and functioning. MRIs can be very useful for looking at things that echocardiography cannot see as well, but MRI scans take a fairly long time and do require anesthesia for young children, so they’re only used when necessary. During an MRI, the child is put into what looks like a big tube in a machine which then sends detailed images of the child’s heart to a monitor where they can be viewed by medical professionals.

CT scans are similar to MRIs but are much quicker. They do require the use of radiation, but newer CT techniques have significantly reduced the amount of radiation used. This test has become a good option for viewing heart structures that echocardiography sometimes struggles with.

## Catheterization

Cardiac catheterization (often called “cardiac cath” or just “cath”) is one of the oldest tests that cardiologists use to help evaluate, manage and treat patients with CHD. In the past, cardiac catheterization was often used to diagnose CHD, but today, doctors typically use echocardiography and MRI instead.





More and more procedures are being done in the cath lab instead of in the operating room, and catheterization has provided a great alternative for some types of heart disease that would have required surgery in the past. Some interventions done via catheterization include opening up tight valves, closing unwanted holes or vessels in various chambers of the heart, evaluating and treating abnormal heart rhythms and even replacing some types of valves without surgery.

This is an invasive test, meaning that needles and tubes are put into the child's body, so it is only used when it is really needed. Because it is invasive, there are risks associated with it, but most children do well. Radiation is used in catheterization so that doctors can see images of the heart and vessels during the procedure.

Before a cardiac cath, the child will typically be anesthetized so that they are not awake during the procedure. This is sometimes done via an IV in the arm. The child may be told not to eat or drink for a period of

time before the procedure so that he or she doesn't get sick from the anesthetics. The child is then taken to the cath lab. (You can look at pictures of cath labs online. If your child is undergoing a catheterization, some hospitals will show you the cath lab if it will make you more comfortable.)

During the cath, long hollow tubes are inserted through the skin and placed in various chambers of the heart to measure pressures, take pictures of various structures and perform interventions on the heart. These tubes may be inserted through the groin, neck or other areas of the body.

After the cath, the child will have to lay flat for a period of time to make sure there is no bleeding where the tube went into the body. Recovery time from cath procedures is usually much shorter than for surgery. Sometimes, the child will be able to go home that evening; in other cases, they will remain in the hospital for one or more nights to recover.



# Valves and Devices for CHD Patients

## Valves

A normal heart has four valves that are like one-way doors. These “doors” open and shut to control the blood flow to and from the heart. The four valves are the:

- Aortic valve
- Pulmonary valve
- Mitral valve
- Tricuspid valve

Each valve has leaflets — either two or three depending on the type of valve — that open and close to let the blood go through and to stop it from going back in the wrong direction.

In some CHDs, one or more of the valves does not work properly. Some infections and diseases, like endocarditis, rheumatic fever and Kawasaki disease, can damage the heart valves, too. The two most common problems with the valves are narrowing of the valves and leaky valves. Sometimes the valve is extremely narrow or missing, and there is no opening where there should be one (**atresia**).

Cardiologists treat heart-valve problems differently depending on how severe the problem is. Some children with heart-valve problems have no symptoms for many years and will not need surgery. Other times, cardiologists will prescribe medicine to treat valve disease and to prevent more damage to the valves. In severe cases, heart surgeons may need to repair or replace the valve.

Valve repair is more common for the tricuspid valve and the mitral valve. In some cases, the repair can be done without open-chest surgery, but this is typically not an option if your child has other heart problems that need to be fixed at the same time.

Valve replacement is done when the valve cannot be repaired. The old valve is removed, and an artificial valve is put in its place.

There are two types of artificial valves: tissue valves and mechanical valves. Tissue valves are made from pig heart valves or cow cardiac tissue. Both of these work a lot like human heart valves. Another option is a homograft, which is a human valve from a human donor. A benefit to tissue valves is that people who get them often don't have to be on blood-thinning medication (**anti-coagulants**) for life. However, a disadvantage is that tissue valves may not last as long as mechanical ones.

Mechanical valves are made to work just like a normal heart valve, and they are designed to last for life. In children, however, the valve may need to be replaced as the child grows because it cannot grow with the child. People who get mechanical valves will need to take **anti-coagulants** to prevent blood clots from forming on the valve.

Today, cardiologists are able to do some replacements for pulmonary valves and aortic valves through cardiac catheterizations, but this is mostly done in adults. Once children reach a certain size, the pulmonary valve may be able to be replaced via cardiac catheterization rather than open-chest surgery.

## Devices

### Arrhythmias

A healthy heart has an electrical system that helps it beat in an organized pattern. Sometimes this rhythm will get blocked or become irregular, causing the heart to beat too fast, too slow or out of order. This irregular rhythm may or may not cause symptoms. An



electrophysiology (EP) study, which is a painless test that records electrical activity in the heart, may be ordered to diagnose any arrhythmias in your child.

Some arrhythmias will not require treatment, but an electrophysiologist (EP) — a special type of cardiologist — may still monitor your child to make sure the arrhythmia is not harming the heart. If the heart rate is too slow or too fast, the heart may not be able to pump enough blood, and your child's arrhythmia may need to be treated. Also, if the heart has extra beats or is skipping beats, treatment may also be recommended.

### ***Pacemakers***

A pacemaker is a tiny computer with wires (leads) that send electrical impulses to the heart when it senses the heart is beating too slow or not beating. Pacemakers also store information about your child's heart rhythm. The pacemaker has batteries that will need to be replaced, usually every five to 10 years. The batteries are not like normal batteries that can die suddenly. Instead, they decrease in strength slowly and give

plenty of warning. Children with pacemakers may have some activity restrictions, so be sure to ask his or her doctor.

A pacemaker is put into the chest through surgery. Your child's cardiologist will schedule follow-up appointments to monitor the pacemaker. Sometimes a wand is put over the spot where the pacemaker is to collect information that the pacemaker has stored. Other times the data is sent to the cardiologist's office wirelessly.

### ***Implantable Cardioverter Defibrillation (ICD)***

An ICD is a small computer that detects when the heart rate is dangerously fast. When this happens, it sends a small shock to your child's heart to stop the fast cycle. Sometimes people with ICDs feel the shock, but others barely notice it. The small shock typically restores the normal rhythm so the heart can pump blood. ICDs are put in through surgery, and people with ICDs will be monitored, typically by an electrophysiologist.

# Glossary of Common CHD Terms and Abbreviations

To see diagrams of and get more information about specific congenital heart defects, visit [pted.org](http://pted.org).

- ♥ **Amniocentesis:** A prenatal test used to determine if your baby has any chromosomal abnormalities and/or if his or her lungs are developed enough for birth.
- ♥ **Aneurysm:** A bulging of the wall of an artery, vein or heart wall
- ♥ **Anti-coagulant:** A medication that prevents the forming of blood clots
- ♥ **Aorta:** The main artery that supplies blood and oxygen to the body. It usually comes off the left ventricle (main pumping chamber) of the heart.
- ♥ **Aortic valve:** The valve between the aorta and the left ventricle (main pumping chamber). The aortic valve usually has three leaflets.
- ♥ **Arrhythmia:** An abnormal pattern of the beating of the heart
- ♥ **AS:** Aortic stenosis, in which the vessel going from the heart to the aorta is narrow or blocked
- ♥ **ASD:** Atrial septal defect, a hole in the wall that separates the right and left atria (top chambers of the heart)
- ♥ **Atrial Septum:** The muscular wall between the two collecting chambers of the heart (left atrium and right atrium)
- ♥ **Atrio-Ventricular Node (AV Node):** Part of the electrical (conduction) pathway of the heart that tells the ventricles when to beat
- ♥ **Atresia:** absence or abnormal narrowing of a passage
- ♥ **Atrium:** An upper chamber of the heart. (There are two.) The right atrium collects un-oxygenated (blue) blood from the body. The left atrium collects oxygenated blood from the lungs.
- ♥ **AVC or AV Canal Defect:** Atrioventricular canal defect, also known as endocardial cushion defect
- ♥ **BE:** Bacterial endocarditis, an infection of the inner layer and/or valves of the heart, caused by bacteria
- ♥ **Blalock-Hanlon:** Surgical septostomy performed for palliative treatment of transposition of the great vessels
- ♥ **Blood Pressure:** The pressure of the blood in the arteries. Systolic blood pressure is the top number (when the heart is contracted). Diastolic blood pressure is the bottom number (when the heart is relaxed).
- ♥ **Bradycardia:** Abnormally slow heart rate
- ♥ **BT Shunt:** Blalock-Taussig shunt, a surgical, systemic-to-pulmonary artery shunt procedure

- ♥ **Cardiopulmonary Bypass:** A machine that can perform the function of the heart and lung
- ♥ **Catheterization:** A test used to diagnose and/or treat CHD in which a catheter is inserted into the heart to take pictures (angiography) and measure pressure and oxygen
- ♥ **CAVC:** Complete atrioventricular canal, the main heart defect seen in patients with Down syndrome
- ♥ **CHD:** An abbreviation that can stand for either congenital heart defect, congenital heart disease or congestive heart disease
- ♥ **CHF:** Congestive heart failure, a condition in which the heart cannot pump well enough, creating a backup of blood and congestion in the veins and lungs
- ♥ **CoA:** Coarctation of the aorta, a blockage in the aorta that may be caused by narrowing of the vessel
- ♥ **Comorbidity:** When two or more disorders or illnesses happen in the same person, either at the same time or after each other. Comorbidities can worsen the first illness.
- ♥ **CXR:** Chest x-ray, a test where a picture is taken of the heart, lungs and blood vessels in the chest
- ♥ **Cyanosis:** Blueness of the lips and fingernails caused by a reduced amount of oxygen in the blood
- ♥ **D-TGA:** Dextro transposition of great arteries, the aorta and pulmonary artery are connected to the wrong chambers of the heart — the aorta leaves the right ventricle and the pulmonary artery leaves the left
- ♥ **ECG or EKG:** Electrocardiogram, a test where movement in electrical charges across the heart are recorded
- ♥ **ECHO:** Echocardiography, a diagnostic tool that uses Doppler techniques to evaluate blood flow patterns and pressures
- ♥ **ECMO:** Extracorporeal membrane oxygenation, a technique that provides respiratory support. Blood is circulated through an artificial lung made up of two compartments separated by a permeable membrane, with the blood on one side and the ventilating gas on the other.
- ♥ **Fenestration:** Surgical creation of an opening, sometimes used in Fontans
- ♥ **Fetal Echo:** Fetal **echocardiogram (echo)** is an echo performed on a pregnant mother to diagnose or monitor CHD in a baby before birth
- ♥ **Fontan:** A combined surgical procedure for complex congenital heart defects that redirects blood flow to bypass the right side of the heart and send oxygen-poor blood directly to the lungs
- ♥ **FTT:** Failure to thrive, meaning the child has inappropriate weight loss or insufficient weight gain
- ♥ **Glenn or Bidirectional Glenn Shunt:** A surgical procedure in which a large vein (the superior vena cava) is connected to the right pulmonary artery so that blood can bypass the heart's right chambers and be taken directly to the lungs for oxygenation
- ♥ **HLHS:** Hypoplastic left heart syndrome, characterized by a very small and non-functioning left ventricle and problems with the mitral valve (absent or non-functioning)

- ♥ **HRHS:** Hypoplastic right heart syndrome, characterized by a very small and non-functioning right ventricle and problems with the tricuspid valve (absent or non-functioning)
- ♥ **HTN:** Hypertension, high blood pressure in the vessels that carry blood from the heart to the body
- ♥ **Hypoplastic:** When an organ does not completely develop or stops developing.
- ♥ **IAA:** Interrupted aortic arch, in which the aortic arch is divided or interrupted and a hole in the muscle wall between the two ventricles (VSD)
- ♥ **Ischemia:** Lack of blood supply to an organ or tissue
- ♥ **Jantene Operation:** A type of arterial switch surgical procedure
- ♥ **LA:** Left atrium, the left of the two top chambers of the heart
- ♥ **L-TGA:** A condition in which the ventricles are on the opposite side of the heart compared to a normal heart, and the pulmonary artery and aorta are also switched
- ♥ **MI:** Myocardial infarction, a heart muscle that dies due to lack of oxygen, usually called a heart attack when it occurs in an adult
- ♥ **Mitral Valve:** A valve of two leaflets between the left atrium and left ventricle
- ♥ **MPA:** Main pulmonary artery, one of the two main vessels that carries un-oxygenated blood from the heart to the lungs
- ♥ **Murmur:** An extra heart sound that may be heard between normal heart sounds. Murmurs may be normal or abnormal. They are caused by increased turbulence of the blood as it moves through the heart, much like water flowing over rocks in a stream.
- ♥ **Myocarditis:** An inflammation of the heart muscle, usually caused by a virus or bacteria
- ♥ **Non-invasive:** This term typically describes tests that are performed on babies, children with CHD or pregnant mothers. Non-invasive means that nothing goes into the skin. A pulse oximetry test, for example, is non-invasive.
- ♥ **Non-Stress Test:** A **non-invasive** test performed on pregnant mothers to monitor the health of the baby before birth by making sure the baby's heart rate increases with movement.
- ♥ **Norwood Procedure:** The first of a series of open-heart surgeries that are typically used for single-ventricle defects. It reroutes blood flow around defective areas of the heart by creating new pathways for blood circulation to and from the lungs.
- ♥ **OHS:** Open-heart surgery, surgery performed on the open heart while the blood flow is diverted through the heart-lung machine
- ♥ **PA:** Pulmonary artery, a vessel that carries un-oxygenated blood from the heart to the lungs
- ♥ **PaO2:** Partial pressure of oxygen, a measure of oxygen in arterial blood
- ♥ **Palliative Care:** Treating symptoms without curing the underlying cause

- ♥ **PAPVR:** Partial anomalous pulmonary venous return, where one or more of the pulmonary veins carries blood from the lung to the right side of the heart instead of the left atrium
- ♥ **PDA:** Patent ductus arteriosus, in which the small vessel in the fetal anatomy that connects the aorta to the pulmonary artery remains open. It should close soon after birth.
- ♥ **Pericarditis:** An inflammation of the sac that surrounds the heart
- ♥ **PFO:** Patent foramen ovalae, an opening that allows blood to go back and forth between the right and left atrium that normally closes soon after birth
- ♥ **PGE1:** Prostaglandin E1, medication administered to maintain the patency (openness) of the ductus arteriosus (a blood vessel connecting the pulmonary artery to the proximal descending aorta)
- ♥ **Pulmonary Hypertension:** High blood pressure in the vessels that carry blood from the heart to the lungs
- ♥ **PS:** Pulmonary stenosis, a condition in which the valve and/or the area in the right ventricle where the blood goes into the pulmonary artery is blocked, possibly from narrowing
- ♥ **PV:** Pulmonary valve, the valve between the right ventricle and pulmonary artery
- ♥ **RA:** Right atrium, the right of the two top chambers of the heart
- ♥ **Septum:** A dividing wall in the heart
- ♥ **Shunt:** An abnormal passage of blood between two blood vessels or between the two sides of the heart
- ♥ **Stenosis:** A narrowing of a heart valve or blood vessel
- ♥ **SV:** Single ventricle, where there is only one functional ventricle
- ♥ **SVC:** Superior vena cava, the large vein that returns blood to the heart from the head, neck and arms
- ♥ **Tachycardia:** An abnormally fast heart rate
- ♥ **TAPVR:** Total anomalous pulmonary venous return, where the pulmonary veins (which carry blood back from the lungs to the heart) don't return blood to the heart in the normal manner
- ♥ **TGA:** Transposition of the great arteries, usually is referring to **D-TGA**
- ♥ **TOF:** Tetralogy of Fallot, a condition that consists of four heart defects — a large **VSD**, **pulmonary stenosis**, an enlarged aorta that sits right over the VSD, and a thickened right ventricle of the heart
- ♥ **Truncus:** Truncus arteriosus. In the most common type the pulmonary artery and the aorta join together as a single blood vessel coming out of the right and left ventricles.
- ♥ **Ventilator:** A machine that breathes for a patient or helps his or her breathing
- ♥ **Ventricle:** One of the two lower chambers of the heart. The left ventricle pumps to the aorta and supplies blood to the body. The right ventricle pumps to the pulmonary artery and supplies blood to the lungs.
- ♥ **VSD:** Ventricular septal defect, a hole in the muscle wall that separates the right and left ventricles



# Part 2: Prenatal Diagnosis



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► Things You May Be Feeling After a Prenatal Diagnosis

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◇ Lack of "Normal Pregnancy Feelings"

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◇ Guilt

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◇ Fear

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► During Pregnancy

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**Part 2: Prenatal Diagnosis**



# Things You May Be Feeling After a Prenatal Diagnosis

Congenital heart defects are the most common birth defects in the U.S. About 1 in every 110 babies will be diagnosed with one or more heart defects, but nothing can prepare expectant parents for hearing that there is something wrong with their baby's heart. If the child will need surgery or other medical procedures either before birth or soon after, the news becomes even scarier.

The diagnosis of a heart problem will bring questions, concerns and many complicated feelings. Some of these feelings — grief, anger, fear, guilt and confusion — are described in detail in the [Things You May Be Feeling](#) section of this Mended *Little* HeartGuide. There, you'll also find helpful tips for coping with these emotions. In this section, we will address issues that are unique to parents who are coping with a prenatal diagnosis.

## Lack of "Normal" Pregnancy Feelings

Pregnancy is usually a time of excitement and joyful expectation, but after your unborn child has been diagnosed with a heart problem, you may feel less — or even none — of the enthusiasm and positive emotions typically associated with pregnancy. You might even find yourself trying not to get too attached to a child who may not survive. It's not uncommon for expectant mothers of children with CHD to refuse to have a baby shower because they can't bear the thought of having gifts for a baby who might not come home. When the pregnancy becomes visible, they may feel fear and sadness when people ask about the baby rather than joy. It can be difficult to shake these feelings.



Bear in mind that most babies with CHD do well and go home to their families. Many babies with severe heart problems end up going home and doing "normal" baby things. Avoiding the fun and joy of expecting a child will not make it less painful if the worst does happen, so as much as possible, enjoy the pregnancy as you would if you were having a baby without a heart problem. When you begin to feel fear or sadness, remind yourself that Mended *Little* Hearts is full of kids, teens and even adults with CHD who are living happy and healthy lives.

## Guilt

Most parents feel guilty when their unborn child is diagnosed with a heart problem. There are many reasons for this guilt, including the idea that they may have done something to cause their child's CHD, and several of those reasons are described in the [Things You May Be Feeling](#) section of this Guide.

Expectant mothers believe that they should be happy during their pregnancy and may feel shame and guilt when they feel sad or fearful instead. They may dread their baby's birth because they know that it will not be the experience they had hoped it would be — especially if the baby will need surgery. Pregnant mothers may feel anger or resentment toward the child or situation, which leads to more guilt. They may also worry that their negative emotions are somehow harming their unborn child.

These feelings of guilt are very normal, but it is important to try to not let them overcome you. Pay attention to the things you are saying to yourself. Would you say those things to your best friend? Treat yourself with kindness and compassion. You are going through trauma, and you are human. Some negative feelings are expected. When the feelings occur, allow them to pass through you and then focus on what you can do to prepare for the arrival of your baby. Don't spend time around people who feel sorry for you or who want to dwell on your child's heart problems. Ask friends and family to think of your baby as healthy and strong and to talk to you about normal baby things rather than about his or her CHD.

## **Fear**

Fortunately, when you find out about your baby's heart defect before he or she is born, you will have more time to educate yourself and prepare than a parent who is faced with an unexpected emergency situation after the birth. Unfortunately, the early diagnosis leaves a lot of time for you to develop fear and anxiety about the birth and any upcoming surgeries. After diagnosis, the pregnancy can feel very long and frightening. You may imagine any number of terrifying scenarios; remind yourself that these are only in your imagination. Start envisioning a more positive but realistic outcome instead. Picture your child crawling, walking or even heading to school.

The reality is that you can't predict the future, so try to focus on what you can control. Spend your time preparing and educating yourself. The more you understand what to expect, the more in control you'll feel. Don't be afraid to ask questions, get tours of the hospital and talk to other parents who have experienced what you're going through. Find out what resources are available in your community to help you care for your child. You may want to visit the cardiac unit at your local hospital, but be cautious. On one hand, it may make you feel better by eliminating some of the unknowns and giving you a better idea of what to expect. On the other hand, seeing babies and children in an intensive care setting could frighten or overwhelm you as you begin to visualize your baby in that situation.

## **Disappointment**

Let's face it, this birth experience is probably not going to be the one you wanted. Most expectant mothers imagine their labor and birth experience as an exciting and happy time when they will get to meet and bond with the new life they brought into the world. When your child has a heart problem, your labor may need to be induced at a certain time and you may even need to have a cesarean section. You may not be able to do some things you expected to do, like hold your baby and feed him or her after birth. It's not fair that this happened to you,, and while your experience may not be the one you wanted, the key is finding things you can do to make it as pleasant as possible given the circumstances. To do this, you'll need to ask a lot of questions at the hospital where you'll be delivering and where your baby will have surgery. (See the **Preparing for Birth** section in this guide for some sample questions.) It will also require a lot of support from your friends and family.



## Envy

Envy is seen as a negative emotion, so many people don't want to admit that they feel it, but most of us experience it at some point. It is not uncommon for parents of babies who have been diagnosed with a heart problem to envy other expectant parents. After all, they are blissfully expecting a healthy newborn while you are burdened with the knowledge that your child will face immediate health issues. When other mothers complain about their pregnancy, you may feel like they are taking their healthy babies for granted. These feelings are normal, but it's important not to hold on to them. Let them come and then put them out of your mind. The reality is that you don't have any way of knowing what those other parents will face during their child's lifetime. Everyone has their own journey. Their journey is not yours.

## Become a member of Mended *Little* Hearts.

If you do not have a Mended *Little* Hearts group near you, you can still join Mended *Little* Hearts as a Member At Large to receive emails and news about Mended *Little* Hearts activities, webinars, educational materials and resources for families. There is no cost to join and the information you share is always kept private. You can join by visiting the **Mended Little Hearts website** or calling 1-888-HEART99 (1-888-432-7899).

# During Pregnancy

Congratulations on your pregnancy! This should be an exciting time of anticipation and preparation, but we know how easily fear can override your excitement after your baby has been diagnosed with CHD. Many families describe the prenatal diagnosis as both a blessing and a curse. They miss out on some of the excitement and joy of a typical pregnancy, but have the time to better prepare themselves and family members to welcome a baby with a special heart. We hope that the following tips help you continue to enjoy your pregnancy while preparing to meet your son or daughter:

## Fetal Cardiology Appointments

In most instances, expectant mothers will continue to see a fetal or pediatric cardiologist for monitoring throughout their pregnancy after their baby has been diagnosed with CHD. The frequency of cardiology visits depends on the baby's diagnosis, gestational age, other medical issues and the mother's health. These visits typically include a **fetal echo**, which is an ultrasound that looks specifically at the heart. (Learn more about fetal echos in the **Common Prenatal Tests** section of this Mended *Little HeartGuide*.)

## OB/GYN Appointments

It is important for mothers to continue to attend regular OB/GYN appointments throughout their pregnancy. The responsibility of the OB/GYN is to monitor maternal health during pregnancy. In some instances, the OB/GYN will work with a maternal fetal medicine specialist or perinatologist who monitors fetal growth and wellness. In other cases, the maternal fetal specialist may recommend an **amniocentesis** or other tests to assess the baby's chromosomes before delivery. (Read more about amniocentesis in the

**Common Prenatal Tests** section of this Mended *Little HeartGuide*.) As mothers head toward the end of their pregnancy, the OB/GYN or maternal fetal specialist may suggest specialized monitoring called a non-stress test or monitoring that includes ultrasound and heart rate monitoring. In most cases, this is a precautionary measure to assure that the baby is doing well in the womb. (Learn more about the **non-stress test** in the **Common Prenatal Tests** section of this Mended *Little HeartGuide*.)

## Questions About Delivery

There are many questions you can ask to prepare for your baby's birth. It is a good idea to prepare these ahead of time. (Use the **Questions and Answers Form** in this Mended *Little HeartGuide*.) It may also be helpful to bring a trusted friend or family member to take notes. Parents and caregivers may be so caught up in the emotions of the delivery, that they miss key information. Your baby's fetal cardiologist and your OB/GYN team may have to work together to answer your questions. Here are some questions to consider:

- **Where will I deliver my baby?**  
In some cases, you will be able to deliver in the hospital you would normally use. Be sure to deliver in a location that is equipped to deal with emergency situations, in case one should arise. Some parents may need to change their delivery hospital to ensure that their baby receives the specialized care that newborns with CHD may require, including a heart surgery or cardiac catheterization procedure. In some cases, your baby may require transport to a specialized hospital. If he or she will need surgery in another city or state after birth, know how your son or daughter will be transported.





- **How will I deliver my baby?**

Many women can deliver vaginally, despite their baby's heart condition, but it is important to discuss your options and preferences with your fetal cardiologist and OB/GYN. Sometimes, your labor will need to be induced to best prepare for your baby's surgery or other procedure, but induction is only done when medically necessary. Recent studies show that the chance of complications is higher when labor is induced, so it is best to avoid this if possible. There are instances where you will need to have a cesarean section. This may not be your first choice of delivery method, but your child's doctors would not choose it if it weren't necessary for the health of you or your baby.

- **What will happen after delivery?**

You may want to ask about the time that you and your baby will have together following birth. Find out whether you will be able to hold your son or daughter after delivery. Even if you can't, you can ask to see your baby before they take him or her out of the room. The ability to see and hold your baby immediately after birth will depend upon your baby's diagnosis and delivery plan. Speak with your cardiologist about the implications of your child's diagnosis on breastfeeding, circumcision and vaccinations.

# Preparing for Birth

After receiving a prenatal diagnosis of CHD, parents may feel overwhelmed when preparing for their child's birth. In addition to the regular preparation activities, there are unique considerations for parents who are expecting a baby with heart problems.

Familiarizing yourself with the hospital where your baby will have surgery will help you feel more comfortable when you get there, and speaking with the medical professionals who will treat your child can help answer many of your questions. In addition, making plans ahead of time to address the needs of siblings, manage work responsibilities and understand the resources available to you and your child can help minimize your stress after your child's birth. Here are some things to do before delivery:

## The Hospital

Ask for a tour of the hospital and unit(s) where your baby will receive care. This will help you familiarize yourself with the resources that will be available for you and your baby after delivery. You will also be able to better anticipate what you'll need to bring to the hospital. During the tour, you may want to ask about:

- **Sleeping arrangements for parents and families:** Discuss the hospital's policies on visitation and overnight stays by parents. Although many hospitals now allow (and welcome!) parents to stay overnight with their baby, this is not the case in every hospital.
- **Hospital visitors:** Most hospitals have policies regarding sibling and non-family member visitation. Familiarize yourself with these policies before your baby arrives so that you can prepare your family members and friends.
- **What to bring to the hospital:** Speak with your

**PLAY VIDEO****Preparing for Birth—Questions to Ask**

social worker or nurse about what to bring to the hospital. Pack two bags: one for you and one for the baby. Hospital policies vary regarding what is provided and what you can bring so find out what is acceptable ahead of time. Common items to include for your baby are booties, mittens, front-snap onesies, small stuffed animals and family photos. For parents, consider comfortable clothing, shower shoes, toiletries, nursing bras, phone chargers, a journal and a good book. (You may also find the [Packing List](#) in this Mended *Little Heart*Guide helpful.)

## The Medical Team

Ask your cardiologist if it is possible to meet with the team who will be managing your baby's care after delivery. This team may include the surgeon, cardiologist, nurse practitioner, social worker and nutritionist. Identify a pediatrician who will provide routine care once your baby is home from the hospital. Your child's pediatrician will work with his or her cardiologist to manage your child's unique needs.

## Siblings

Spend time preparing siblings for the arrival of the newest family member and for your time away from home. Think strategically with your partner, family members and friends about how to ensure that your newborn's siblings do not feel left out.

Take breaks from the bedside of your baby to spend time with your other children and have siblings make visits to the hospital. Inquire about Child Life Services at your hospital and discuss ways to prepare siblings for their first visit. (For more tips, see the [\*\*What About Siblings\*\*](#) and [\*\*Taking Care of Other Children While in the Hospital\*\*](#) sections of this Mended *Little HeartGuide*.)

## Leave Benefits and Time Off Work

Familiarize yourself with your leave benefits and make a plan for how to best use your maternity/paternity leave. Find out if your employer has a donated leave policy and, if so, inquire about how to access the donated leave bank to extend your time off. For prolonged hospitalizations, some parents find it helpful to return to work earlier than anticipated in order to preserve leave for when their child is discharged. It may be helpful to speak with your employer before your child is born to discuss options such as teleworking and returning to work part-time. (See the section on [\*\*The Financial Impact of CHD\*\*](#) in this Guide for more information.)

## Insurance/Health Coverage

Contact your employer's human resources department to find out how to add your baby to your insurance policy. Because it can be easy to overlook this in the days immediately following birth, make a plan to complete any paperwork ahead of time. (For more information, see the section on [\*\*Navigating Insurance\*\*](#) in this Mended *Little HeartGuide*.)

## Childbirth Preparation Classes

Explore birth and childcare classes that are available in your community. Popular courses include birth preparation, basic childcare, infant CPR and infant massage. If you would feel uncomfortable in a traditional birth/child care class due to the medical needs of your baby, speak with your social worker or nurse about alternative options, including private sessions.

## Breastfeeding

If you plan to breastfeed, research lactation consultants through your hospital. If your baby will be hospitalized for any length of time, look into buying or renting a quality breast pump and learn how to use it. (For more information, see the [\*\*Nutrition\*\*](#) section of this Guide.)

## Family Members

Research options on how to keep your family members and friends up to date on your baby's health. Some families choose Facebook, [\*\*CaringBridge\*\*](#), [\*\*Care Pages\*\*](#) or other online options. Others designate a point person (usually not Mom or Dad!) to handle updates and questions. Making a plan ahead of time will make it easier for you to focus on your baby after delivery.

## Information and Binders

It is never too early to start a medical binder to store information about your baby's special heart. Use it to organize drawings, printed information and business cards of your baby's care team. (Instructions on [\*\*Creating a Binder\*\*](#) are available in this Mended *Little HeartGuide*.)

## After Delivery

The period immediately after birth can be physically and emotionally exhausting and you may feel pulled in many different directions. It is vital that you take care of yourself in order to provide the best care for your baby. Please refer to the [\*\*Taking Care of Yourself\*\*](#) section of this Mended *Little HeartGuide* for tips on how to do this.

For helpful information about a hospital stay with your child, see [\*\*Part 3 of this Mended Little HeartGuide\*\*](#).





# Common Prenatal Tests and Procedures

## Fetal Echocardiogram (Fetal Echo)

A fetal echo is an ultrasound test that uses sound waves to create an image of your baby's heart to see how it has formed and how it is working. It can also show blood flow through the heart. This test is typically conducted around 20 weeks into pregnancy and may be used to diagnose CHD, to confirm a diagnosis that was made during an obstetrical ultrasound and get more information about your baby's heart. If your family is at high risk for congenital heart disease, or if you already have one child with CHD, a fetal echo may be used to determine if there is a heart defect in your baby.

A fetal echocardiogram is usually performed by an ultrasound technician but may also be conducted by a

fetal cardiologist or perinatologist (maternal fetal medicine specialist). It is painless and does not involve radiation, so it cannot harm you or your baby. The technician will place a transducer, like a wand, with gel on it onto your belly. The gel helps transmit the sound waves (you won't hear them because they're too high pitched for human ears to detect). The probe will be moved around to get pictures of your baby's heart. Sometimes, it may be left in one location for a few minutes to get an image. The images are usually shown on a screen, but unless you're trained to read echoes, it is very difficult to figure out what you are looking at. Some technicians will show you the valves, atria, ventricles and other parts of your baby's heart but they typically cannot tell you anything about your son or daughter's CHD. You'll get that information after a cardiologist has reviewed the results.



The fetal echo can be a long test — lasting up to two hours — so make sure you've had something to eat and arranged to have someone care for any other children you have. You don't need to do anything to prepare for a fetal echo, but bring your medical records with you. Sometimes, you'll have an appointment to get the results right after the test has finished. Other times, it will take a few days or a week to get results. If you can, bring someone with you who can take notes. Don't forget to ask any questions you can think of. If you think of a question after the appointment, call back and ask to make sure you have the information you need. It's important to note that not all heart defects and/or heart disease will be diagnosed during a fetal echo, so the diagnosis may change after your baby is born as his or her blood flow changes.

After CHD is diagnosed, your baby's cardiologist will likely want to perform more than one fetal echo during your pregnancy so that they can prepare for your baby's birth. You may feel like you are getting new information at every appointment, but that is probably just because it is hard to take everything in at the first visit. List your questions before each appointment. (Use the [Questions and Answers](#) form in this Guide.)

## Non-Stress Test

A fetal non-stress test is a test done by the obstetrician that monitors a baby's heart rate and allows doctors to see whether your baby's heart rate pattern is normal and varying with movements. This information helps the doctor determine whether there are any problems that need to be addressed. This test is usually done once or twice a week after 26 weeks of pregnancy. It is non-invasive and there are no risks.

You don't need to do anything to prepare for this test, but if you eat a little something or drink some juice right before it, your baby may be more active, which can help the doctor get better information. If your baby is asleep, you may have to schedule another non-stress test sooner than planned.

The non-stress test is usually done at your obstetrician or maternal fetal medicine specialist's office. You will be on a reclining chair or bed and belts/bands will be placed across your belly. These have monitors attached that record information. You may be asked to press a button when your baby moves. It takes around 20 minutes but may take longer if your baby isn't moving much. You might hear your baby's heart rate and it may speed up and slow down several times during the test. Usually, you will not need additional tests or monitoring at that time unless the results cause concern.

## Amniocentesis

Amniocentesis is a test used to check for chromosomal abnormalities like Down syndrome. It is also sometimes done to determine whether a baby's lungs are developed enough to be born.

During amniocentesis, a small amount of amniotic fluid (the water-like fluid that surrounds your baby before he or she is born) is removed with a thin, hollow needle. The spot on your belly where the needle is inserted will be cleaned before the procedure, and you may get a local anesthetic to relieve discomfort. An ultrasound will be performed at the same time so that the doctor can see where to place the needle in the uterus without getting too close to your baby. The amniotic fluid is then sent to a lab for testing. Your doctor will tell you when to expect the results.

You may have some cramping during the amniocentesis and for a few hours afterward. You should rest for the remainder of the day after the procedure. Your doctor will tell you if you can take any medication for discomfort. Have your spouse, a relative or a close friend drive you to and from your appointment. This test can be stressful, and you'll want someone there to support you.

There are some risks with amniocentesis, but complications are rare. The risk of miscarriage is less than 1 percent, but be sure to ask your obstetrician about risks and complications.

# Frequently Asked Prenatal Questions

**Important:** The questions and answers below address some common concerns that parents and caregivers have about the birth of a child with CHD, but always turn to your medical team for questions about medical issues.

**Q: I feel like I did something to cause my baby's CHD. What did I do wrong?**

**A:** Some congenital heart defects may be linked to genetic or environmental factors, and certain things that mothers do or are exposed to may increase the likelihood of having a baby with CHD, but that doesn't mean you did anything to cause your child's heart condition. Most cases of CHD have no known cause, so no one can say that anything you did or did not do caused your child's heart problem. Let go of the guilt.

**Q: I am having trouble bonding with my unborn baby. Is this normal?**

**A:** It is not at all uncommon. When parents hear that their baby has CHD, they may distance themselves from the child in an attempt to protect themselves from the unknown. Some parents feel that they would not be able to bear it if they bonded too much with the baby and then he or she did not survive. The truth is, there is nothing you can do to mentally or emotionally prepare for the loss of a child. There are, however, some things you can do to help you start bonding with your baby. Learn his or her gender, start a journal about your baby, write letters to your son or daughter, pick out a name and use it when thinking of or referring to your child. If you are still struggling, your obstetrician can recommend someone for you to talk to about your feelings.

**Q: Even after it was explained, I don't understand my baby's heart defect. What can I do?**

**A:** Ask your cardiologist or surgeon to explain it again, draw a picture or have someone else explain it to you in another way. If you want to understand the heart defect, your medical staff will go out of their way to help you. Don't be afraid to ask. Sometimes people who deal with hearts all day, every day, forget that most of us don't understand medical jargon. Keep asking until you get the information you want and need. Also, ask them to refer you to reliable online or printed information that will help you learn more.

**Q: My doctor called my baby's heart defect "rare." Does that mean there is no hope?**

**A:** Even though congenital heart defects are the most common form of birth defect in the U.S. — affecting about 1 in every 110 babies — there are 35 commonly recognized types of congenital heart defects and variations on many of them. Because of this, nearly every type of heart defect can be classified as "rare." The good news is there is treatment and/or surgery available for most types of CHD. Talk to your baby's cardiologist or heart surgeon before giving up hope. Get a second opinion to be sure you have as much information as possible. (Also refer to the [\*\*Making Health Care Choices\*\*](#) section of this Mended *Little HeartGuide*.)



**Q:** Can any procedures be performed to help my baby before he or she is born?

**A:** As there are more and more medical advances in the area of CHD treatment, fetal catheter intervention possibilities are becoming more common, but they are not without risk and are not available at every hospital. Talk to your baby's cardiologist or surgeon about which prenatal options, if any, are available for your baby and what the risks are. (For more information, refer to the **Making Health Care Choices** section of this Mended *Little HeartGuide*.)

**Q:** What can I do during my pregnancy to help the baby? Are there things I should or should not do in terms of physical activity, stress and work?

**A:** This is a question to ask your obstetrician, but many women carrying babies with CHD have pregnancies that are no different than any other pregnancy. Get good prenatal care. Eat well. Get enough rest. Do things to relax your mind and body. Be sure to visit your obstetrician and fetal cardiologist regularly. They can tell you whether there is anything you need to know, do or avoid to take the best care of yourself and your baby.

# Part 3: In the Hospital



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**Part 3: In the Hospital**



# Packing List for the Hospital Stay

As a parent or primary caregiver, you'll want to be as comfortable as possible during your baby's hospital stay. Having some of the comforts of home can make a big difference for both you and your son or daughter. Be sure to check with your hospital to learn what you can and cannot bring. Here are some hospital packing suggestions from other Mended *Little* Hearts families:

## For parents and primary caregivers:

- Books, magazines, crossword puzzles, Sudoku
- Electronics: laptop, phone, camera, iPad, etc.
- Charging cords for your electronics
- Medications and vitamins, especially prescription medications
- Tissues
- Eye drops (hospital rooms can get dry)
- Lip balm
- Hand lotion
- Re-usable water bottle
- Snacks (with protein, if possible)
- Sweatshirt/sweater (for chilly hospital rooms)
- Slippers/flip-flops
- Comfortable clothes
- Your own pillow
- Toiletries
- Quarters for vending and laundry machines
- Pad of paper for taking notes

## For your baby:

- Accessories: socks, hats, hair bows
- Snap-up onesies or sleepers for when you can dress your child
- Large swaddle blanket
- Photos from home (to personalize the room)
- A special stuffed animal or blanket
- Sound machine for soothing noise/music
- Infant car seat for the trip home
- Collapsible stroller



# Things You May Be Feeling in the Hospital

You'll experience many emotions while your child is in the hospital, and those may change many times a day, depending upon how your son or daughter is doing. Here are some of the emotions you may experience:

(See the **Things You May Be Feeling** section of the Mended *Little HeartGuide* for more information on things you may feel after a CHD diagnosis.)

## Uncertainty

Parents and caregivers have to constantly adjust to news delivered by medical professionals, so your feelings may go from devastation to hope to intense gratitude (or vice versa) in a short amount of time. Your child may recover in a different pattern than expected. They may, for example, do really well for one or two days then worsen on the third day and then start doing well again.. It can seem like taking two steps forward and one step back. Some parents compare the experience of having a child in the hospital to a roller coaster ride — but without the fun.

## Disconnectedness

If you are in the hospital for a few weeks or longer, you may feel very disconnected from events outside of the hospital. You may find it hard to believe that life is going on as usual for many people. This creates feelings of disconnection and sometimes anger. You may feel discouraged, as though you'll never get to leave the hospital. You will.

## Confusion

For many reasons, you may also feel confused. You may Google unfamiliar medical jargon, only to end up more perplexed by what you find. Consent forms for procedures are long and scary and may make you feel as if you are always signing something that agrees to the



risk of death or severe disability in order for your child to get the care that he or she needs. When shifts change, well-meaning nurses may give information in a different way than the previous nurse, which can add to your confusion and make it hard for you to understand what is actually happening with your child. Reports may even seem to conflict with one another. Finding your way around the hospital and locating resources can also be challenging.

(See **Tips for Managing a Hospital Stay** in this Guide.)

## Surprise

Some parents and caregivers put themselves into automatic pilot mode during a hospital stay, not allowing themselves to feel anything during that stressful time. The problem is that these suppressed feelings catch up with them once they have returned home, which can be unexpected and alarming.

## Fear

Bringing a child home from the hospital is a relief, but is also a frightening experience because you are no longer surrounded by doctors and nurses who can support you in caring for your child. You may feel discouraged when you continue to feel sad and angry, or just sad, instead of happy that you made it through the hospital stay.

# Tips for Emotional Wellness During a Hospital Stay

Your child's stay in the hospital will not be an easy experience, but there are things you can do to minimize the inevitable stress. Here are a few important things to remember:

## Take care of yourself.

If you are going to be the best possible caregiver for your child during a hospital stay, you will need to take care of yourself. Your child needs you to be able to make the best decisions about his or her care and you can't do that if you are neglecting your own health and well-being. When you feel overwhelmed, sad or angry, find ways to take care of yourself and get a break if you need one. The [Taking Care of Yourself](#) section of this Mended *Little Heart*Guide will give you tips on how to do this.

## Take care of your other children.

The hospital stay can be a frightening time for your sick child's siblings as well. Let them know when hospitalizations are coming up and help them prepare. Here are a few tips:

- Let them know who will care for them and when they will see you.
- Get help from social workers and child life specialists to give them age-appropriate information about their brother or sister's surgeries and/or procedures.
- Read them books to help explain what will happen in the hospital. There are some good children's books about hospital visits that you might find helpful.

### Do Something Special



#### PLAY VIDEO

Supporting Siblings While Your Child Is in the Hospital

- Make sure that their caregivers and teachers know what is going on and that they might need to expect unusual emotions and behaviors.
- Try to keep some aspects of siblings' lives routine to reduce their anxiety.
- Involve brothers and sisters in the sick child's care by encouraging them to do things such as making homemade cards to hang in the hospital room. Honor their important role in helping the family get through this hard time.
- Do something special with your other children. Even a few minutes of your time will go a long way. If you will be away from them for a long period, schedule some special time when you return.

## Talk to the hospital's social worker about your feelings.

He or she may have information and resources that can help you manage the emotions that come with being in the hospital.



## Connect with others who have been in the hospital with a child.

Talk with people who have been through similar experiences. This will help you express your feelings and concerns, ask questions and better understand some of the emotions you are experiencing. Ask the social worker or your child's medical team what support resources are available at your hospital or in your area.

## Ask questions until you understand.

Don't ever think that a question is stupid. Keep asking until you truly understand the answer. Doctors and nurses would rather have you ask questions than not understand what is happening. Record questions and answers using the **Question and Answer** form in this Mended *Little HeartGuide*.

## Ask for a conference if you feel very confused about your child's status.

If you believe you are getting conflicting opinions and reports, you can ask for a conference of the medical professionals who are treating your child to get information from all of them at once. This will help you get a unified opinion about how your child is doing and what the plan is for him or her.

## Don't be afraid to ask for a hospital tour, even if you have already had one.

Understanding where everything is in the hospital can help you feel much less lost and confused. There may be facilities for you to do laundry, get a snack, use the computer and even just relax.



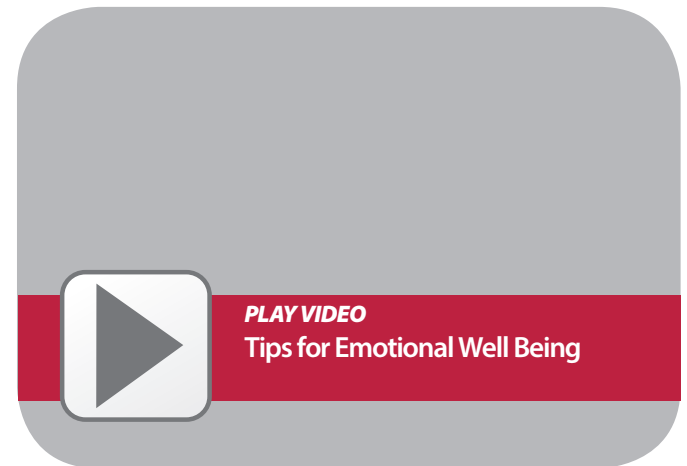
# Tips from Parents for Managing a Hospital Stay

Parents who've been through the experience of having a baby or child who needed heart surgery answered this question: **"What is the one thing you wish you had known when you were in the hospital with your child that would have made your stay easier?"** Here is their advice to you:

## Take Care of Yourself

In addition to the information on [Taking Care of Yourself](#) in this Mended *Little Heart* Guide, there are things you need to know specific to a hospital stay. It can be difficult to take care of yourself while your child is in the hospital, but it's important for your well-being. You will be a better caregiver for your child if you take care of yourself.

- **Take a break.** You need to get out of the hospital room, even for five or ten minutes at a time to give yourself a little time away from all of the stress. Go outside if you can and just breathe. If someone comes into the room and asks what they can do, have them stay and/or play with your child so you can get out for a little while. Don't spend your break time getting things done or working — really take a break. Get a snack and just sit and enjoy it.
- **Get sleep.** Being in the hospital, especially if you've just had a baby, is exhausting. Find a place where you can get some sleep. Hospitals sometimes have parent sleeping rooms where you can rest. You may have to sign up for the room, so be sure to find out.
- **It's okay to cry.** Sometimes parents and caregivers feel embarrassed about crying in front of medical professionals or others. It's okay to cry and release some emotions. It's normal to be sad and scared, and crying is a normal response to these feelings. In



fact, caregivers expect parents to feel and respond in this way. Be sure to keep tissues with you.

- **Stay warm.** It's often cold and dry in the hospital, so bring a sweater and slippers to keep warm. You may want to bring hand lotion and lip balm as well to prevent dry skin.
- **Eat regular meals with fruits and vegetables.** Healthy meals are especially important if you just gave birth. Breastfeeding moms are often able to get a meal from the hospital, so be sure to ask. Eating a well-balanced diet will make you feel better and less exhausted. Ask your hospital's social worker if they offer any discounts for patient families.
- **Connect with other parents or find a support group.** Most parents wish they had had someone to talk to who had been through heart surgery with a child. There is truly nothing like it, and connecting with other parents or caregivers can help ease the fear. Again, a social worker at your hospital should be able to help connect you with these types of resources both inside and outside the hospital.
- **Remember: This, too, shall pass.** It will not seem like it at times, but you will make it through this. Don't be afraid to ask for counseling or help. Hospital life is very challenging, but you won't be there forever.

# Get Involved with Your Child

Be hands-on with your baby or child and his or her care as much as possible. Don't be afraid to ask nurses to teach you to take care of your child. It can be difficult to bond with a new baby who has just had heart surgery or is sick, but being hands-on in his or her care can help. Here are a few ways to do this:

- If you'd like to breastfeed your child, ask if the hospital has a lactation consultant. Also, find out what the arrangements the hospital can make to store breast milk. If your baby is bottle fed, ask if you can feed your baby.
- Get involved in your newborn's care. Ask to help change your baby's diapers and to bathe and dress him or her. The more comfortable you get with caring for your child in the hospital, the more in control and confident you will feel when you get home.
- Ask to hold your baby. Many parents and caregivers are afraid to ask to hold their baby, but it's important that you do so when you can. Nurses can often come up with creative ways for you to hold your baby, even with tubes and wires attached.
- Bring clothes for your baby or child and dress him or her once it's okay to do so, but be sure it is clothing you don't mind getting stains on. Try to avoid clothing with zippers or Velcro. Clothes with snaps or buttons are better because wires and tubes can go through the holes.



## Tips for Improving Life in the Hospital

- Ask one of the nurses or doctors treating your child to take you on a tour of the unit where your child is staying.

- Ask if alarms can be silenced in your hospital room. Sometimes, especially with babies who are **cyanotic**, alarms will go off frequently. Some of these alarms can be silenced in the room but will continue to alert staff at the nursing station.
- Unless your baby or child needs certain procedures or medications at set times, you can ask that no one wake up your child. Sleep is important for your child's recovery.
- Many parents and caregivers are concerned about their child getting IVs. It's very hard for parents to watch their child get stuck with a needle over and over again for an IV. Ask the staff to send someone who has a lot of experience drawing blood or starting IVs in children. You can also ask that IVs or blood draws not be done in your child's bed. The bed should feel like a safe place for your child as much as possible.
- Be prepared for differences between the amount of care your child receives in the ICU/NICU/PICU/CICU versus the step-down unit. Many medical professionals are present in the ICU around the clock. In comparison, you may feel abandoned when your child is moved to the step-down unit because, suddenly, your baby or child is alone much of the time, and nursing care is less frequent. This is a good sign because it means your child is well enough to be in the step-down unit, but many parents and caregivers report feeling terrified about this. Before moving to the step-down unit, ask a nurse to describe the differences in the level of care so you are well prepared.
- Use websites or blogs to keep family and friends informed about your child. There are several ways to do this. Some people use [Care Pages](#) or [CaringBridge](#) sites.



PLAY VIDEO

Tips for Managing Hospital Life

Others like to create closed, or private, pages or groups on Facebook and invite family and friends to view their status updates. These are all good options to update many people at once and avoid the hassle of making multiple phone calls or sending separate emails. If you have a close friend or relative with you, that person can post for you when you're unable to.

## Plans for Your Child's Feeding, Clinginess, Pain Management and Emotions

Each baby or child will have a different experience in the hospital, but there are some things to know that can help parents or caregivers manage a hospital stay.

- Feeding your baby or child in the hospital can be challenging. For breastfeeding or bottle feeding, see the sections on [Nutrition](#) in this Mended *Little Heart* Guide. Some babies or children will not be able to eat for a period of time and will get nutrients through an IV. This can be scary for parents and caregivers, but know that your child is getting nutrition. Other children will need a feeding tube so they can get the nutrition they need. Babies with a feeding tube can still be breastfed and/or bottle fed, but sometimes they need extra calories they can get through a feeding tube.

Older children may refuse to eat or change their food preferences during a hospital stay. This is normal behavior. Don't force your child to eat while in the hospital. Most children will eat when they get hungry enough.

- Some children get clingy in the hospital and want you to stay at their bedside around the clock. Find ways to entertain your child without having to be bedside 24/7, and make a plan so you can take a break. Child Life Specialists and volunteers can play with your sick child and his or her siblings while you step away. Many pediatric hospitals also have playrooms with age-appropriate activities, games and toys for patients and their siblings. Ask if your hospital has a Child Life department or volunteer group.
- Bring familiar toys or stuffed animals that your child loves, but keep close track of them so they don't get lost or dirty. Also, you may want to bring items to entertain older children, including a few surprises that are just for the hospital.
- Have a plan for managing your child's pain. Make sure you understand what can be done to keep your child more comfortable. It's very hard for parents and caregivers to see their child suffering, and understanding pain management will help you feel like things are more in control.
- Parents and caregivers worry that their children will have emotional distress from their hospital stay. Keep in mind that although parents and caregivers may remember every detail of the hospital stay, babies and very young children do not. You may see your child's behavior change for a little while after their hospital stay, but this often doesn't last. In fact, some kids even remember positive things about their stay — like riding in the wagon or playing in the playroom — and they may want to go back. However, older children are likely to remember more details about the hospital stay. Find

resources to help them deal with the emotions they are feeling, such as being scared. Often these emotions will improve with time.

- Don't forget about your own emotional health. Your social worker should be able to put you in touch with a counselor if you need one.



## Advocating for Your Child

Most parents or caregivers who've a child in the hospital will tell you to remember that YOU are the best advocate for your child. Don't be afraid to speak up if you feel something is not right or if you have ANY questions. You will not offend your child's medical caregivers. You can also ask for a child/patient advocate if you need help.

Parents and caregivers should trust their instincts when they feel like something is wrong and should not be afraid to speak up. Most of the time, things are under control and will go as planned, even if it may not seem that way to parents and caregivers. Most of the care our children receive while in the hospital is very good, but medical professionals are human and mistakes can occasionally happen. Also, each child is different and will react differently to medications and procedures. Unexpected complications can arise. If you see something that concerns you, talk about it with a nurse or doctor so that they can address it.



# Hospital Services

**Ask the hospital social worker to see if your hospital has these services for you and your child:**

- ☐ Someone to call about any concerns:

Contact Info \_\_\_\_\_

- ☐ Lactation consultant:

Contact Info \_\_\_\_\_

- ☐ Counseling services:

Contact Info \_\_\_\_\_

- ☐ Chaplain or Rabbi:

Contact Info \_\_\_\_\_

- ☐ Food discounts

- ☐ Snacks for parents and families

- ☐ Meals for breastfeeding mothers

- ☐ Showers

- ☐ Laundry facilities

- ☐ Sleeping rooms for parents

- ☐ Parking discounts

- ☐ Computers for parents and families

- ☐ Rooms for pumping breast milk

- ☐ Music therapy

- ☐ Playroom/toys

- ☐ Activities for siblings

- ☐ Katie Beckett and/or supplemental insurance

- ☐ Nearby grocery stores



**Print a PDF of  
this list**

# Financial Considerations During the Hospital Stay

You may be wondering, “Why would I want to think about financial considerations now? I am focused on my child in the hospital. I’ll worry about that later. Financial information will just give me more stress than I already have.” That is a valid point, and you do need to focus on your son or daughter, but many of us who have been through a hospitalization with our child wish that we had known some of this information earlier. It could have actually reduced stress and saved us some money too.

Regardless of their socio-economic status, families of children with CHD are financially impacted when their child requires surgeries or other medical interventions. They are not only faced with medical costs but also normal financial obligations, such as mortgage payments, household expenses and childcare for their other children. Many have to make lifestyle changes such as changing or quitting a job and reducing expenses. This impacts the entire family.

Although costs involved in having a child with CHD are often unpredictable, planning for these expenses as early as possible can help your family stay financially healthy throughout your child’s hospital stay and CHD treatment.

Obviously, having a child in the hospital incurs medical costs, but many people don’t realize that there are other costs involved as well. Understanding what these additional expenses are and becoming familiar with the resources available to you can help. Here are some tips for reducing and managing the cost of a hospital stay:

## Gas and Parking

Gas and parking costs can add up if you are driving to and from the hospital regularly. If your child will be in the hospital for an extended period, you may want to consider public transit or carpool options. Your hospital may also have rooms where you can stay from time to time to reduce the amount of driving you’ll need to do. If you travel to another city or state for your child’s hospital stay and are staying near the hospital, there may be shuttles or other forms of transportation that are free or less expensive than gas and parking. There is often a parking discount available for parents and family members of hospitalized children. Ask your hospital social worker about this as soon as possible.

## Lodging

If you are traveling to another city or state for your child’s surgery, you’ll likely need to pay for accommodation. Extended family members who are traveling to be with you during this time might also need a place to stay. Here are a few options that can save you money:

- **Ronald McDonald Houses:** In many cities, Ronald McDonald Houses, hospitality houses or other facilities are available for the immediate family of children in the hospital if the family lives more than a certain distance away (typically 30 to 50 miles). Ask your hospital social worker about this as soon as you find out that you will be in another city for your child’s hospital stay. In many cases, you will need to let them know that you are coming ahead of time to get your name on a list for a room. The cost

of this lodging, if any, is usually low (around \$15 a night) and many Ronald McDonald Houses offer a shuttle to the hospital to save you from paying for gas and parking.

- **Hospital sleeping rooms:** Some hospitals have sleeping rooms for parents, but they are often on a first-come, first-serve basis and not ideal for long stays. They may, however, be a good short-term solution for parents who need a place to sleep immediately after their child's surgery or procedure. Siblings of a child in the hospital usually cannot use the hospital sleeping rooms and will need another place to stay.
- **Nearby hotels:** Sometimes nearby hotels offer discounts to families of children in the hospital. Ask hotels to see if they offer any type of discount for families and if they need any documentation showing that your child is in the hospital. If you have friends or family members with hotel rewards points, consider asking them if they would donate them to you to help you reduce lodging costs. Many people are very willing to share these reward points.

## Food

Until you stay in the hospital for a while, you don't realize how expensive hospital food can get — especially during long stays. There are some ways to save money on food though. Many hospitals give discounts (usually 10 percent) to parents of children who are in the hospital for treatment. Some hospitals also have hospitality rooms or other areas where there may be food for families. Find out if there are days and times when food is available at your hospital. Ronald McDonald Houses and hospitality houses often prepare dinners for families staying there and put leftovers in the refrigerator for families to eat when they get back from visiting at the hospital. Occasionally,

hospitals have funds to help families with food costs while their child is hospitalized. Your hospital social worker will know if there are any programs like that available to you. Breastfeeding moms are eligible for a meal in some hospitals; ask whether this is an option in your hospital (even if you are pumping).



## Medical Bills and Insurance Benefits

Families incur many medical costs when their child is in the hospital. Start talking to your insurance company as soon as possible. (See the [Navigating Insurance](#) section of this Guide to learn more.) We know how hard it is to think about insurance while your child is sick and in need of surgery or other procedures, but a call to your insurance company can help save money and reduce stress later.

Bills will begin to show up very quickly after your child receives services, sometimes even arriving before you get home from the hospital. Always review these bills carefully. Sometimes, there are mistakes that you can have corrected to reduce your costs. For example, if insurance companies see that a child has had a procedure (such as an x-ray) twice in one day, they may deny coverage of the second procedure because they think that it is a duplicate charge from the hospital when it is not.

Read the Explanation of Benefits information you received from your insurance company to make sure that your coverage is correct and that valid procedures are not being denied. Sometimes, procedures and treatments get coded wrong and they are either denied or end up costing you much more than they should. If you have ANY questions, ask your insurance company. These real-life scenarios have saved families thousands of dollars.

Knowing your insurance deductible (the limit on your out-of-pocket costs) will help you feel less stressed when bills start coming in because you will know that you can only owe up to that amount — even if it is a high amount. Your insurance company can assign you a case manager to help you manage your coverage. Often, you will get bills from different practices (cardiology, radiology, anesthesiology, etc.) within one hospital, which can be very confusing. Get help with this right away so that you understand all of the charges.

If possible, make sure everyone treating your child is an in-network provider. If your child needs to be seen by an out-of-network provider, ask your insurance company what you need to do. Talk to the hospital staff and your insurance company to be sure you understand your financial responsibilities.

## Prescriptions

Another medical expense is the cost of prescriptions for your child. Make sure you know which medications are covered and what your costs are. Some medications are very expensive, and you need to know this up front. Most pharmaceutical companies offer assistance to people who can't afford medications, so ask your pharmacist or go online to see if help is available to you.

## Other Medical Costs

Formula costs, monitor costs and other products your child may need are not covered by insurance. Ask your

hospital social worker to recommend resources that can help you reduce or cover these costs. Some formula companies, for example, may have programs to help you pay for special formulas for your child. Your state's Department of Health may also have information about options to help cover these costs. You may qualify for the Women, Infant and Children (WIC) program that will help cover infant formula cost. For more information, go to [www.fns.usda.gov/wic/women-infants-and-children-wic](http://www.fns.usda.gov/wic/women-infants-and-children-wic).

## Waivers

Waiver programs may be available to you, even if you are above the income level required to receive Social Security benefits. Some programs are provided for medically fragile children, regardless of income level. Contact your Department of Social Services or Department of Health and Human Services to find out which waivers are available for your family.

## Expenses at Home

While you are at the hospital with your child, it feels like your whole world has changed. It's hard to think about life as usual continuing outside the hospital walls, but it does. Unfortunately, your mortgage company, credit card companies and utility providers do not stop billing during this difficult time. Here are a few things that may help:

- Make a list of bills that need to be paid and when they are due. If possible, set up automatic bill pay.
- If you traveled unexpectedly for your child's surgery, you probably did not arrange to have your mail checked. Ask a neighbor, friend or someone from your church to check your mail for you and to forward anything you may need during your family's hospital stay.





- If you explain your situation, some companies, such as mortgage companies, will allow you to delay payment for one month as long as you pay it the following month. It may be worth making a call to find out. If you do get late charges, call the company and explain why payment was late. Sometimes these charges will be removed.
- Your yard and house may need care if you are away for an extended period of time. Rather than paying landscapers or a housesitter, ask a friend, neighbor or family member if they would be willing to cut the grass and check on your house.
- Don't forget your pets! Ask a trusted friend or family member if they can keep and care for your companion animals while you are away.
- Be sure to keep up with childcare payments for your other children. Talk to your childcare provider if you will be unable to make payments on time, or make arrangements if they will be with your family at the hospital.

# Transitioning From Hospital to Home

After the much-anticipated birth of a child with CHD, the reality of bringing him or her home can be both exciting and terrifying. While your child was in the hospital, doctors and nurses were his or her primary caregivers. Once you've returned home, you are faced with taking over care, which can be very scary. Here are some things you can do to help you feel more at ease:

## Educate yourself on your child's heart defect.

A diagnosis of CHD should come with an honorary diploma for parents who, in a matter of days, go from blissfully expecting to incredibly well-informed about an unfamiliar medical condition. If your child was diagnosed before birth, you may have had some time to prepare yourself and absorb the information you were given. This is both a blessing and a curse. On one hand, knowing about a child's CHD before birth allows you to educate yourself and make more informed decisions about care. On the other hand, the knowledge can create a very stressful pregnancy. If your child was diagnosed after he or she was born, you may be caught in a whirlwind of information that is difficult to manage.

Before being discharged from the hospital, ask as many questions as necessary to get a solid understanding of your child's heart defect and any surgeries or procedures your son or daughter had. Research his or her heart defect using **ONLY** reliable resources. (Your child's doctor may provide you with some and Mended *Little* Hearts website at [MendedLittleHearts.org](https://www.MendedLittleHearts.org) has a list under the heading "[CHD Resources](#).")



## Learn everything you can from the nurses.

Nurses are the closest thing hospitals have to parents. They are at the bedside doing everything from changing diapers to providing life-saving surveillance and care. When you get home, you'll take over their role, so don't be afraid to ask them to teach you how to do something that you have seen them do. Keep in mind that nurses are people, and not all people are good teachers. You will quickly learn which nurses provide the best information and will benefit from working with them and asking questions.

## Know emergency techniques.

Plan for the worst but expect the best. Start with cardio pulmonary resuscitation (CPR) training. As the parent or caregiver of a child with CHD, you'll probably be taught how to do CPR at the hospital. If you have not been taught before discharge, ask. Also, learn when you should call 911 or your child's doctor, and make an emergency plan. (You can use the [Emergency Plan](#) form in this Mended *Little* HeartGuide.)

Some areas have advance 911 systems that allow you to pre-register your child's medical conditions, preferences and needs with your area's emergency services. Call your local fire/rescue department to find out what you can do before an emergency. You may also want your child to wear medical identification with basic information about his or her condition. Many companies make medical ID products. Talk to your cardiology team about what information should be included.

## Understand your equipment.

You may be discharged with no equipment other than a pacifier, or you may be sent home with an order for home health to provide you with a pulse oximeter, monitor, feeding pump or even oxygen tank. Sometimes, there is equipment or other things your child used in the hospital that will be discarded because they are opened or used, and the nurse may be willing to give them to you to take home, so be sure to ask before you leave the hospital. When home health arrives, have them teach you how to use and troubleshoot your equipment. Home health companies often provide 24-hour coverage; ask how to get in touch with them after hours.

## Learn about medications.

When your child is put on medication, find out what it does, how it works, what side effects may occur, how much he or she needs and when it should be given. (You can record this information using the **Medication** form in this Mended *Little Heart*Guide.) Plan ahead and ask for prescriptions to be arranged and possibly filled before your child is discharged. Some prescriptions need to be compounded (made into liquid), and not every pharmacy is able to do this. Get help to find out which pharmacies can manage your child's medications. The pharmacist will explain how to store the medications properly; some need to be refrigerated. Pharmacists can help you double check

the instructions you received from the discharging nurse and physician.

## Reach out to your primary cardiologist before discharge.

Many families who have a child with CHD will need to travel to another city for their son or daughter's surgery or procedure. If possible, before discharge, find a cardiologist close to home who can follow up with your child. If your family did not have to travel for surgery, you will still need to choose a primary cardiologist. Make sure you are comfortable with your choice and don't be afraid to try someone different. You need to feel good about the care your child is receiving.

## Find a pediatrician/primary care doctor who knows how to care for children with CHD.

Your child will need a primary pediatrician to manage routine care and non-cardiac issues. In most cases, you will be required to designate a pediatrician for your child after he or she is born. When selecting, ask about their experience with children who have CHD. Use a pediatrician who understands that people living with CHD need lifelong specialized care.

## Know who your contact person is.

There is often a contact person, such as a nurse practitioner, for the cardiology practice where your child had surgery. This person can help you coordinate anything from appointments to medication refills. Be sure to find out who this person is before you leave the hospital.

## Understand your monitoring responsibilities.

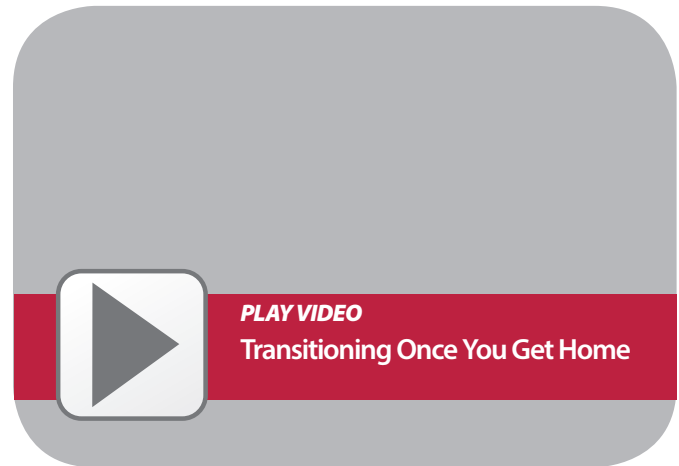
You may be asked to do monitoring at home for infants with single ventricles. A nurse or other medical professional may call your home to help you keep track of pulse oximeter and weight readings, for example. Be sure you understand your responsibilities; know what you need to monitor and how.

## Don't feel trapped in your home.

Many parents and caregivers are afraid to take a baby or child with CHD outside of the house for fear that they will be exposed to germs. During cold and flu season, it might be a good idea to limit outings with your child, but in general, getting outside and interacting with others is helpful for your mental state and your child's. Use common sense: Keep hands washed, avoid people who are sick, drink plenty of fluids, eat a balanced diet and get enough sleep. These things will help your whole family stay healthy. Talk to your doctor about immunization options that may minimize risks during cold and flu season.

## Get support.

It is also natural for parents and caregivers of children with CHD to feel like they can't leave their son or daughter in anyone else's care, but you need to find ways to take brief breaks and stay healthy. (See the **Taking Care of Yourself** section of this Guide.) Find someone you trust to babysit and take a 15-minute walk around your neighborhood once a day. Remember, your child would not have been discharged from the hospital if he or she was not well enough to be at home. Reach out to your family, local support group, church and your state's Department of Health and get support! There are resources available for you. Depression is not uncommon in caregivers. It needs to be addressed and treated. You are not alone.



## Don't feel guilty when things don't go perfectly.

Sometimes you can do everything right and something will still go wrong. Your child may fail to grow or gain weight. He or she may have symptoms that need to be addressed. There is enough guilt involved in having a child with CHD; the last thing you need is to blame yourself for setbacks that may occur. You are doing the best that you can. If you feel like you can't manage, get help. Caring for a child with CHD right after surgery is scary. You may be afraid that your child will get seriously ill or even die. It's normal to feel that way.

## Trust your instincts.

If you feel like there is something wrong with your child, don't doubt yourself. It is far better to check it out and find out that there is nothing wrong (even if you feel a little embarrassed) than to have something wrong with your child that isn't addressed. As a parent, you know your child best, so trust your instincts. Never feel bad about being persistent. No one advocates for a child as well as a parent.





## Write it out.

Keeping a journal is a great way to work through the stress and emotional ups and down of having a child with CHD. It is also a great place for making notes about questions you'd like to ask your doctors and information that you learn at your appointments.

## Prepare for your child's first appointments.

If you didn't do it while your son or daughter was in the hospital, make an appointment with your child's primary pediatrician and local cardiologists when you get home from the hospital. Again, be sure you have selected a pediatrician who has experience in caring for children with CHD, who understands the need for

lifelong specialized care and who is willing to work with your cardiologist. Before your child's first appointment, send any necessary medical records to the pediatrician so that he or she can better understand your child's condition and procedures. You can ask the pediatrician's office staff if they are able to get the records for you or ask the hospital to send them.

Remember, your child has CHD but will also need routine care. Go to all well-baby and well-child visits recommended by your child's doctors. Write down any questions that you have before your appointments and don't be afraid to ask for clarification. You can track your **child's appointments, medications and growth** using the **forms** in this Mended *Little Heart* Guide.

# Part 4: Living With CHD



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**Part 4: Living With CHD**

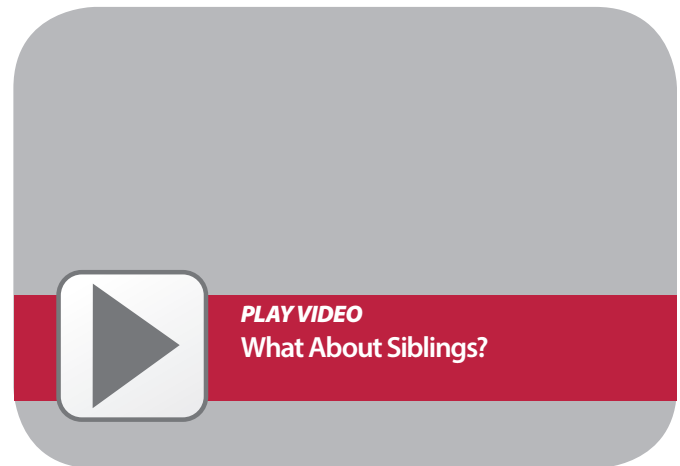
- ▶ What About Siblings?
- ▶ Your Child's Nutritional Needs
  - ◇ Nutrition During Infancy
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# What About Siblings?

If you have other children besides your child with CHD, you may worry about how their sibling's heart condition will affect them. If their brother or sister's heart defect is severe and requires surgeries, hospitalizations or special services, they will feel an impact. The good news is that most of these kids do just as well — sometimes even better — than their peers. They may show more independence, maturity, understanding, compassion and tolerance than other children their age. Further, studies have shown that the siblings' relationships with each other tends to be more nurturing and positive than that of typical siblings.

Even though they will likely adjust well, you might still see some changes in behavior, particularly during times of stress. They need your ongoing support. Here are a few ways to provide that:

- Keep them informed with truthful, age-appropriate information about their brother or sister's health. (For age-appropriate information, please talk to a social worker or child life specialist.) Kids know when you are hiding something, which can make them even more scared. Ask if they have questions and check for misunderstandings.
- Involve siblings in their brother or sister's care. They will feel more in control if they can help in some way.
- Provide them with opportunities to talk about their worries, feelings, questions and themselves. If needed, get help from a counselor or someone who can help them open up about their concerns. Sometimes, smaller children can express feelings through art or play.
- Form connections with other families so that your children can meet other kids with CHD and their siblings.



- Try to treat your children fairly and equally. Sometimes we have very high expectations of our healthier children and don't have the same expectations of our child with CHD. Rewards, punishments and expectations should be as equal as possible.
- When you can, give your healthy children some solo time and your undivided attention. Schedule one-on-one time on your calendar — even if it is just playing a game for 10 minutes.
- If you see signs of serious depression, violent behavior or excessive anger in your child, seek help immediately.

## The Toughest Question

Sometimes, particularly when a surgery is coming up, a sibling will ask if their brother or sister is going to die. This is a devastatingly painful question for a parent or caregiver to answer, particularly when the same question is going through our own minds. Answer as honestly as possible, but focus on positive aspects. You might, for example, say, "The truth is, we really don't know the answer to that. We certainly hope not. What we do know is that the doctors and nurses are going to do everything they can to make your brother or sister's heart work the best it can. They are very good at what they do and are going to do their best."



# Your Child's Nutritional Needs

Good nutrition is extremely important for growth and development, especially for babies and children with CHD. It can be tricky because a child with CHD may have trouble gaining enough weight, but you want to instill healthy eating habits to help them avoid acquired heart disease later in life. You may notice that it is hard for your child to gain weight because babies born with critical CHDs (those that require surgery or other procedures) usually need more calories to grow than other babies. This section contains information that will make it easier for you to provide your child with the nutrition he or she needs.

Your child's medical team — including cardiologist, primary care doctor and any nutritional specialists — should be your first source for information about your son or daughter's nutritional needs. Ask questions and express any concerns you have. If something isn't working, be sure to communicate that so that they can help you adjust the plan. Feeding a young child can be frustrating at the best of times, but feeding a child with CHD can be even more challenging.

## Nutrition During Infancy

Your baby's nutritional needs are highest during their first year of life. This time period is also most critical for growth and development.

### *Breastfeeding*

Breast milk is almost always the number one recommended source of nutrition, but for many reasons, you may choose not to breastfeed or may not be able to breastfeed. If your child has a CHD that requires



intervention or surgery soon after birth, for example, you may not be able to breastfeed for a period of time. It is important to follow orders about feeding so that your child can have surgery as scheduled. If you cannot breastfeed before surgery, be sure to pump your breast milk every two to three hours to develop a good milk supply. If you are in the hospital with your baby, ask a nurse or doctor if there are special rooms where you can pump. You can store this pumped milk to feed your baby later. Follow guidelines for proper breast milk storage. The [CDC's website](#) has more information. If you are in the hospital, they may have procedures for storing breast milk. Just ask.

Breastfeeding can feel frustrating or scary at first (that's normal), but with patience and persistence, many mothers have been able to breastfeed babies with CHD. If you have trouble pumping or breastfeeding your baby, or just want someone to work with you when you're getting started, find a lactation consultant to help. Most children's hospitals have one. If you are not at the hospital, your pediatrician can recommend one.



Although it may not seem like it, breastfeeding is actually less work for your baby than bottle feeding. Breast milk is easier to digest and also contains antibodies that help fight infection. If your child is having trouble gaining weight, you may need to fortify your breast milk with formula. This may be frustrating if you want to exclusively breastfeed your child, but it is important for your baby to get enough calories to grow. He or she will still get all of the benefits of breast milk, even if it is fortified.

### ***Bottle Feeding***

For some babies, it may not be possible to breastfeed exclusively or, in some cases, at all. Sometimes breastfeeding creates more stress and anxiety than mothers of babies with CHD feel they can handle. Do what works best for you and your family without feeling guilty. You will not harm your baby by giving him or her formula. Work with your child's medical team to find the right formula. Some babies need special, easier-to-digest formulas; these can be expensive, so ask about discounts or places where you can save money. In the beginning, babies usually take two to four ounces of formula at every feeding and need to be fed every two to four hours. Work with your child's medical team to set up a schedule, but understand that adjustments might be needed.

### ***Feeding Tubes***

Because of certain medical issues or because they are unable to drink enough formula or breast milk, some babies will need to be fed through a feeding tube. These are used for a short period until your child is able to feed and gain weight on his or her own. Most babies with CHD can begin eating infant cereal and puréed baby foods at the usual age of five to six months. Your child's medical team, and sometimes a home health team, will help you use a feeding tube if necessary.

## **Nutrition During Childhood**

As they grow, children with CHD may have greater nutritional needs than other children. Like any other child, it is also typical for them to become picky eaters and to experience food jags (when they like one food for a period of time then don't want it anymore). Feeding a child may be frustrating and emotional if he or she refuses to eat or becomes excessively picky. Remember that most children will eat when they are hungry. Here are a few tips to make feeding your child less of a battle:

- Offer your child three balanced meals (items from multiple food groups) and two snacks daily.
- Avoid forcing or bribing your child to finish a meal or snack.
- Always offer one food item per meal that you know your child will eat.
- Experiment with different textures and consistencies.
- Know that when your child is hungry enough, he or she will eat. Avoid becoming a short-order cook in your home.

Be sure to ask your child's cardiologist, pediatrician or nutritionist to help you create a plan for your son or daughter. If you or your child's medical team notices that your child is not gaining enough weight, that doesn't mean you are doing anything wrong. You will likely need to increase the number of calories he or she is taking in each day. Here are a few tips on how to do that:

- Add a teaspoon of canola oil when preparing your child's food.
- Add a tablespoon of dry milk powder to puréed foods or liquids.

- Avoid low-fat and fat-free items.
- In addition to fruits and vegetables, offer foods that are naturally high in calories: peanut butter, avocados, cheese, nuts/seeds, beans, meats, etc.

For more helpful information on increasing calories, see this [list of high-calorie foods](#) from Cincinnati Children's Hospital.



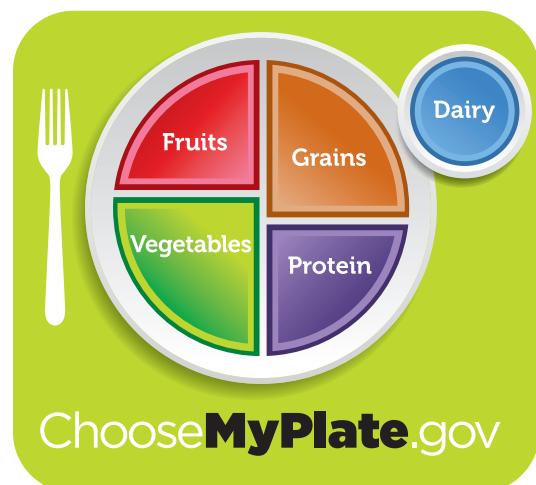
## Heart-Healthy Nutrition for Life

At the beginning of your child's life, you may have needed to increase calories so that your son or daughter would gain weight, but as he or she grows older, it is important to encourage a heart-healthy diet. A balanced diet will not only help your child avoid acquired heart disease and other conditions, it will also keep their weight at a healthy level. Pairing a nutritious diet with exercise where possible (see the section in this Mended *Little Heart* Guide on [Exercise and CHD](#)) will help children stay healthy into adulthood.

It may be necessary for your child to follow a low-sodium or fat-restricted diet at some point. It is also possible that his or her energy needs will always be higher than someone without CHD. Here are some general guidelines to follow. For more information, consult a dietitian:

- Eat foods from all food groups (vegetables, fruits, meat/protein, dairy, grains).
- Choose whole grains when possible (whole wheat bread, whole wheat pasta, brown rice, oatmeal, whole grain cereal, etc.). Avoid foods made with white flour.
- Choose lean meats (turkey, chicken, lean beef, fish).
- Use low-fat methods to cook foods (baking, broiling or grilling instead of frying).
- Limit the use of a salt shaker and limit frozen, canned and boxed foods, which are generally higher in sodium/salt.
- Choose fresh fruits over fruit juice.
- Eat a variety of non-starchy vegetables daily.

For more information about healthy eating for the whole family, visit [ChooseMyPlate.gov](https://www.ChooseMyPlate.gov).

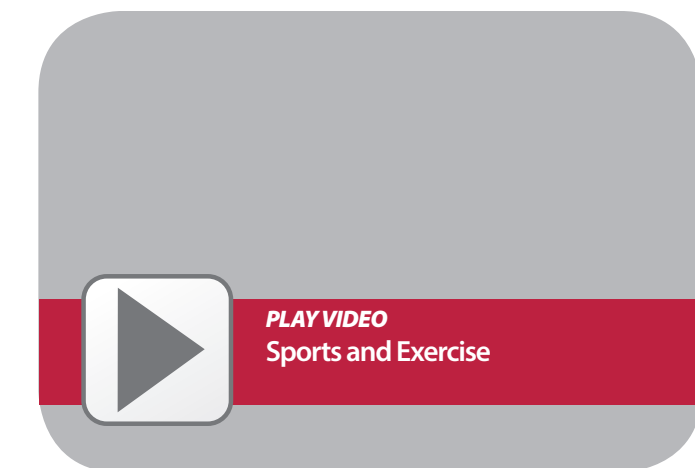


# Exercise for Patients With Congenital Heart Disease

In the past, children with CHD were often advised not to exercise to “be on the safe side,” but as more children with CHDs started surviving into adulthood, this approach changed. Preventing them from getting the health benefits of exercise, such as weight and blood pressure control, may end up doing more harm than good. Because we now expect most people with CHD to live into adulthood, we also have to consider how lack of exercise could negatively impact their cholesterol levels. In addition to its well-known cardiovascular benefits, exercise can also significantly improve a person’s sense of well-being. Preventing a child from participating in physical education classes, recreational sports or even competitive sports can have negative social and emotional effects.

Many parents wonder whether it is safe to let a child with CHD exercise. They fear that their son or daughter will push his or her heart too hard or make it beat too fast. Children also tend to get out of breath during exercise, and it can be frightening to see your child panting or trying to catch his or her breath. Despite these worries, exercise can help children with CHD stay healthy. Your child’s cardiologist will be able to advise you on your child’s needs and limitations. Although you may not want a teenager with certain heart problems to play high school football, it might be okay to let them play some other competitive sport that does not involve bodily collisions. It’s unlikely that turning your teenager into a couch potato will be good for him or her in the long run.

For certain people with CHD, the risk of some forms of exercise does outweigh the benefits. These individuals include, but are not limited to, those at high risk for dangerous heart rhythms (long QT syndrome,



hypertrophic cardiomyopathy, etc.); those at risk for tearing an enlarged or weakened blood vessel (Marfan’s syndrome, aortic aneurysms, etc.) or for bleeding (anticoagulation treatments); those with severe aortic stenosis, certain coronary artery problems, uncontrolled high blood pressure or vital medical hardware that might be damaged (pacemaker, defibrillator, etc.). Additionally, most children will need fairly significant exercise restrictions for several weeks after heart surgery but can eventually return to full activity. Anyone with CHD who has had symptoms associated with exercise should talk to their cardiologist.

Overall, there are many more questions than answers when it comes to this topic, and the risk of exercise is different for every patient. That’s why it is important to have a discussion with your child’s cardiology team to determine what kinds of exercise are appropriate. Make sure the discussion focuses on what your child can and should do to stay healthy rather than what he or she cannot do. Focusing on the risks of exercise while ignoring the benefits may shortchange your child in the long run.

For more information on exercise for CHD patients visit [CardioSmart.org](http://CardioSmart.org) and [Heart.org](http://Heart.org)’s online resources.

# Neurodevelopmental Issues in Children With CHD

The American Heart Association recently published a **statement** indicating that children with more severe congenital heart defects are at higher risk for neurodevelopmental issues. In simple terms, this means that kids with some forms of CHD (usually those that require surgery and regular follow-ups) will not meet developmental milestones at the same time or perform at the same level academically as their healthy peers. (The CDC has information about **normal developmental milestones**.) These children may also have behavioral issues such as attention deficit disorder (ADD) more often than other children their age.

Parents and caregivers of these children should be aware of potential neurodevelopmental issues so that their child can get early treatment for any problems that may arise. Addressing these issues early will help your son or daughter feel more confident and give him or her a better chance for developing life skills and attaining educational success. Not all children with CHD will have neurodevelopmental issues, and those who do often adjust very well and do not appear any different from their peers. Still, it is important to get screenings to avoid any learning problems your child may have.

## What is a neurodevelopmental issue?

There are two types of neurodevelopmental issues:

- **Developmental disability:** A limitation or disability of the cognitive function of the brain or the way the brain handles emotion, behavior and learning. It may also be a physical limitation.
- **Developmental delay:** Developmental, physical and/or mental skills that are not at the same level as other children of the same age.

In addition to social and psychological issues, children with complex CHD have a significantly higher risk of disability in the following areas:

- Intelligence
- Academic achievement
- Language (development, expressive and receptive)
- Visual construction and perception
- Attention
- Executive functioning
- Fine and gross motor skills
- Psychosocial maladjustment (internalizing and externalizing problems)

## Who is at risk?

Children with milder forms of CHD, such as atrial septal defects (ASDs), do not seem to have a higher incidence of developmental disabilities than their peers. Children who were on cardiopulmonary bypass during surgery or children who were born cyanotic (decreased blood oxygen) seem to be at the highest risk. Some types of CHD that increase the risk of neurodevelopmental issues include:

- Coarctation of the Aorta (Coarc)
- Tetralogy of Fallot (TOF)
- Ventricular septal defect (VSD) with **comorbidities**
- Total anomalous pulmonary venous return (TAPVR)
- Single ventricle defects
  - Hypoplastic left heart syndrome (HLHS)
  - Hypoplastic right heart syndrome (HRHS)
  - Tricuspid atresia



- Double outlet right ventricle (DORV)
- Double outlet left ventricle (DOLV)
- Transposition of the great arteries (TGA)
- Truncus arteriosus
- Interrupted aortic arch
- Children with syndromes associated with CHD
  - Down Syndrome
  - 22q 11 Deletion
  - Noonan Syndrome
  - Williams Syndrome

## How do I find out if my child has a neurodevelopmental issue?

If you notice problems with your child's development at any point, contact their primary care doctor or cardiologist right away. Early detection and treatment of issues is important. All children in the high-risk category should be screened for developmental disabilities at 12 to 24 months, again at three to five years and again at 11 to 12 years of age. Your child's primary care doctor or pediatrician may be able to conduct this screening during a normal wellness visit. Neurodevelopmental pediatricians are also able to perform these screenings, and some children's hospitals have specialized clinics for screening and treating neurodevelopmental issues in children with CHD. The **Development and Education** form in this HeartGuide can help you keep track of your child's progress and screenings.

## What resources can help me get the best care for my child?

Most cities, counties and states have resources to help children with developmental delays and disabilities. Before you even leave the hospital, your hospital's social worker may be able to recommend resources such as physical therapy, occupational therapy and early intervention services if needed. Record these on the **Development and Education** form in this Mended *Little HeartGuide*. If you are connected with a local support group, other parents and caregivers in that group can also guide you to resources and programs in your area.

Many school systems have a process to help detect delays and disabilities in school-aged children. If you have concerns about your child's academic performance, ask for a meeting to discuss any problems you are seeing. Your state's Department of Education website will help you find educational resources and provide you with information that can help guide you through the process of handling any special educational needs your child may have. There are also probably educational consultants in your area who can work with your child and help you coordinate the services that he or she needs. Finally, there are helpful resources for parents with disabilities at the **Center for Parent Information and Resources website** and on the **Special Education Advisor website**.

## Don't be discouraged.

Parents and caregivers often find it hard to come to terms with the fact that their child may have neurodevelopmental issues, but please don't feel discouraged. Most children with CHD — even those with the most severe forms — appear no different than other kids their age. They are usually happy, well-adjusted children. Being aware of the risk of neurodevelopmental issues will help your child get the services he or she needs to have the highest chance of success.

# Congenital Heart Disease: A Lifelong Journey

The good news is that most children born with CHD will survive into adulthood. In fact, today there are more adults than children living with CHD. However, people living with CHD will require specialized care throughout their lives. Living with CHD is a lifelong journey, but it can be a happy and healthy one with appropriate care.

Often, parents believe (and some are even told) that their child is “fixed” after their surgery or heart procedure. While your child may appear normal and may have absolutely no restrictions, he or she still needs specialized lifelong care. Even people who have technically minor congenital heart defects that were repaired during childhood should visit a cardiologist who specializes in CHD at least once as an adult. Children with more complex defects should receive regular cardiac care throughout their lives, even if everything seems fine. CHD patients who don't receive regular treatment could end up in an emergency situation that could have been avoided with regular care. Always follow your child's cardiologist's recommendations for check-ups.

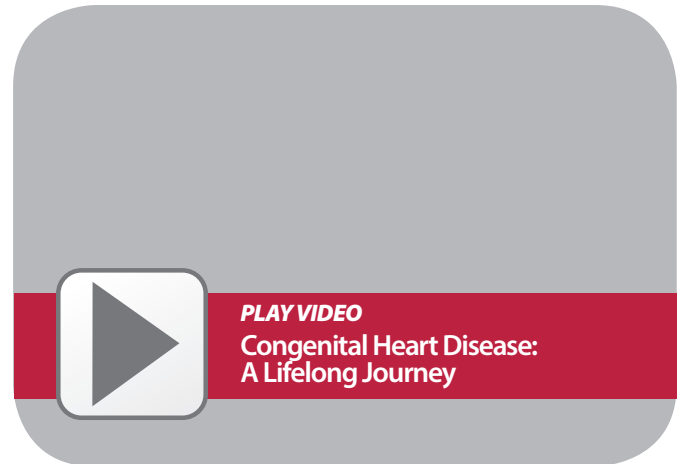
The American College of Cardiology and the American Heart Association have published a guide, **“Management of Adults With Congenital Heart Disease,”** on this topic.

## Empowering Your Child to Become a Healthy Adult

A big fear of many parents and caregivers is that their child with CHD will not take proper care of themselves and their heart during adulthood. There are some things you can do to facilitate the transition from pediatric to adult CHD care:

### **Talk to your child, in age-appropriate ways, about his or her heart defect.**

Don't hide information. As soon as your son or



daughter is old enough, discuss and provide information about his or her heart defect. Share the name of the defect. Some CHD names are tough, even for adults, but helping your child learn about their CHD will help with proper lifelong care.

There is some helpful information written for Teens with CHD on the **Pediatric Heart Network Web site.**

### **Help your child learn which medications he or she takes and why.**

Sometimes, when children with CHD are on their own, they stop taking some medications because they don't like the side effects or don't want to pay the high price to get refills. If your son or daughter understands the reason for each medication, he or she is more likely to keep taking it as an adult.

### **Involve your child in medical care.**

Encourage your child from an early age to ask the cardiologist and other doctors questions. This will help him or her feel more empowered and in control, and that feeling will continue into adulthood. Get your child in the practice of writing down questions before appointments. By the age of eight, your child should be able to answer some of the doctor's questions. Parents and caregivers often answer out of habit, but

stop and let your child answer questions such as, “How are you feeling?”; “Is anything new happening?”; or “What medications are you taking?” (Children may not know the dosages or spelling of medications, but they may know the names.)

### Let your teen talk to the cardiologist and other doctors alone.

Yes, we know how uncomfortable this makes you feel. Parents and caregivers can talk to the doctors after the appointment. Get teenagers used to managing their own health by allowing them to practice before they are out on their own. We know this is very difficult and that you will worry, but the goal is to raise adults with CHD who can care for themselves.

### Help your teen find an adult congenital heart disease (ACHD) specialist.

Help your teen find an ACHD specialist and make an appointment with that specialist before your child reaches the age of 18. Better yet, have your son or daughter make the appointment. The Adult Congenital Heart Association has a listing of ACHD specialists on their website at [ACHAheart.org](http://ACHAheart.org).

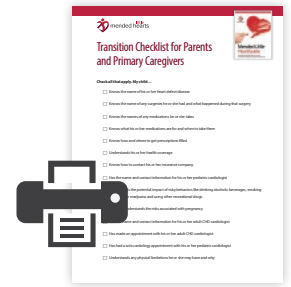
### Teach your child how to keep and organize medical records.

You may use a binder, keep scanned copies on the computer or flash drive, or use another method that works well for you. Keeping organized medical records in one place is an important part of managing care and extremely helpful when changing medical providers. It will also help your child relay the proper information to his or her adult CHD cardiologist.

## Transition Checklist for Parents and Primary Caregivers

Check all that apply. My child...

- ☐ Knows the name of his or her heart defect/disease
- ☐ Knows the name of any surgeries he or she had and what happened during that surgery
- ☐ Knows the names of any medications he or she takes
- ☐ Knows what his or her medications are for and when to take them
- ☐ Knows how and where to get prescriptions filled
- ☐ Understands his or her health coverage
- ☐ Knows how to contact his or her insurance company
- ☐ Has the name and contact information for his or her pediatric cardiologist
- ☐ Understands the potential impact of risky behaviors like drinking alcoholic beverages, smoking cigarettes or marijuana, and using other recreational drugs
- ☐ If female, understands the risks associated with pregnancy
- ☐ Has the name and contact information for his or her adult CHD cardiologist
- ☐ Has made an appointment with his or her adult CHD cardiologist
- ☐ Has had a solo cardiology appointment with his or her pediatric cardiologist
- ☐ Understands any physical limitations he or she may have and why



Print a PDF of this list

# The Financial Impact of CHD on Families

The financial impact on your family is probably the second-most stressful part of having a child with CHD. We make health care decisions based on what is best for our children, not what is best for our wallets, so we are often faced with intimidating medical bills after a hospital stay. This can cause a huge strain on young families. Being aware of financial considerations early in your child's life can help you plan (as much as possible).

## Living With Uncertainty

Having a child with CHD means living with a lot of uncertainty when it comes to expenses. Obviously, this can lead to stress. Talking with other parents of children with CHD about how they managed may be very helpful. They may also be able to point you toward some useful resources in your city, county or state that can help ease the financial burden on your family. Your hospital social worker may also be able to recommend options to help during and after your child's hospital stay. While life has definitely become less certain for you and your family, remember that you will get through this and that help is available.

## Managing Your Expenses

While you may have a lot of financial uncertainty now, there are things you can do to help keep your finances manageable. Many people want to avoid even thinking about or looking at their financial situation, but that uncertainty just leads to more stress. Facing it head-on will help you manage it and feel more in control. Here are a few tips:

- Create a new budget that includes any medical payments you may have. Schedule a day of the week to look at your bank account and pay your bills. If possible, pay off or at least reduce



the balance of credit cards to minimize the interest you'll pay on your debt.

- If you have to give up something to save money, find out if there is a less expensive alternative.
- Talk to a financial consultant. Sometimes there are ways to save money that you may not have considered. There are resources available to help families like yours manage their finances.



- Create a payment plan with your hospital or doctors. Many parents and caregivers take one look at medical bills and panic. The bills may be too big for you to handle at this time. Call the billing department and set up a payment plan you can manage. Even paying a little each month is better than avoiding bills altogether.

## Lifestyle Changes

While this Mended *Little* HeartGuide is designed to be a useful resource that helps to reduce stress, parents and caregivers do need to be aware of lifestyle changes that families experience. The truth is, understanding and mentally starting to accept that these changes might be necessary can reduce stress down the road by helping you avoid surprises. Lifestyle changes experienced by many families who have children with CHD include:

- **A parent changing or leaving a job:** Sometimes, a parent will need to change employers or quit his or her job to stay home with a child who has CHD. Changes in employment can happen for a variety of reasons — a need for better insurance coverage, more flexible hours, more time off or a shorter commute. These choices can cause significant stress on the family, both in terms of reduced income and reduced satisfaction for the unemployed parent, but they can also help both parents feel more secure and in control of their child's care.
- **Changes in spending:** Some families who have children with CHD need to reduce spending because of medical bills or changes in employment. This can cause anger and resentment, both of which are completely normal. The best way to reduce negative feelings is to find fun things you can do as a family that are low-cost or free. Focus on the

many things you have rather than the things you have to give up. This is hard to do, and there may be days when you still experience negative feelings, but focusing on the positive creates a better atmosphere for your whole family.

- **Day care/childcare arrangements:** Childcare may be a little trickier for the parent or caregiver of a child with CHD. Some choose to avoid day care/childcare entirely because they are concerned about exposure to illnesses. Others have to change childcare because their former provider is not willing or equipped to care for a child with CHD (CPR training, AEDs, emergency plans, etc.). Still others avoid day care around the time of surgeries but use it at other times. Ask your child's cardiologist about day care if you are a single parent or if your family needs both parents' incomes to pay the bills. Many children with CHD do fine in childcare situations, but others may not.
- **Relying more on extended family and others.** While having help from friends and extended family is a blessing, it can also cause stress for everyone involved. Parents and caregivers may feel guilty and uncomfortable about needing help, and friends and extended family often don't know what to do to help. Remember that your friends and family want to help you, so let go of the guilt. Make a list of things that need to be done to keep your life running, and be realistic about what you have the time and energy to accomplish. Keep the list handy, and next time a friend or family member asks how they can help, pick something from the list.

# Building Positive Self Esteem in Children With CHD

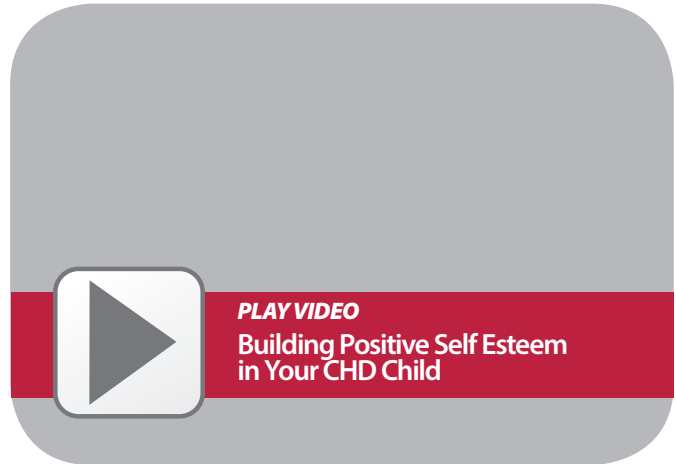
Many parents and caregivers of children with CHD worry that their kids will lack self-esteem because of their illness and/or scars. All children have phases where they feel better or worse about themselves. Your child will experience the same thing. These phases are normal, but your child may associate negative feelings with his or her CHD. While kids, especially teens, do struggle with feeling “different” from their peers, there are things you can do to help your child build a positive self-image:

## Check your own attitude first.

The attitudes of parents and primary caregivers have the greatest impact on a child's attitude and beliefs about him- or herself. If parents believe their children are fragile, sickly, weak or helpless, that is exactly what their kids will believe. Parents who are angry about their child's CHD or feel sorry for their child make their sons and daughters feel like victims and teach them that their CHD is something shameful that should be hidden. If you put yourself down or are angry, over-tired or always stressed, children are more likely to go down the same path. Avoid negative statements about yourself, too, so your child will be less likely to copy that behavior.

It is understandable and normal to have negative feelings about CHD. It isn't fair that your child has to have surgeries, medical procedures, medications, many appointments, etc., but most children are a lot stronger and more resilient than we think they are ... if we allow them to be. Stay positive. That doesn't mean denying your child's CHD, but it does mean thinking of your child as your son or daughter first rather than as a CHD patient.

One trick parents can use is what we call “pattern



interrupt.” When you find yourself feeling sorry for your child or thinking of your child as sick and fragile, notice those thoughts and think, “Pattern interrupt!” Then, quickly replace these feelings with something positive about your child so that the vacuum you have created will be not fill with more negativity. Think something like, “Wow! My child made it through open-heart surgery! That shows how strong she is!” or “My son is such a happy child even though he has been through so much. That shows his resilience and courage.” The more you can do this, the more positive your attitude will be about your child — and yes, even about CHD.

## Talk openly about your child's CHD.

Of course you would eliminate your child's CHD if you could, but it is here, so you need to accept it. Some parents try to avoid any mention of their child's condition in an attempt to live a “normal” life. That's understandable, but what happens when your son or daughter needs a procedure or surgery? They will be caught completely off guard and may feel angry or



betrayed. Children would rather understand what is going on than know that they have a problem no one will talk about. Kids know when something is different about them, and they know when parents are trying to hide something. Avoiding the topic of CHD will make your child feel that there is something wrong with him or her. Learn to talk about it early in an age-appropriate way. Talk to a social worker or counselor if you need help with this. Being open and honest about your child's health problems will make it seem like he or she has nothing to hide or be ashamed of. It will help your whole family accept the situation and live a more "normal" life — just a different kind of normal.

### **Focus on your child's abilities, not limitations.**

Parents and caregivers may believe that their child has the same limitations as another child with the same

CHD. Don't make those assumptions. Finding out what your child can do and what his or her limitations are will require an honest talk with your child's cardiologist and pediatrician. Things change as your child grows, so you may need to have the conversation several times. Sometimes, for example, children with CHD can play a rigorous sport when they are younger but have to stop as that sport becomes more physically taxing and competitive. When your child wants to do something that he or she can't do because of CHD, offer other options. If your child really wants to play football but can't, suggest baseball, golf or another sport recommended by his or her doctor. When your child is old enough (usually around eight years old), allow him or her to talk to the doctor about limitations and activities. Having someone other than a parent explain the reasons for limitations can help.

## **Allow your child to have privacy.**

As soon as your child is old enough to understand what is happening, avoid showing off scars and making your child the center of attention if it makes him or her uncomfortable. Many times, parents and caregivers are so busy trying to support other parents or raise awareness about CHD that they don't notice how uncomfortable their child is about being showcased. Children's scars are part of their bodies and should be kept private if that's what they want. Some kids like to show off their scars and talk about CHD; it makes them feel brave and strong. Other kids do not. Respect your child's wishes and allow for privacy. That doesn't mean you can't tell their story to others or raise awareness, but do so without involving your child.

Some kids are very uncomfortable with their CHD for a year or two but then come out of that phase if they are given space. Always make it okay for your child to refuse to talk about their heart defect, no matter who asks — even teachers or other adults. Teach your son or daughter to politely answer: "I would rather not talk about that right now. It's private." This will help your child feel secure and in control.

## **Admit that CHD isn't fair, but don't encourage wallowing.**

Let's face it, CHD is not fun or fair, but the fact is, your child has to live with it. If they feel angry or sad about it, don't minimize those feelings with platitudes like "It could be worse," and "You should be grateful you are alive," but don't participate in complaining, self-pity or anger, either. Sometimes, your child just needs a listening ear or someone to say, "Yes, this does stink." Sometimes a hug, a smile or a fun outing together can make a big difference. If your child goes through an angry or depressed phase, don't try to fix it (yes, you'll have a hard time with this), just keep giving them love — even if they won't let you close — until the phase passes. Seek counseling if you feel it would help or if

they become depressed or experience extreme emotions.

## **Understand that adversity isn't always bad.**

Many times, parents assume CHD is bad and that their child's struggle will cause harm, but many people who travel through adversity are kinder, stronger and more self-confident because of the experience. Living with a chronic illness can also make kids more compassionate toward others. Recognizing your child's strength and resilience will help build confidence. Tell your child how courageous he or she is. Parents and caregivers would take away their child's CHD in an instant if they could, but most acknowledge that the experience of dealing with it has somehow made them a better person. It is the same for your child.

## **Find other families with children who have CHD.**

Often, meeting other kids with the same or similar CHD can make your child feel more "normal" and confident. This is true for the siblings of children with CHD too; talking to other siblings makes their experience seem less scary. Even meeting adults with the same CHD can be inspiring to children, especially teens, and make them feel more hopeful.



# Frequently Asked Questions

Many families have questions about how various activities will affect children with CHD. The biggest worries are about exercise, but other activities such as air travel and even rollercoaster rides raise concern. The truth is, there are no clear answers to some of these questions, but experts agree on some things, and those are the answers we are presenting here. These recommendations do not come with any guarantees, and following these guidelines does not eliminate the possibility that something could go wrong. These are, however, the best answers we have to some common questions.

## Is it safe for children with CHD to travel by plane?

Many parents worry that commercial air travel might be dangerous for children with CHD. There are a few important things to know: Commercial airplanes are usually pressurized to the equivalent of an altitude of 5,000 feet (about the same as Denver, Colorado) to 8,000 feet (a little higher than Mexico City). Private aircraft may not be pressurized to the same degree.

Higher altitudes can make it just a little harder to get blood to move through the lungs, but that doesn't mean your child can't travel by plane. Although they tend to have lower oxygen saturations at higher altitudes, many children with CHD do surprisingly well with commercial air travel. Some people with CHD, particularly those with cyanotic conditions (where the blood oxygen is lower than normal) or single ventricle heart disease, may be affected, but most who are not cyanotic and do not have lung disease will not experience problems during commercial air travel. Always ask your child's doctor, but most children with CHD can travel safely by commercial airline.

## What if my child needs oxygen on a flight?

Unless they are on home oxygen, very few, if any, patients with heart problems will need in-flight oxygen. If your child is on home oxygen, check with your airline to learn about their policy on in-flight supplemental oxygen. Most airlines need advance notice about a patient's need for in-flight oxygen. Don't assume that you will be able to bring your home oxygen tanks on the flight!

## Is there anything else I should watch out for while flying with a child with CHD?

There are a few issues that might come up during air travel that are frequently overlooked but probably more important than the effects of altitude:

- It is easier to get dehydrated at higher altitudes, so make sure you and your child are getting enough to drink.
- Sitting for long periods of time can increase the chance of a venous blood clot, so make sure that you get up and move around now and then.
- Make sure you have access to your child's medications. Don't put them in your checked baggage. You might need access to them during a long flight or while at the airport, and if your luggage is lost, getting refills will certainly be a hassle.
- If your child has liquid medications, learn about the airline's policies and procedures for those before arriving at the airport.

- Take pictures of all medications or keep a record with you. Get refills before traveling so you don't run out.
- If your child needs special foods or formula, be sure to bring it with you on the plane.
- Make a list of doctors at your destination who could treat your child, if needed. Keep this list handy. Ask your child's cardiologist for recommendations if you can't find the information yourself.

Again, it is always best to talk to your doctor before air travel to make sure your child is okay to travel via plane. If your child has both lung disease and heart disease, you should speak with both your cardiology and pulmonary teams.

## Can my child play football or other contact sports?

Many parents of children diagnosed with a critical CHD are told that their child will never play contact sports or be a marathon runner. Parents have different reactions to this based on their hopes and dreams for their child. The fact is that some kids with CHD can play football and run marathons. One young man with CHD biked all the way across the nation. Other kids with CHD cannot do these things because their heart disease creates more limitations on what they can do. Kids with arrhythmias, for example, may have more medical restrictions than kids without them. Also, kids on blood thinners may be at greater risk for bleeding. Sometimes, children with CHD can play a sport like football when they are young (before it gets too competitive) but will not be able to keep up with their peers as they get older. Some kids will try a sport, like soccer, and find that they get out of breath too easily to enjoy the game. Each child is different.

The first step is to talk to your child's doctors to find out what his or her true limitations are and, more

importantly, what he or she is able to do. If your child is old enough, let your child ask the doctor directly. Some activities, like martial arts, might seem off limits but can be done in the right environment with the right precautions. When your child shows an interest in a sport you know they cannot play, you may feel sad, guilty or angry, but try to think in terms of what your child CAN do. If he or she loves football and baseball, focus more on baseball.

Don't set limits because of your fears; only limit your child if a doctor has set restrictions. Many kids with CHD are able to play sports and stay active, and we need to let them be kids.

## Can we live at high altitudes?

Many parents who have children with complex CHD are concerned about visiting or living in a place at high altitude. While babies with complex CHD in Denver do have lower blood oxygen saturations than babies living at sea level, that does not mean that those families can't live in Colorado. Ask your child's cardiologist about the considerations involved in living at higher altitudes.

## Can my child ride rollercoasters and other thrill rides?

This topic causes a lot of controversy. Unfortunately, there is no clear answer. It is something to discuss with your child's cardiologist. On one hand, parents and caregivers want kids to be kids and to have fun. On the other hand, we don't want our kids taking potentially life-threatening risks. Many thrill rides have signs warning people not to ride if they have a heart condition because there is a risk involved for heart patients, and that risk includes the possibility of death. Some kids with heart conditions have died on thrill rides. Most parents of children with CHD want their son or daughter to have a "normal" life with "normal experiences," but some risks may be too high. That is a decision to make with your child's doctors.

## Does my child need antibiotics for dental treatment?

Some children with certain congenital heart defects need antibiotics, like amoxicillin, one hour before dental treatments or procedures throughout their life to prevent endocarditis. Endocarditis is a condition where bacteria takes up residence in the heart and begins to grow. As the bacteria grows, it damages the heart. The best way to prevent endocarditis is to practice good dental care. People with CHD should see a dentist every six months. Parents should begin familiarizing their child with the dentist at age two. If your child has teeth, brush them twice daily.

The practice of providing antibiotics prior to procedures is called antibiotic prophylaxis. It should also be used for dental treatments that take place during the first six months after a surgery or heart catheterization where a device was used. The list of conditions requiring antibiotic prophylaxis is frequently revised, so ask your cardiologist if your child's condition warrants antibiotics before dental treatments.

## Should my child with CHD get immunizations?

This is another issue that needs to be discussed with your child's cardiologist and pediatrician. They may decide to wait on certain immunizations or to give immunizations (such as those for RSV and pneumonia) that other kids without CHD do not get. They may also encourage you to give your child an influenza (flu) vaccination every year because children with severe heart defects are at higher risk of death and serious illness from the flu.

It is important for parents and caregivers to understand what immunizations are for and why their child needs them. Don't hesitate to ask your child's doctors questions until you understand immunizations, and ask for a schedule for your child's immunizations. If you

want to have your child immunized on a different schedule than the one suggested, let doctors know. Often there is flexibility in the schedule. If you are strongly opposed to an immunization, discuss it with your child's doctor to find out whether there are any alternatives and to understand the true risks if your child does not receive that particular immunization.

# Part 5: Forms



Print a PDF of  
**Part 5: Forms**

- ▶ About My Child's Heart
- ▶ Diagram of My Child's Heart
- ▶ Diagram of a Healthy Heart
- ▶ Creating a Binder to Stay Organized
- ▶ My Child's Doctors
- ▶ Medications
- ▶ Other Specialists and Resources
- ▶ Appointment Log
- ▶ Growth Tracking
- ▶ Feeding My Child
- ▶ Tests and Procedures
- ▶ Development and Education
- ▶ Transitioning to Adult CHD Care (For Your Child)
- ▶ Emergency Plan
- ▶ Letter to Family and Friends
- ▶ Questions for Doctors
- ▶ Notes



# Creating a Binder to Stay Organized

When you receive a lot of information and paperwork, it can be hard to stay organized. Here are steps you can take to create a binder to store important information and documents:



1. Get a one- to two-inch, three-ring binder (two inches is better if you have a LOT of papers).
2. Get or borrow a three-hole punch.
3. Get dividers with tabs and pockets.
4. Create the following tabs (these are just suggestions — you may want others):
  - a. My Child's Heart
    - Diagram of your child's heart
    - Information about your child's CHD
    - Information about surgeries and procedures
  - b. Doctors & Specialists
  - c. Medications
    - Put prescriptions in this section
  - d. Resources
    - Support team with contact information
    - Early intervention services
    - Educational services
  - e. Insurance Information
    - Insurance policy and number
    - Explanation of benefits (EOB)
  - f. Medical Bills
    - You may divide this further by type of bill: cardiologist, primary care doctors, anesthesiologist, radiologists, etc.
  - g. Other Information
  - h. Emergency Plan

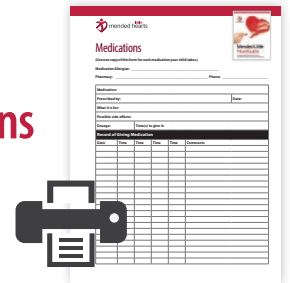


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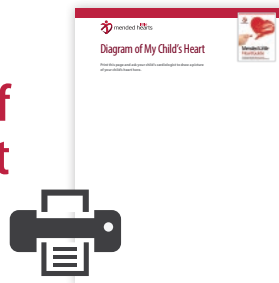
## About My Child's Heart



## Medications



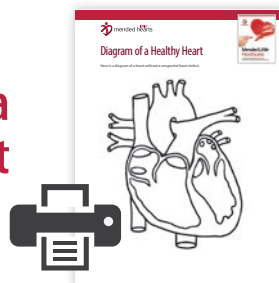
## Diagram of My Child's Heart



## Other Specialists and Resources



## Diagram of a Healthy Heart



## Appointment Log



## My Child's Doctors



## Growth Tracking

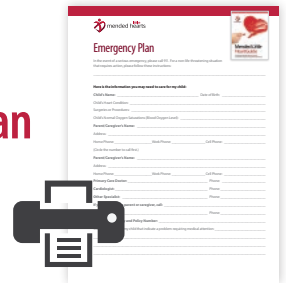


## Feeding My Baby



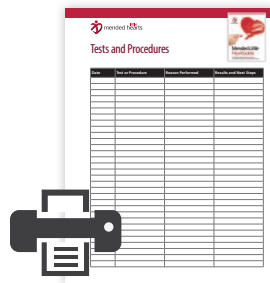
The 'Feeding My Baby' form is a checklist for parents to track their baby's feeding progress. It includes sections for 'Feeding My Baby' and 'Feeding My Baby' with a table for recording feeding times and amounts. The form is titled 'Feeding My Baby' and has a 'Print' button.

## Emergency Plan



The 'Emergency Plan' form is a checklist for parents to prepare for emergencies. It includes sections for 'Emergency Plan' and 'Emergency Plan' with a table for recording emergency contacts and procedures. The form is titled 'Emergency Plan' and has a 'Print' button.

## Tests and Procedures



The 'Tests and Procedures' form is a checklist for parents to track their baby's medical tests and procedures. It includes a table for recording test results and procedures. The form is titled 'Tests and Procedures' and has a 'Print' button.

## Letter to Family and Friends



The 'Letter to Family and Friends' form is a template for parents to write a letter to their family and friends. It includes a section for 'Letter to Family and Friends' with a table for recording family and friends' contact information. The form is titled 'Letter to Family and Friends' and has a 'Print' button.

## Development and Education



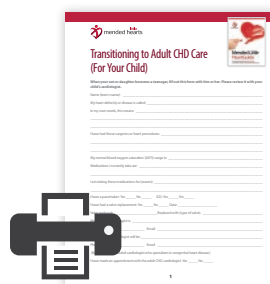
The 'Development and Education' form is a checklist for parents to track their baby's development and education. It includes a table for recording development and education milestones. The form is titled 'Development and Education' and has a 'Print' button.

## Questions for Doctors



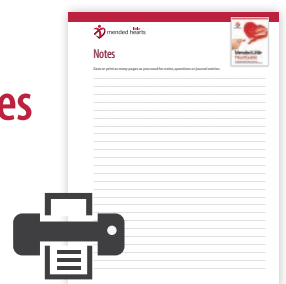
The 'Questions for Doctors' form is a template for parents to write questions for their doctors. It includes a section for 'Questions for Doctors' with a table for recording questions and answers. The form is titled 'Questions for Doctors' and has a 'Print' button.

## Transitioning to Adult CHD Care (For Your Child)



The 'Transitioning to Adult CHD Care (For Your Child)' form is a checklist for parents to track their child's transition to adult care. It includes a table for recording transition milestones. The form is titled 'Transitioning to Adult CHD Care (For Your Child)' and has a 'Print' button.

## Notes



The 'Notes' form is a template for parents to write notes. It includes a section for 'Notes' with a table for recording notes. The form is titled 'Notes' and has a 'Print' button.



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