



little  
mended hearts

**Family  
Information  
Pack**



## Dear Friend,

Mended *Little* Hearts is made up of many parents and caregivers who have had a child diagnosed with a heart defect or heart disease, and we understand the emotions that can come with this diagnosis. Having a child who needs heart surgery or other procedures is often devastating, and parents and caregivers need support that can come from others who have been through similar experiences. We also understand that parents and caregivers are often searching for answers as they try to make the best decisions in caring for their child.

Mended *Little* Hearts designed this Family Information Pack to empower parents and caregivers by providing educational information written and reviewed by medical professionals, but edited by parents and caregivers of children with heart defects. There are some informational materials to help you connect with other moms, dads, caregivers and family members who have kids that were born with heart defects or heart disease. This Family Information Pack also provides some educational materials about heart defects in kids. In addition, there are forms to help you keep organized during your child's hospital stay and when you return home. Often you are given so much information that it is difficult to keep track of it all, so this Family Information Pack will help you feel more in control.

Please know that Mended *Little* Hearts is there 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.

Best Wishes,  
Mended *Little* Hearts

**Note to Reader:** There is often a lot of confusion and discussion 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 Family Information Pack, “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 is 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 of its use.



## **CONNECTING WITH OTHERS**

Many times, when parents and caregivers find out their child has a congenital heart defect or heart disease, they feel very alone. Through Mended *Little* Hearts, you can connect to other parents and caregivers who have children with congenital heart defects and heart disease and join a caring support network. Here are some ways you can get connected:

### **Connect with a local support group**

Mended *Little* Hearts has over 80 groups throughout the nation for parents and caregivers of children who have congenital heart defects and heart disease. Please visit our website at [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org) and click on "Find A Group" to get the information about a group near you. You can also call 1-888-HEART99 (1-888-432-7899) 8:00 a.m. – 5:00 p.m. CST and someone will be glad to help connect you.

### **Join a closed Facebook group or follow us on social media.**

Mended *Little* Hearts has a closed Facebook group, "MLH CHD Chat," where parents, caregivers and people affected by congenital heart disease can join with others who have had similar experiences. In MLH CHD Chat you can feel safe asking questions, expressing concerns and talking about your child or your experiences. Simply request to be added to that group on Facebook, and you will be added.

Mended *Little* Hearts also has an open Facebook page, "Mended *Little* Hearts National Organization," where followers can learn about new groups around the nation, find out about national and local activities, and learn about new technology, research and treatment for congenital heart disease. We are also on Twitter at MLH\_CHD, and you can follow us.

### **Join Parent Matching**

Mended *Little* Hearts has a Parent Matching program where we connect parents via email to other parents who have a child with the same heart defect or a similar heart defect. Parent Matching participants will receive email messages of support from other parents. Participants will also have the opportunity to give support, if they choose, as parents join who have a similar heart defect to their child. 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, and educational materials and resources available to families. There is no cost to join. You can join on the Mended *Little* Hearts website or call 1-888-HEART99 (1-888-432-7899).

## THINGS YOU MAY BE FEELING

Parents and primary caregivers of children with congenital heart defects often experience many emotions when their child is diagnosed with a congenital heart defect, especially if their child needs surgery or other heart procedures such as cardiac catheterization. You are suddenly thrust into a world that is scary and confusing. It is important to acknowledge negative feelings and know that feeling grief, anger, fear, and confusion after your child is diagnosed with a congenital heart defect (CHD) is completely normal. However, it is also important to seek help if you believe these feelings are taking over your life or causing depression.

### Grief

It is completely normal for parents and caregivers to feel grief when their child is diagnosed with a CHD, when their child needs surgery or is hospitalized, and even occasionally throughout the lifespan of the child. Grief is often strongest in times of crisis, but it can pop up at other times—sometimes unexpectedly—during a child’s life as well.

There are some common reasons for the grief that parents may not even realize. When talking about the gender of a child before birth, many parents will say, “I don’t care so long as the baby is healthy.” When a child has a CHD, the child is not the “healthy child” the parents had hoped for, and although they didn’t lose a child, it is normal for parents to mourn the healthy child without a heart defect that they didn’t have. It is not that parents don’t love their child with CHD, but they expected to have a child that wouldn’t be faced with many of the challenges some CHD children have. Also, if limitations are placed on the child (such as limitations on sports or activities) parents feel grief that their child won’t be able to participate in some things “normal” children can do. In addition, there is grief for other children in the family whose lives are changed because they have a sibling with CHD.

Grief can be worsened by guilt. Parents often feel that they should be grateful their child is alive or that their child’s situation is not worse, and they feel guilty that they are sad instead. These guilty feelings are also normal, but they increase the grief.

### Helpful Tips in Managing Grief

- Acknowledge the grief. If you try to fight or avoid the grief, or if you feel guilty about the grief, it will just get 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 those feelings. However, understand your goal is to move out of grief rather than to stay in it.
- Keep a journal about your feelings. Sometimes writing feelings out on paper helps to lessen their impact on you. Keep your grief journal separate from your everyday journal, if you have one. Don’t go back and read what you wrote—just get it out as a means of letting it go.

- Keep a list of things you are grateful for. We know it is very, very hard to feel grateful for anything during this time, but if you can, simply list one thing in your life you are grateful for each day, even something that may seem very minor. Gratitude helps heal.
- Talk to others who understand what you are going through. If you can, connect with a support group or a support system. Be sure the support you join gives positive support even though you may be discussing negative feelings and emotions.
- If your child will have limitations, ask about the things your child can do. Focusing on what your child can do will help create a different attitude that, in the long run, will help both you and your child.
- Talk to a grief counselor. Often people who specialize in grief can help you work through the process. Again, you may think you don't need a grief counselor if you didn't lose a child, but you did lose a child—a child without CHD.

## **Fear**

There is no doubt about it, CHD is scary. Most parents and caregivers worry about their children to some extent, but those who have children with CHD often worry far more than others. The biggest fear parents and caregivers of children with CHD have is that their child will die. Another major fear is that their child will be exposed to germs and other illnesses that could harm them. Some parents are even afraid to leave their home with their child. Parents and caregivers are also often afraid of their ability to care for a child with medical condition that needs special care. Again, it is completely normal to be afraid. There still are more questions than answers for children living with CHD, and not all children with CHD do well. However, you want to avoid having fear control your life because fear about something doesn't change it, but it does decrease the quality of life for you and the whole family.

## **Helpful Tips for Managing Fear**

- Follow this three-step process:
  - a. Acknowledge your fears. Ask yourself, "What am I afraid of?" Be specific and write them down if you can.
  - b. Control the things you can. For example, if you are afraid of your child getting sick, take steps to keep the whole family healthy like eating healthy foods, exercising, washing hands often and avoiding people who are sick. If you have fears about your child's medical condition, talk to your doctor about it. Sometimes, an honest conversation with the cardiologist can reassure parents.
  - c. Let go of the things you can't change. There are some things you will not be able to control, and as much as you can, release those fears. Going into the "what ifs" doesn't do anything but rob you of quality time with your child.
    - i. One "letting go" technique is to schedule a time during the day (no more than 15 minutes) to let your mind go and think about everything you are afraid of. The rest of the day, when the fear comes up, remind yourself that you have a time scheduled to deal with it, but you are not going to think about it right then. This increases your sense of well-being the rest of the day.
    - ii. Another technique is to write your fear down (write each fear separately) on a piece of paper. Fold it and place it in a sealed container (a jar with a tight seal or a box you can close). When you place that fear in the container, give it to a

higher power than yourself to handle (depending on your belief system).  
Putting that fear away can help you to release it.

- Find out what the biggest concerns are. Ask your child's doctor so you understand what things are true concerns and what things are not. Your child's doctor will be able to explain real limitations and concerns about your child's condition. Ask about exposure to other kids and families and to illnesses. You might be surprised to find your child and your family can do more than you believed.
- Join a support network. Often parents see other kids with the same condition as their child and adults living successfully with CHD for the first time at a support group meeting or event. This can help lessen fears and give parents hope that there can be a bright future for their child. They also see other parents and caregivers caring for their child with CHD and managing well.
- Talk to others who understand. Sometimes just stating your fears to someone who has walked your path, no matter how silly they may seem to you, can be very helpful. When you learn that others have the same fears, it gives you reassurance that it is not uncommon to feel the way you do.
- Stay in the present moment. The second the "what ifs" start, take some deep breaths and come back to here and now. You cannot control the future, and you don't know what may happen. Thinking of the future is scary for many parents, so stay focused on now. The truth is, we don't know what the future holds for any of us, and we don't want to waste the time we have right now living in fear. Replace fear thoughts with better thoughts as soon as you notice they are taking over.

## **Guilt**

Many parents, especially moms, feel like they did something wrong to cause their child's CHD. These feelings of guilt are very real, and you should acknowledge them, but you do need to let them go.

***There is no known cause of CHD at this point.*** There are factors that may make it more likely for you to have a child with CHD, but that doesn't mean you caused it or that you should feel guilty. You might hear about things mothers can do to help prevent having a child with CHD, and while this is good information for you in the future and for others you know who may be thinking about having a child, it does not mean anything you did caused your child's CHD. Making something more likely and causing it are not the same thing.

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

## **Helpful Tips for Letting Go of Guilt**

- Talk to someone you trust—someone who won't judge you—about your feelings of guilt. If you know another parent of a child with a birth defect who is doing well, he or she may be a

good person to talk to because it is very likely that person has had the same feelings you do and worked through them.

- Do NOT listen to anyone who blames you for your child's CHD. Unfortunately, sometimes even well-meaning people will place blame on a parent for their child's CHD. Again, there is no known cause of CHD. Therefore, it is not possible for someone to say anything you did caused the CHD..
- Treat yourself kindly. Even if you actually *had* caused your child's CHD (which there is absolutely no evidence for), feeling guilty about it does not help you or your child. Every time you start to feel guilty or start negative self-talk, focus on something positive and beautiful about your child instead. Look at your child as the miracle you were part of creating, CHD and all. Treating yourself kindly and loving yourself allow your child to feel positive about growing up with CHD.

### **Anger**

Most parents don't want to admit they feel anger when their child is diagnosed with CHD because they feel like it is wrong to be angry. However, it is very normal to feel anger when your child has CHD. You may feel like it is not fair (it isn't) and wonder why this happened to you. You may feel resentment towards others who have healthy children, especially when they don't appreciate how lucky they are. Well-meaning people may say things to you that are offensive and hurtful. Depending on your beliefs, you may also feel angry at God or feel like CHD is a punishment. All of these are feelings most parents and caregivers of children with CHD have felt at some point or another, and you are not a bad person for feeling them. (However, if your anger reaches a point where you feel violent towards yourself or others, seek help immediately.)

### **Helpful Tips for Managing Anger**

- Breathe. When you feel anger welling up, take deep breaths and ground yourself. Focusing on your breathing can both calm you and bring you back to the present moment.
- Count to ten. You may have been told as a child to count to ten before reacting when you are angry. This is good advice for adults too. Counting to ten in your mind can help you get in a better place and make better decisions about how to react.
- Assume good intentions. No one knows what it is like to have a child with CHD except those who do have a child with CHD, and even people who do have a child with CHD will have different experiences. When people say or do something that offends you, don't automatically assume they meant to be hurtful. Many people think they are being helpful and supportive, even when they are not.
- Don't react to anything over email for 24 hours. Giving yourself a day to calm down can really help when you are dealing with people over email or on a social media site.
- Find others who understand. Many parents feel resentful towards others, maybe even friends and family, who just don't seem to get what they are going through. Additional resentment can come when parents around you have perfectly healthy kids and don't seem to appreciate how lucky they are. Join a support group in your community or online to find other parents like you who do understand.

## **Confusion**

When your child is diagnosed with a CHD, you often receive a huge amount of medical information that you are not able to fully understand. You also may look on the internet for information, and this can add to your confusion and fear. Other parents of children with CHD may give you additional information which can be helpful, but may also add to your confusion because each person's experience is different.

### **Helpful Tips for Eliminating Confusion**

- **Ask questions.** Don't be afraid to keep asking your child's doctors, nurses, and other medical professionals' questions until you truly understand what they are saying. Keep a written list of questions you have so you don't forget anything. (You can record in this Little Heart Guide.) Write down answers so you can go back to them as needed.
- **Use reputable information.** Go to reputable websites ONLY. Mended *Little* Hearts has a listing of reputable websites on their website ([www.mendedlittlehearts.org](http://www.mendedlittlehearts.org)) under "CHD Resources." Use these websites to educate yourself about your child's condition. If you don't have access to the internet, there are written materials that can help you learn more. Children's Heart Foundation has a book called *It's My Heart* that you can order. The American Heart Association also has a booklet called, "If Your Child Has a Congenital Heart Defect" that you may find helpful.
- **Trust Yourself.** So many times, parents know the answer if they listen to their gut. Learn to trust your gut to make decisions. You will be able to tell when a decision is right for your family and when it is wrong by the way your body feels. Also, often there are no "right" decisions, so trust yourself to make the best decision you can with the information you have, and then don't go back and second-guess yourself.
- **Connect with others.** Finally, connect with a reputable support network that can help you find resources you may need in caring for your child. If there is a Mended *Little* Hearts group near you, they can help you connect to resources in your area and to others who have been on a similar journey. While other parents and caregivers cannot answer medical questions you may have, they can help you learn how to care for your child in your everyday life and once you are home from the hospital.

### **Get Help from a Counselor or Specialist When:**

- 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 towards 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.
- You avoid others or don't want to leave home.

## **TAKING CARE OF YOURSELF**

### **DO NOT SKIP!**

Parents and caregivers often think taking care of their child comes first—WRONG! You **must** take care of yourself to be able to effectively care for your child. (We know this is easier said than done.) The truth is that people are unlikely to make the best decisions if they are too tired, have very high levels of stress and anxiety, and are physically unwell, but when your child is in the hospital or you are faced with choices in caring for your child, you **need** to be able to make the best decisions. Please follow these tips and take care of yourself first.

#### **Ask for and accept help**

Acknowledging that you need help can be just as difficult as accepting it. However, your family and friends often want to help you and giving that help lets them feel like they are supporting you during this stressful time. 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, let them know what they could do to help.

#### **Give yourself a break, literally and figuratively**

You do not need to have all the answers or be there every second. Please give yourself a break! We know it is scary to leave your child's side, particularly after surgery or when in the hospital, but you do really need to get away—even for a little while. It is essential to schedule time away from the dual responsibilities of parenting and caregiving for your own mental health. Make plans for a friend, family member or healthcare provider to spend time with your child while you spend time away. Read a book, go shopping, have a meal at a restaurant, nap – but be sure to relax!

#### **Connect – with your care team, your 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 on the journey. Ask your medical provider or social worker for referrals to community support groups or to put you in touch with another family who has experienced a similar situation. Use the internet to keep your distant family and friends updated on your child's condition and plan of care. Utilize the support services that your hospital offers such as social work services, child life, pastoral care or parent navigators.

#### **Eat and drink regularly**

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

#### **Exercise**

Whether your child is in the hospital or at home, regular exercise is important to both your physical and emotional well being. Try to schedule at least twenty 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.

### **Distraction, Distraction, Distraction**

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

### **Take care of your own health**

When you are caring for your child, your health becomes secondary. However, if you aren't healthy, meeting your child's needs will be more difficult. Make the time to see your physician regularly. If you have recently given birth, it is important to follow your physician's recommendations regarding activity restrictions and keep your follow up appointments. Pay attention to your emotional state as well, and contact your physician or social worker if you are concerned about depression.

### **Get organized**

Keep all of the information you've received regarding your child's diagnosis safely in one place. This Little Heart Guide will help you record important information. Also, get a binder to store and organize papers given to you by the hospital or doctors. Directions on creating a binder are in this Little Heart Guide.

### **Educate yourself**

Knowledge is power! Learn about your child's diagnosis, medication and treatment plan. (Be sure to ask your doctor for reputable websites ONLY.) If your hospital allows, participate in medical rounds on your child and request family meetings for updates or to discuss care plan changes. Keep a notebook nearby and write down questions as you think of them, and be sure to ***ask questions*** if you don't understand!

### **Take back your family**

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

## **TESTS AND PROCEDURES**

Children born with congenital heart defects (CHDs) often have medical tests and procedures to help with diagnosis, to fix problems, and to get more information before surgery or treatment. These procedures and tests help provide physicians and nurses with the information necessary to care for children who have CHD. Several common tests are explained below.

### **Pulse Oximetry**

Pulse oximetry or "pulse ox" is a common test that shows how much oxygen is circulating in the blood at any given time. Oxygen saturation for a healthy person without a CHD is measured in a percentage and is typically 95% to 100%, but this percentage is often lower in children with severe CHDs.

Pulse ox testing is painless and involves placing a little monitor, often on a finger or toe that sends out light and can measure the amount of oxygen in the child's blood. Nothing goes into the child's skin except light. Often, this test is used in screening for critical congenital heart defects, but it can be also used to monitor patients with CHD, for altering treatments and planning for future procedures. It is not uncommon for some patients with congenital heart disease to be sent home with a pulse oximeter where they can measure the amount of oxygen in the blood as part of a home monitoring program. In addition, many states have begun adopting routine screening pulse oximetry measurements for all newborns before going home. These programs have allowed earlier detection of critical CHD using this very inexpensive and non-painful test.

### **Electrocardiogram**

An electrocardiogram will often be referred to as an EKG or an ECG. It is designed specifically to look at the electrical activity of the heart. It was one of the first tests ever invented to check to see how a patient's heart was doing. In children with CHD, it is mostly used to look at how the electrical activity of the heart functions; so, it is not surprising for cardiologists to use this test to check for abnormal heart rhythms or to see whether all chambers of the heart are having problems beating together.

This test, like pulse oximetry testing, is painless. It involves placing wires with clips onto the child with a sticky, round pad. Nothing goes into the skin or hurts the child. Then, 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 and baby oil may be helpful in getting it off.

Many children with severe CHD may be sent home for periods of time with monitors that are electrocardiograms and can measure the electrical activity of the heart during normal daily activities. A Holter monitor is one that patients wear for 24 hours and can give physicians a good idea of what the heart rhythm is doing during various parts of the day. On bigger 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. An event monitor is a lot like a Holter monitor but it requires the parents to recognize when their child has symptoms of an irregular rhythm and to record it at that time.

### **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 getting better and better, medical professionals don’t need to use more invasive tests as often. The echocardiogram is essentially a sophisticated ultrasound machine (like the ultrasound pregnant moms have). A gel is put on the child’s skin and then a probe is placed on top of the skin and moved around so 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 in the neck area. Also, small children may become restless during the test. It can help to play a video or to read to a small child getting an Echo to help keep the child still. In some cases, children are given a medication to sedate them before an Echo (called a “sedated Echo”). This is to help the child remain very still to get clear pictures of the heart. An echocardiogram is painless and does not require any radiation.

The echocardiogram can take two-dimensional pictures of the heart to evaluate how it's put together and how it's functioning. It is excellent for checking to see how patients are doing before surgery and after surgery. Aside from looking at the structure of the heart and finding out how it is functioning, medical professionals can also look at pressures in various parts of the heart and look at the flow of blood as it moves through the heart. This helps them figure out what the best treatment is for your child. It has become an essential tool for cardiologists in both diagnosing and managing patients with CHD. Furthermore, improvements in this machine have led to the ability to take three-dimensional pictures and begin to assist with procedures patients with CHD may be undergoing.

### **MRI/CT**

MRI and CT scans are two other techniques that help medical professionals get a good look at parts of the heart. MRI is becoming more often used because it involves no radiation and can provide significant amounts of information about how the heart is put together and how it is functioning. MRI can be very useful at looking at things that echocardiography cannot always see as well; however, having these scans does require anesthesia for young children, and it is somewhat of a long test, so it is only used when really needed. During a MRI, nothing goes into the child’s skin—the machine looks like a big tube that the child is put into. The machine sends very detailed images of the child’s heart to a monitor where they can be viewed.

A CT scan is similar to a MRI, but it is a much quicker process and does require the use of radiation. However newer CT techniques have shown significant reduction in the amount of radiation used, and this test is becoming a very good alternative to look at heart structures that echocardiography sometimes struggles with.

### **Catheterization**

Cardiac catheterization (often called “cardiac cath” or just “cath”) is probably one of the oldest tests that cardiologists use to help evaluate, manage and treat patients with CHD. In the past, cardiac cath was often used as a tool to diagnose CHD, but it is used less for diagnosis now because echocardiography and MRI have gotten much better at this. Instead, it is being used much more to do repairs on the heart. It is an invasive test, meaning parts do go into the child’s body, so it is only used when really needed like before surgery or to make repairs.

Before a cardiac cath, the child will typically get anesthesia so they are not awake during the procedure. This is sometimes put in through an IV in the arm. The child may be required to have nothing to eat or drink for a period of time before the cath to prevent him or her from getting sick from the anesthesia. The child is then taken back into the cath lab. (You can look at pictures of a cath lab online or some hospitals will show you the cath lab if it will make you more comfortable.) During the cath, long hollow tubes are put through the skin and placed into various chambers of the heart to measure pressures, take pictures of various structures, and perform interventions on the heart itself. These tubes might be put in through the groin, the neck, or through other places on the child's body. After the cath, the child will have to lay flat for a period of time to make sure there is no bleeding from the place the tube went into the body. Sometimes, the child will be able to go home that evening, but in some cases the child will stay in the hospital overnight or for a few nights during recovery.

Some interventions done via cath today include opening up valves that may be a little bit tight, closing unwanted holes or vessels in various chambers of the heart, evaluating and treating abnormal heart rhythms, and even replacing some types of valves instead of having to go to surgery. Recovery time from cath procedures is usually much shorter than surgery, and often children will go home in less than 24 hours. Because the cath is an invasive procedure, there are risks associated with it, but most children do fine. There is also radiation involved with cardiac cath because the doctor performing the cath needs to see images of the heart and the vessels during the procedure. Today, more and more procedures are being done in the cath lab instead of in the operating room, and it has provided a nice alternative for some types of heart disease that would have required surgery in the past.

## **TRANSITIONING FROM HOSPITAL TO HOME**

After the much anticipated birth of your child who has a congenital heart defect (CHD), the reality of bringing your child home can be terrifying on one hand and liberating on the other. Parents and caregivers become so used to life in the hospital, that they haven't had time to mentally adjust to life once they get home. While your child is in the hospital, the doctors and nurses have likely been the primary caregivers for your child. Now you are faced with taking over the care, and it can be very scary. Here are some things that can help you feel more at ease.

### **Understand your child's heart defect**

With a diagnosis of CHD comes an honorary diploma. In a matter of days, parents go from being blissfully expecting to incredibly informed. If your child was diagnosed before birth, you often are given some information to educate yourself and prepare ahead of time. This can be both a blessing and a curse. On one hand, knowing in advance allows you to educate yourself and make more informed choices about care. On the other hand, this knowledge can create a very stressful pregnancy. If your child was diagnosed after birth, you may be caught in a whirlwind of information that can be hard to manage.

Before being discharged, ask questions as often as necessary until you feel like you have a good working knowledge of your child's heart defect and any surgeries or procedures your child had. Research your child's heart defect using reliable resources ONLY (the doctor may provide you with some and there are resources on the Mended *Little* Hearts website [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org) under "CHD Resources), and educate yourself as much as possible. Ask questions until you don't have any more questions to ask!

### **Learn everything you can from the nurses**

The nurses are at the bedside doing everything from changing diapers to providing life-saving surveillance and care. They are the closest thing to "parents" in the hospital. When you get home, you will be doing what they did in the hospital. You are never wrong to ask a nurse to teach you how to do a task that you have seen them do. Nurses are people, and not all people are teachers. You will quickly learn which nurses provide the best information, and you will benefit from working with them and asking questions.

### **Learn Techniques for Emergencies**

Part of discharge planning is planning for the worst while expecting the best. Start with CPR training. CPR is Cardio Pulmonary Resuscitation. Being a parent of a child with a heart defect, you will quite likely be taught how to do CPR. If you have not been taught CPR before discharge, ask to be taught! Also, learn what things to look for that would require a call to 911 or your child's doctor and make an emergency plan. (You can use the form in this Little Heart Guide.) Some areas also have advance 911 systems that allow you to pre-register your child's medical conditions, preferences and medical needs

with the emergency services in your area. Call your local fire/rescue department to learn what you can do in advance of any emergency.

You also may want to put some sort of medical identification on your child with some basic information about his or her condition. There are many companies that make medical ID products, and you can talk to your cardiology team about what information is best to put on a medical ID bracelet or other forms of ID.

### **Understand your equipment**

You may be discharged with no equipment other than a pacifier, but you may be sent home with an order for home health to provide a pulse oximeter, a monitor, a feeding pump, or even an oxygen tank. Before discharge, ask the nurse for any medical equipment your child has that will be discarded.

When home health comes to your home, be sure to have them teach you how to use your equipment. Learn how to troubleshoot your equipment. Home health companies often provide 24 hour coverage – be sure to ask how to be in touch with them after hours.

### **Understand medications**

Ask about what the medications do, how they work, what the side effects are, and how much your child needs and at what times. (You can record this information on the forms in this Little Heart Guide.) Plan ahead with medications and ask for prescriptions to be arranged and possibly filled before discharge. There are some prescriptions that will have to be compounded (made into liquid), and not every pharmacy can do this, so be sure to get help learning what pharmacies can manage your child's medications. The pharmacist will be able to explain how to store the medications properly as well—some need to be refrigerated. Pharmacists are a great way to “double check” the instructions that you have received from the discharging nurse and physician.

### **Reach out to your primary cardiologist before discharge**

Many families with a child who has CHD will need to travel to a city away from home for their child's surgery or procedure. Before discharge, you will want to find a cardiologist who can follow up with your child where you live, if possible. If your family did not have to travel for surgery, you will still want to choose a primary cardiologist for your child. Be sure that you are comfortable with the choice of cardiologists, and don't be afraid to try someone different if you are not comfortable. You need to feel good about the care your child is receiving.

### **Find a pediatrician/primary care doctor who knows how to care for a child with CHD**

Your child will need a primary pediatrician who will manage routine care and non-cardiac issues. In most cases, you will be required to designate a pediatrician for your child after that child is born. When choosing one, ask him or her about his experience with children who have CHD. You will want 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 for the doctors or cardiology practice that you used for your child's surgery, such as a nurse practitioner. This person can help with coordinating anything from

appointments to medication refills. Be sure to find out who this person is before you leave the hospital.

### **Understand your responsibilities with monitoring**

For infants with single ventricles, parents and caregivers may be asked to do monitoring at home. There may be a nurse or other medical professional who will call your home and help you keep track of pulse oximeter readings and weight readings, for example. Be sure you understand what your responsibility is in monitoring, what you need to monitor and how.

### **Don't feel like you are unable to leave your home!**

Many parents and caregivers are afraid to take their baby or child out of the house because there is a chance of exposure to germs. During cold and flu season, it may be a good idea to limit outings with your child, but getting outside and interacting with others can also be helpful to your mental state and to your child. Be sure to keep hands washed, avoid people you know to be sick, drink plenty of fluids, eat a balanced diet and get enough sleep. These things will help your whole family stay healthy. Also, talk to your doctor about immunization options that may minimize the risks during this season (influenza, RSV, etc.).

It is also natural for parents and caregivers of children with CHD to feel like they can't leave them in someone else's care. (See "Taking Care of Yourself" in this packet.) Find ways to get out and away from being the caregiver 24-hours a day. Find someone you trust to babysit even so you can take a 15-minute walk around your block once a day. Reach out to your local support group, your church, your State Department of Health, and your family, and GET SUPPORTED! There are resources out there for parents. Also, recognize that depression is not uncommon in caregivers, and it needs to be addressed and treated – you are not alone, and should never feel that way!

Know that your child would not have been discharged if the expectation was that you never leave his or her side. The point is that your little one is doing well enough to do well at home!

### **Don't feel guilty when things don't go perfectly!**

Sometimes you will be doing everything right and something will still go wrong. Your child may not gain weight, fail to grow, or have symptoms that need to be addressed. There is enough guilt involved in having a child with CHD, that the last thing you need is additional guilt. Know that you are doing the best you can, and it is not your fault. If you feel like you can't manage, get help. Often, caring for a child with CHD right after surgery is scary—parents are often afraid their child will die or get seriously ill. This is normal. Connect to other parents who can give you support.

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 there is nothing wrong (even if you feel a little embarrassed) than having something wrong with your child that isn't addressed. Also, as a parent, you know your child the best, so trust your instincts. Never feel bad about being persistent. Once again, no one advocates for a child as well as a parent!

Finally, writing a journal is a great way to work through the stress of having a child with CHD. It will be a great resource for going to doctor's appointments and for helping you work through the

emotions involved in being a parent. Make a list of questions and call when you think of the questions you have not yet asked! Having a child with CHD is like being strapped down into a roller coaster seat – there will be ups and downs, terrifying hair pin turns and vertical drops, but ALL roller coasters end up on level ground.

### **Preparing for Your Child's First Appointment**

When you get home with your child, if you didn't do it while in the hospital, you need to make an appointment with your child's primary pediatrician and with your child's local cardiologists. Again, find a pediatrician who has experience in caring for children with CHD, who understands the need for life-long specialized CHD care, and who will work with your local cardiologist.

Before you go to your child's first appointment, make sure that any necessary medical records are sent to the pediatrician. You can ask the pediatrician's staff if they are able to get the records for you, or you can ask the hospital where your child had surgery to send them. These records will help the pediatrician understand your child's condition and procedures.

Remember, that your child does have CHD, but your child will also need routine care from the pediatrician. Be sure to go to all well-baby and well-child visits as recommended by your child's doctors. As with the cardiologist, write down questions you have ahead of time. You can track your child's growth, appointments and medications on the forms in this Little Heart Guide too.

***At the end of the day, don't be afraid to ask questions!***

## MEDICAL LANGUAGE AND ACRONYMS

Sometimes parents and caregivers of children who have congenital heart disease (CHD) get lost in the medical jargon and acronyms that even the most well-meaning doctors and nurses use. Sometimes language becomes so common to medical professionals that they forget most people don't understand what they are saying. Below, Mended *Little* Hearts has put together what we call a "Cheat Sheet" of some forms of CHD and common terms you might hear.

Type of Congenital Heart Disease	Most Common Surgical Procedures or Treatment	Palliation (not cured or "fixed) or Repair	Acyanotic (normal blood oxygen) or Cyanotic (decreased blood oxygen) after repair
<b>Aortic Stenosis</b>  <i>(narrowing of the aortic valve)</i>	Balloon valvuloplasty (catheterization lab), valvotomy, or Ross procedure	Valvotomy <i>may</i> only be palliation; Ross procedure is final repair	Acyanotic
<b>Atrial Septal Defect</b> <i>(hole in the atrial septum, or muscle wall, that separates the right and left atria)</i>	Device closure (catheterization lab), patch closure	Repair	Acyanotic
<b>Complete Atrioventricular Canal</b> <i>(large hole in the top and bottom of the heart with a central common valve that did not form as two)</i>	Pulmonary atresia (PA) band (not first choice), patch closure	PA band is palliation	Acyanotic
<b>Coarctation of aorta</b> <i>(narrowing of the aorta)</i>	Balloon dilation (catheterization lab), subclavian flap, end-to-end anastomosis or patch repair	Repair	Acyanotic
<b>Dilated Cardiomyopathy</b> <i>(muscle wall of left ventricle is weak and may become enlarged)</i>	No treatment for mild cases. Sometimes medication. Transplant for severe cases.	Either palliation or repair depending on treatment.	Acyanotic

<b>Interrupted aortic arch</b> ( <i>missing part of the aorta, it stops and restarts</i> )	Reconstruction of arch, ventricular septal defect (VSD) closure	Repair	Acyanotic
<b>Patent ductus arteriosus</b> ( <i>vascular connection between pulmonary artery and aorta</i> )	Coil, device occlusion (catheterization lab), ligate or clip via video-assisted thorascopic surgery	Repair	Acyanotic
<b>Ventricular Septal Defect</b> ( <i>hole in the bottom of the heart between the bottom chambers, ventricles</i> )	Patch closure	Repair	Acyanotic
<b>Pulmonary stenosis</b> ( <i>narrowing of the pulmonary valve</i> )	Balloon valvuloplasty (catheterization lab), valvotomy	Repair	Acyanotic
<b>Pulmonary atresia</b> ( <i>absence or severe narrowing of the pulmonary (lung) artery</i> )	Homograft placement	Repair (may require further surgeries as child grows)	Acyanotic
<b>Tetralogy of Fallot</b> ( <i>thick right side of heart, hole between two ventricles (VSD), narrowing of various degrees of pulmonary artery and enlarged and slightly displaced aorta</i> )	Blalock-Taussig, BT. shunt	Palliation	Cyanotic
	Pulmonary artery correction and VSD closure	Repair	Acyanotic
<b>Transposition of great arteries (most common form)</b> ( <i>aorta and pulmonary artery reversed and over wrong side of heart</i> )	Arterial switch	Repair	Acyanotic
<b>Tricuspid atresia</b> ( <i>absence of right ventricle and right sided valve</i> )	Shunt	All are palliations	Cyanotic
	Bidirectional Glenn shunt		Cyanotic
	Fontan		Acyanotic (with no fenestration)

<b>Truncus arteriosus</b> ( <i>common vessel from center of heart that provides blood flow to lungs and body as well as a hole in the bottom of the heart</i> )	Placement of homograft conduit and VSD closure	Repair, but children will need further surgeries as they outgrow homograft	Acyanotic
<b>Hypoplastic left heart syndrome</b> (absence of left ventricle, severe narrowing of mitral valve (left sided valve) and string like aorta)	Norwood procedure  Bidirectional Glenn shunt or Hemi Fontan  Fontan	All are palliations	Cyanotic  Cyanotic  Acyanotic (with no fenestration)

### Glossary & Common CHD Abbreviation Meanings

- ♥ **AS:** aortic stenosis
- ♥ **ASD:** Atrial Septal Defect
- ♥ **AVC or AV Canal Defect:** Atrioventricular Canal Defect; aka Endocardial cushion defect
- ♥ **Aneurysm:** a bulging of the wall of an artery, vein, or wall of the heart.
- ♥ **Aorta:** the main artery that supplies the blood and oxygen to the body. It usually comes off the left ventricle (main pumping chamber).
- ♥ **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.
- ♥ **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 (usually after the atria).
- ♥ **Atrium:** one of the two upper chambers of the heart. The right atrium collects un-oxygenated blood (blue blood) from the body. The left atrium collects oxygenated blood from the lungs.

- ♥ **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 TGV
- ♥ **BT Shunt:** Blalock-Taussig shunt: surgical procedure; systemic-to-pulmonary artery shunt procedure
- ♥ **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.
- ♥ **CAVC:** complete atrioventricular canal; main heart defect seen in Down syndrome
- ♥ **Cardiopulmonary Bypass:** a machine that can perform the function of the heart and lung.
- ♥ **Catheterization:** a diagnostic test in which a catheter is inserted into the heart to measure pressure and oxygen, and to take pictures (angiography).
- ♥ **CHD:** Congenital Heart Defects, Congenital Heart Disease, or Congestive Heart Disease
- ♥ **CHF:** Congestive Heart Failure: a condition in which the heart cannot pump well enough, and there is backup of blood and congestion in the veins and lungs.
- ♥ **CoA:** coarctation of the aorta
- ♥ **CXR:** chest x-ray
- ♥ **Cyanosis:** blueness of the lips and fingernails, caused by a decreased amount of oxygen in the blood.
- ♥ **D-TGA:** dextro transposition of great arteries
- ♥ **ECHO:** echocardiography; diagnostic tool that uses Doppler techniques to evaluate blood flow patterns and pressures
- ♥ **ECMO: extracorporeal membrane oxygenation (ECMO)** a technique of providing respiratory support; the blood is circulated through an artificial lung made up of two compartments separated by a gas-permeable membrane, with the blood on one side and the ventilating gas on the other.
- ♥ **ECG or EKG:** electrocardiogram
- ♥ **Fenestration:** surgical creation of an opening, sometimes used in Fontans

- ♥ **Glenn or Bidirectional Glenn shunt:** surgical procedure; superior vena cava to right pulmonary artery anastomosis (the large vein from the upper body is directly connected to the lung blood vessels )
- ♥ **Fontan:** surgical procedure; a combined procedure for complex congenital heart defects (directs blood from the large vein from the lower part of the body up to the right side of the heart to the lung arteries/Glenn).
- ♥ **FTT:** failure to thrive
- ♥ **HLHS:** hypoplastic left heart syndrome
- ♥ **HRHS:** hypoplastic right heart syndrome
- ♥ **HTN:** Hypertension: high blood pressure.
- ♥ **IAA:** Interrupted Aortic Arch
- ♥ **Ischemia:** lack of blood supply to an organ or tissue.
- ♥ **Jantene operation:** a surgical procedure; a type of arterial switch procedure
- ♥ **LA:** Left Atrium
- ♥ **MPA:** main pulmonary artery
- ♥ **Mitral Valve:** a valve of two leaflets, between the left atrium and left ventricle.
- ♥ **Murmur:** an extra heart sound that may be heard between the 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.
- ♥ **MI:** Myocardial Infarction: heart muscle which dies because of lack of oxygen, usually called a heart attack when it occurs in an adult.
- ♥ **Norwood:** surgical procedure that is typically the first surgery for many single ventricle defects; conversion of Right ventricle into the systemic or working ventricle
- ♥ **PaO2:** arterial oxygen tension
- ♥ **Palliative:** treating or helping symptoms without curing
- ♥ **PA:** pulmonary artery
- ♥ **PAPVC:** partial anomalous pulmonary venous connection
- ♥ **PDA:** patent ductus arteriosus
- ♥ **PFO:** patent foramen ovalae

- ♥ **Pericarditis:** an inflammation of the sac that surrounds the heart.
- ♥ **PGE1:** prostaglandin E1; medication administered to maintain patency of the ductus arteriosus
- ♥ **PS:** pulmonary stenosis
- ♥ **PV:** Pulmonary valve: the valve between the right ventricle and the pulmonary artery.
- ♥ **PVR:** pulmonary vascular resistance
- ♥ **OHS:** Open Heart Surgery: surgery performed on the open heart while the blood flow is diverted through the heart lung machine.
- ♥ **RA:** Right Atrium
- ♥ **Septum:** dividing wall.
- ♥ **Shunt:** an abnormal passage of blood between two blood vessels or between the two sides of the heart.
- ♥ **SV:** Single ventricle
- ♥ **Stenosis:** a narrowing of a heart valve or blood vessel.
- ♥ **SVC:** superior vena cava
- ♥ **Tachycardia:** abnormally fast heart rate.
- ♥ **TAPVR:** total anomalous pulmonary venous return/ **TAPVC:** Total anomalous pulmonary venous connection
- ♥ **TGA:** Transposition of the great arteries
- ♥ **TGV:** transposition of the great vessels
- ♥ **TOF:** tetralogy of fallot
- ♥ **Truncus:** Truncus Arteriosis
- ♥ **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.
- ♥ **Ventilator:** a machine that breathes for a patient or helps his or her breathing.
- ♥ **VATS:** Video-assisted thoracoscopic surgery
- ♥ **VSD:** ventricular septal defect



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# Forms

## Creating a Binder to Keep Organized

When you are receiving a lot of information and papers, it can be hard to keep organized. Here are steps you can take to create a binder to store important information.

1. Get a 1-2 inch, 3-ring binder (2 inches is better if you have a LOT of papers).
2. Get a 3-hole punch or find someone with one you can use.
3. Get dividers with tabs and pockets to put into your binder.
4. Create the following tabs (these are just suggestions—you may want others):
  - a. My Child's Heart
    - Diagram of heart
    - Information About Your Child's Heart Defect
    - Information About Surgeries & Procedures
  - b. Doctors & Specialists
  - c. Medications
    - Put prescriptions in this section
  - d. Resources
    - Early Intervention Services
    - Educational Services
    - Support Group Information
  - e. Insurance Information
    - Insurance Policy and Number
    - Explanations of Benefits
  - 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

## My Child's Doctors

### Cardiologist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Surgeon

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Pediatrician/ Family Doctor

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

Specialist: (Type) \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

Specialist: (Type) \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_













## Other Specialists and Resources

### Social Worker

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Physical Therapist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Occupational Therapist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Nutritionist

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

## Other Specialists and Resources Continued...

### Early Intervention Services

Type of Service: \_\_\_\_\_

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Counseling Services

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_

### Educational Consultant

Name: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Location: \_\_\_\_\_





# Growth Tracking



Parents and caregivers can keep track of their child’s growth here. Please bear in mind, sometimes children with congenital heart defects are smaller than their peers. The important thing is that they are growing steadily. Also, know that surgeries and illnesses may cause temporary delays in growth. When your child is a baby, you may want to track growth more often than when your child is older.

Date	Height	Weight	Head Circumference	Checked By



## Emergency Plan

In the event of a serious emergency, please call 911. For a non-life-threatening situation that requires action, please follow these instructions:

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Here is the information you may need to care for my child:

Child's Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Child's Heart Condition: \_\_\_\_\_

Surgeries or Procedures for the condition: \_\_\_\_\_

Child's Normal Saturations (blood oxygen level): \_\_\_\_\_

Parent/Caregiver's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

(Circle which number to call first)

Parent/Caregiver's Name: \_\_\_\_\_

Address: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Work Phone: \_\_\_\_\_ Cell Phone: \_\_\_\_\_

Primary Care Doctor: \_\_\_\_\_ Phone: \_\_\_\_\_

Cardiologist: \_\_\_\_\_ Phone: \_\_\_\_\_

Other Specialist: \_\_\_\_\_ Phone: \_\_\_\_\_

If you can't reach a parent or caregiver call: \_\_\_\_\_ Relationship: \_\_\_\_\_

Phone: \_\_\_\_\_

Insurance Policy Company & #: \_\_\_\_\_

Things to look for in my child that indicate a problem needing medical attention:

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## Letter to Family & Friends

### Dear Friends & Family,

I need to let you know that my child has been diagnosed with a congenital heart defect (CHD). It was very scary and very hard to find out my child has a heart defect. Right now, I could use your help and support.

There is no known cause of CHDs at this point, so there is nothing anyone did or did not do to cause my child's heart defect. Parents can do everything right prenatally and still have a child with a CHD. CHDs affect people of every race, cultural background and socio-economic status—they do not discriminate.

I know you want to be helpful to me, so please don't tell me that things could be worse, that I should be grateful for all we do have, compare my situation to anyone else's, or give me advice. Please do listen when I need to talk to someone, help me even when I don't ask for it, and send me emails, texts, letters and cards to let me know you are there for me and you are thinking about me. Please just be there for me, and let me grieve if I need to—even if it takes a long time.

Interestingly enough, CHDs are the most common birth defect in the United States, affecting about 1 in 110 babies (40,000) each year. Around 25% of children born with a CHD will need surgery or other interventions to survive. There are about 35 types of CHD, and some children have a combination of two or more. For some types of CHD, there were no surgeries or procedures to help them survive until fairly recently. Luckily, many children born with CHD are now living well into adulthood.

If you want to learn more about my child's condition, please ask me the name of it and go to [www.mendedlittlehearts.org](http://www.mendedlittlehearts.org) under CHD Resources to learn more.

Don't feel afraid to be around me or my child, but if you are sick or even think you are sick, please don't visit or let anyone else visit us who may be sick. Don't be afraid to hold or take care of my child; I will let you know everything you need to know. Please treat my child like a normal child and not like a sick or fragile child. My child is strong and brave.

If I become less social than I was, know it is not about you, but that I am trying to cope with changes in my life and my family's life. Know that sometimes I feel like I don't fit in with "normal" parents anymore, and I may be a little quieter for a while. I feel it's not fair that my child was born with a CHD, but I am trying to accept it. I hope you will too. Sometimes, I need to talk to other parents of children with CHD because they have walked this path and truly understand it, but that doesn't mean I don't value your wisdom. Know that CHD changes people, but in many good ways too.

Thank you for being there for me during this time.

