little mended hearts

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Mended *Little* HeartGuide

www.mendedlittleheartguide.org

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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 has 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.

Mended *Little* Hearts
8150 N. Central Expwy., M2248
Dallas, TX 75206
1-888-432-7899 (1-888-HEART99)
www.mendedlittlehearts.org

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 the Mended *Little* HeartGuide (**www.mendedlittleheartguide.org**) will provide you with the information you need and help guide you to additional resources. This "lite" version gives you a sample of the Guide.

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 and health care professionals. 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

About My Child's Heart

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, if any: _____

_____

_____

Procedures my child will need, if any: _____

_____

_____

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

_____

_____

_____

_____

_____

_____

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

_____

_____

Many more helpful forms can be found at www.mendedlittleheartguide.org.

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www.mendedlittleheartguide.org

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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 **Mended*Little*Hearts.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, **M*L*H 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 at **@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 M*L*H 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 (**www.mendedlittlehearts.org**) 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** (Section 5) 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 Guide.

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 a heart defect 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.

Helpful Tips for Managing Grief

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. 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; 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. Eventually, you'll begin to feel true happiness again.

- **Connect with others who understand what you are going through.**
  If you can, join a positive support group or system.

- **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. This, too, shall pass.

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 them 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.**
  Find things you can control in your family's life, and make positive changes where needed. For things you can control about your child's medical condition, talk to your child's doctor and 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. 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 and don't think about them 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.

- **Find Quiet Time.**
  Finding some quiet time — if only five minutes — every day is vital.

- **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. 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.

- **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.**
  Focusing on your breathing can calm you down and bring you back to the present moment.

- **Count to 10.**
  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 online.

- **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. Write it down questions so you don't forget to ask it during your next visit to your child's doctor and be sure to write down the answers too.

- **Use reputable information.**
  Visit ONLY reputable websites. Mended *Little* Hearts provides a listing of trustworthy websites at MendedLittleHearts.org under the heading "CHD Resources." If you don't have internet access, ask your child's doctor or nurse about written materials that can help you learn more.

- **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. Also, many times, there are no "right" answers.

- **Connect with others.**
  Join a reputable support network that can help you find resources you may need to care for your child. They can give you tips on caring for your child in day-to-day life.

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.

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.

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.

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.

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* HeartGuide 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.
- 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 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 the digital 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.

For much more information and for helpful resources, visit:

www.mendedlittleheartguide.org