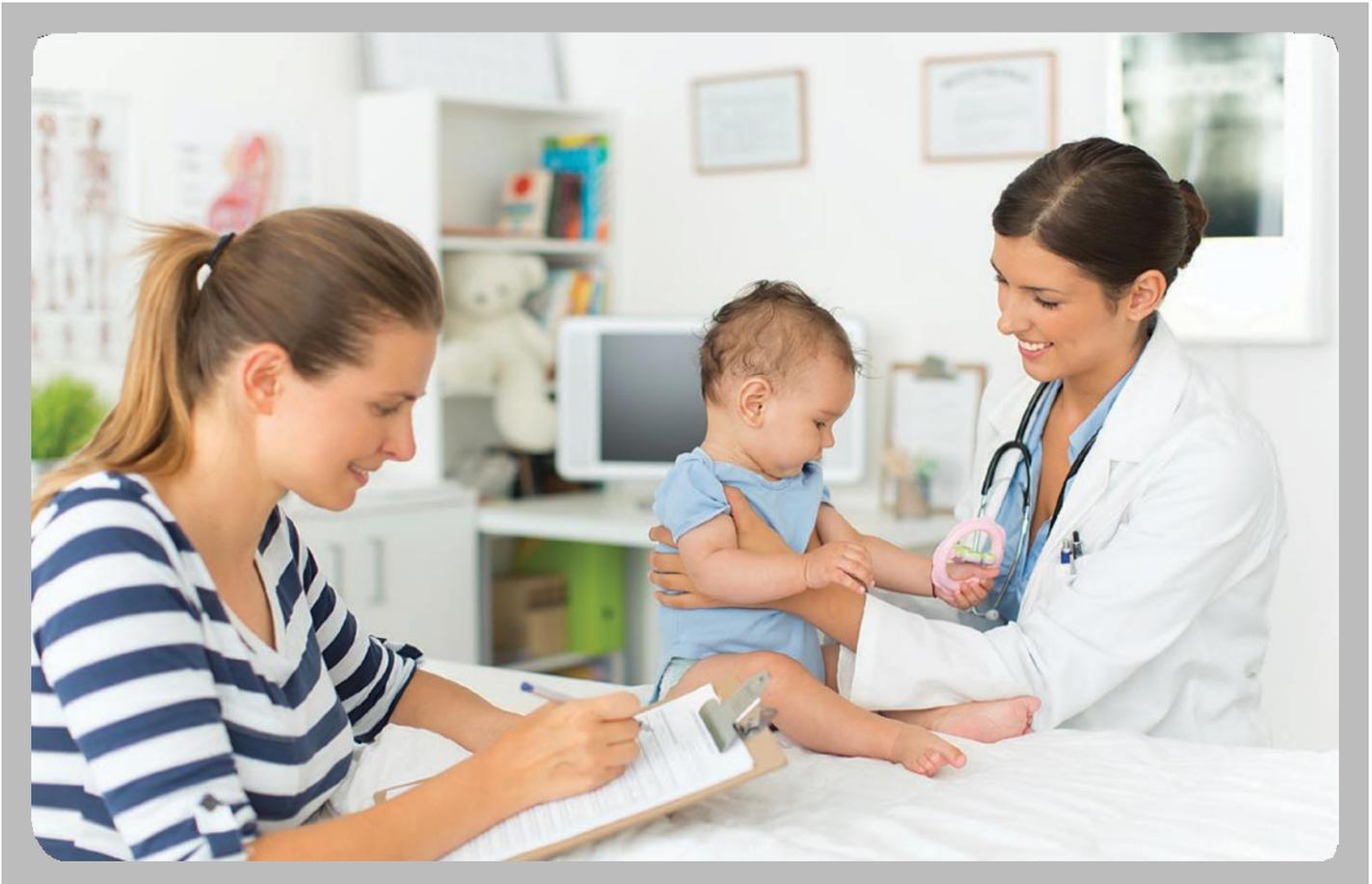


## Empowering Parents to Make Healthcare Choices



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

### Educate yourself via reliable sources

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

There are many reliable sources of information. A few that MZH members

recommend include [pted.org](http://pted.org) (which features moving diagrams), the

Children’s Heart Foundation book [It’s My Heart](#) (available in both paperback and e-book), the [Centers for Disease Control and Prevention](#) website, the [American College of Cardiology’s CardioSmart](#) site, the American Heart Association’s booklet

“[If Your Child Has a Congenital Heart Defect](#)” (available online and in print from many local affiliates) and [SCAI’s Seconds Count](#) website. Your local children’s hospital can also offer information on your child’s condition. Please be aware that some other websites may not only be unreliable but also needlessly alarming for new CHD parents.

## Work with your child’s doctor(s)

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

## Learn about your hospital

Unless your child needs emergency surgery immediately after being diagnosed with CHD, you have time to learn about your hospital and surgeon and to make choices about care. It is your right to choose the hospital and

surgeon that you feel is best for your child. Do not be afraid to ask questions to make sure your son or daughter is getting the best care possible for his or her condition.



## Ask questions such as:

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

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

## You may have to travel

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

Resources such as Ronald McDonald Houses are available for families who need to travel for medical procedures. Learn about these resources to help you decide if traveling is a

feasible option for your family. (More information is available in the **Financial Considerations During the Hospital Stay** section of the 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.

More information and forms can be found in the Mended *Little* HeartGuide at [www.mendedlittleheartguide.org](http://www.mendedlittleheartguide.org).

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