



TIPS FOR EMPOWERING PARENTS TO MAKE HEALTH CARE CHOICES

Mended *Little* Hearts believes parents and caregivers should have information so they are empowered to make the best choices about care and treatment for their child who has a congenital heart defect (CHD). Mended *Little* Hearts supports transparency, information sharing and educating parents and caregivers to help them make decisions for their child's care. Here are some tips for empowering yourself when making healthcare decisions for your CHD child.

Educate Yourself via Reliable Sources

To make good decisions about care, parents and caregivers need to understand their child's condition. This can be very confusing to parents and caregivers who are newly exposed to medical terms and to a world they never knew about before their child's diagnosis, but it is important information that you will need throughout your child's life.

Start your education with your doctor—ask him or her 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 one will think you are stupid. Healthcare providers would rather you understand the condition than leave with unanswered questions. Writing questions down will help you remember to ask questions you have and make sure they are answered.

There are many reliable places to find information on conditions as well. Some that many MLH members like are www.pted.org (with moving diagrams), the Children's Heart Foundation book (both paperback and e-book) *It's My Heart*, the Centers for Disease Control and Prevention website, the American College of Cardiology, the American Heart Association's booklet, "If Your Child Has a Congenital Heart Defect" (available in paperback from many local affiliates and online as well) and the Seconds Count website. You can also find information on children's hospital websites. Please be aware that some other places on the Internet may not only be unreliable, but unnecessarily scary for new CHD parents.

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 your 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. Parents and caregivers should not be afraid to ask questions to make sure their child is getting the best care possible for his or her condition.

Ask questions like:

- 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?

Parents and caregivers need to feel comfortable with the hospital and the surgeon, and should not be afraid to seek care where they are most confident.

Don't be afraid to get a second opinion. Many parents and caregivers believe that their doctor will be offended or that getting a second opinion means they don't like their doctor. This 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 reveal new information that is helpful in choosing the best care for your child.

In addition, *U.S News & World Report* rank children's hospitals, and that is worth reviewing before making a choice about care for your child.

You May Have to Travel

There are not hospitals in every city that perform surgery on children with CHD, and therefore you may have to travel for care. Also, you may decide that a hospital away from home is better able to care for your child. *If you decide to travel to another area, make sure to consult with your insurance company prior to making arrangement to assure that services are covered.*

There are resources available for families that need to travel, like Ronald McDonald Houses, so learn about these resources to see if traveling is feasible for your family. *Note: There are Mended Little Hearts groups in many areas that may be able to give you information on resources available also.* If you travel, you want to get a realistic opinion about how long you will be away from home understanding that no one will know for certain—some children recover much faster than others.

Uniqueness of Experiences

Often parents ask other parents what their experiences were with a hospital, doctor or surgeon. While this can be a good source of information, keep in mind that everyone's experience is different. For a variety of reasons, including severity and complexity of the child's CHD and even personality, two families can have a vastly different experience with the same doctor, surgeon and/or hospital. Also, parents who have had a good experience often think their child's hospital is the best one and will promote that facility. When looking for information about hospitals and doctors, parents will want to further investigate information they get from personal blogs, chats or other social media sources.