



Mended
Little
Hearts

Coping with CHD

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Until the past few decades, there was no recovery for many children with complex congenital heart defects because they did not survive into adulthood. In fact, to put it in perspective, the oldest person living with hypoplastic left heart syndrome, a rare single ventricle defect that is fairly common in most Mended *Little Hearts* groups, is in his late twenties. Until quite recently, there was nothing that could be done for those babies.

Despite the fact that congenital heart defects (CHDs) are the most common defect in the United States, there is no cure for them, and for many CHDs, there is no way to “fix” them. According to the American Heart Association, almost twice as many children die from CHDs as all forms of childhood cancer combined, yet childhood cancer receives five times the research funding. Also, cardiovascular disease remains the number two killer of children under 15 years old. However, more and more people are survivors of CHD; today, up to 1.8 million Americans live with a CHD.



According to Amy Verstappen, president of the Adult Congenital Heart Association (ACHA), and a complex CHD survivor in her late 40s, there is great news for those with CHD. “Most babies born with even the most serious problems now do well,” Verstappen said. “They undergo early repair and have normal or near-normal function. Every day I meet middle-aged ACHA members who had pioneering heart operations back in the ‘40s, ‘50s, and ‘60s. Now they are thriving as doctors, lawyers, parents and grandparents. In the six decades since those first repairs, knowledge and skills have grown. We have every reason to expect that today’s children will do even better than today’s adults.” This is great news for parents of children with CHD.

However, Verstappen cautioned, “Even as things get better, we know that childhood heart repair will never be a ‘cure’—especially for those born with complex problems.” CHD has become much more than a birth defect – it is now a lifelong chronic disease state. Even though most children with complex CHD now have surgical repairs, as opposed to compassionate care (where parents take children home to die) or heart transplants, the “repair” does not create a “normal” heart with normal blood flow. Most repairs are done with artificial materials, such as



Michelle Gonzalez with her daughter, Madison.

Gortex tubing and mechanical valves, and these can create problems over time. Also, there is often scarring in the heart from multiple surgeries. The result can be an increase in rhythm problems and valve problems. Transplant patients often have their own set of problems to deal with, including a chance of rejecting the transplanted heart. According to Verstappen, the incidents of heart failure and cardiac arrest for CHD patients rise by the decade, and currently the life expectancy for these patients is significantly shorter than for the average American. Recent examples of this in the news are Senator Dick Durbin’s daughter, who passed away at age 40 from CHD, and Sophia Gokey, the wife of top 10 American Idol contestant Danny Gokey,

who passed away at 27.

Another issue with CHD recovery, according to Verstappen, is that those with CHD are facing the challenges of living at the cutting edge of medicine – having treatments developed only within the last few decades. The result is that no one really knows what problems might arise from these treatments – and there has been no good tracking method to gather this information. That is why organizations like the ACHA and Mended *Little* Hearts work together to develop tracking for these patients and to increase research dollars for treatment. Recently, the ACHA and Mended *Little* Hearts



joined with five other national CHD groups to host a CHD Lobby Day, the result of which was the introduction in the House and Senate of the Congenital Heart Futures Act, which promotes awareness, research and tracking of CHD as a lifelong chronic disease state. The hope is that this will help treatment and recovery for all of those living with CHD.

So, since recovery from CHD is still fairly new, how do parents of children with CHD, and those living with CHD, cope? Coping can be very difficult for parents – sitting helplessly while their children struggle to survive after open-heart surgery, watching a child get out of breath playing sports while the rest of the kids run around effortlessly, hearing of other Mended *Little* Hearts members who lost their children knowing that ours could easily be next.

Most parents and caregivers of children who have CHD and adults with CHD go through many emotions – anger, depression, shock, denial, despair – making it hard to cope. Len Schendel, father of Caleb, a CHD child, said, “The hardest part is getting past those emotions to the acceptance stage.” There are many paths to this acceptance stage, and unfortunately, some never get there, but it is crucial in moving forward and finding hope. Michelle Gonzalez of San Juan, Texas put it this way: “I accept the life that Madison was given. I accept everything about her. If I can’t accept it, then how can I expect her to do that? I want her to grow up and know that although she has a ‘different’ heart, she doesn’t have to place limitations on herself or feel that she is less than anyone else. The will and determination she had to live when she was so small and overcoming so much can lead her to a life with endless possibilities.”

One of the best ways of coping with things we cannot change is to find the things we can change and start doing something – something that turns a bad and painful situation into a positive one. Many parents and adults with CHD take control by getting involved with Mended *Little* Hearts and helping others. Polly Rames of Sioux Falls, South Dakota said, “I need to know that I can do something for someone else. That’s how I deal with things. We need to lean on each other as parents and say, ‘Hey, I’ve been there. I know what you’re experiencing, but you WILL get through this.’ That in itself is all the comfort I need to feel more at peace with Ethan’s future.” Helping others can also give parents a sense of hope. Maria Torres of our Latino Mended *Little* Hearts group in Madison,



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- Michelle Gonzalez

Wisconsin said, “Having an organization like Mended *Little* Hearts to provide support helps me keep the hope. It helps me know that I’m not alone and there are families that have gone through what I am going through, and sometimes even worse, and in spite of it all they still manage to keep the hope alive. I have learned that there is no need to give up on life, especially to give up on enjoying Joshua. I have also learned to teach him and others that just because he has a defective heart doesn’t mean that his heart doesn’t beat life inside.”

Another way that people cope is to gather information about the CHD so they are informed. Lisa Crane, a CHD mom in Colorado Springs, Colorado said, “At the children’s hospital near us they had lower chances for survival for my child’s CHD, so I found a better hospital. I made lots of phone calls, sent out requests for information, and talked to specialists.

We ended up going to a hospital five states away. It was hard but worth it.” Similarly, Alana Anderson of Tucson, Arizona said, “I made sure that I understood everything about my child’s defect (Tetralogy of Fallot) and her treatment. As a high school biology teacher, I needed to understand it. This proved to be very helpful when Kira changed hospitals and there was some confusion between the hospitals. I knew what was going on and could explain things.”

People cope with CHD through faith as well. Carlie McCorvey of Visalia, California said it beautifully: “Because of my faith I know that there is a bigger plan than what I know. I live my life living each day and don’t take for granted that there will be another. I don’t have a picture in my mind about what my life ‘should’ be, so it’s easier for me to cope with what comes my way because I know it is what it is and it’s what it is planned to be. Many things that have come along with CHD can be very scary, yet at the same time it has brought many blessings. The thought of losing a child is terrifying, but it has also allowed us a greater sense of appreciation and has opened our eyes to cherishing our children and living each day to its fullest. My daughter has had many heart surgeries, and this has not been easy on us or her, but without CHD she would not have met so many awesome heart friends through MLH and Camp Taylor. Without CHD she would not have inspired people at such a young age and had the opportunity to touch so many lives in such a big way.” Lisa Crane said, “My faith has helped. People would tell me if I had enough faith, his heart would be healed, but I knew that wasn’t the case – it would be my heart that would be healed.” ❤️