

“Mommy, Why Am I Different?”

by Lawrence W. Hood Jr.

Recently we asked some “experts” how to tell a child about their heart condition. Our experts included Amy Verstappen, president of the Adult Congenital Heart Association (ACHA), and Amanda Eason, a parent who has talked to her child about his CHD. Amy was diagnosed in early childhood with congenitally corrected transposition.

Mended Hearts: As an organization, what does ACHA suggest that adults know about their condition(s)?

Amy Verstappen: There are three main things that we suggest all people living with a congenital heart defect know. They are:

- 1) Learn the name of the condition — How to spell it, how to say it, etc.
- 2) Learn how to draw it — Especially for kids, this can be a crucial way of sharing information about what exactly their heart does, or does not, do.
- 3) Know the long-term risks, limitations and systems — More important than knowing the name of a particular condition is knowing exactly what it means to have the condition itself.

MH: When did your parents tell you about your condition?

AV: I do not remember a time when I did not know that I was special. Growing up, I had five sisters, but I was the only one who got to go on a special train and see these special doctors. I knew my heart was different and that I needed special care. It was as much a part of me as my brown eyes and brown hair.

MH: Did you face any challenges later in life based on what you knew about your condition?

AV: Growing up, I knew my diagnosis by name, but I did not know anatomy. I didn’t know exactly what it meant, like whether I would need to see a specialist for the rest of my life. My pediatric cardiologist did a good job telling me how

normal I was, but he neglected to tell me things that I was going to need later in life.

MH: Is there anything that you would like to share with parents who must decide what to tell their children?

AV: There are a few things that I have seen over the years that help:

- 1) I use two analogies when describing CHD: Think of the heart as a house. The house has four rooms and four hallways. You can then talk about how the child’s “house” is built. A second analogy helps when a child asks why he or she has to go to the doctor more often than other children. Have the child think of their heart as a fancy race car or luxury automobile. They both work great, but they require some things that most cars do not need. For instance, they need more frequent tune-ups by a special mechanic.
- 2) When dealing with surgical conditions, be careful about the terms “fixed” and “final surgery,” because these terms indicate an end to something. If a subsequent surgery is needed, or symptoms of a condition come back, it can upset a child because they were told they were “fixed” or that they would not need another surgery.
- 3) When a child sees adults taking medication, it is often because the adult is sick. However, we also take medication to stay well. So when my daughter asked why mommy takes medication, I told her I take it to stay well. I think this same explanation works to explain to children with CHD why they take medicine.

Amanda Eason is the mother of 9-year-old Jacob. He was diagnosed with hypoplastic left heart syndrome the day after he was born and had a heart transplant at six weeks of age. She is chair of the national Mended Little Hearts Committee and co-coordinator of Mended Little Hearts of Jacksonville, Fla.



Amanda Eason with son Jacob, 9 years old

MH: Have you talked to Jacob about his condition?

Amanda Eason: Yes, but we never actually sat down specifically to discuss it. It has always been something that we wanted him to know about. We actually met his donor’s parents when Jacob was a little over two years old. While he probably does not remember that, we have discussed it openly with him ever since.

MH: How have you treated Jacob in regards to what he knows?

AE: We wanted to create an environment that showed it was not something to be scared of. We wanted Jacob to know that he was okay. Jacob knows about his condition, about the medication he takes, the precautions he must take and so on.

MH: Do you have any suggestions for parents who are determining what, if anything, to tell their child?

- AE:**
- 1) Be open.
 - 2) Don’t be graphic. It is easy to become engrossed in the details when you are talking about conditions and surgeries, but you don’t want to scare your child. You want them to be comfortable with asking for more details if they like.
 - 3) It is important to explain the situation in terms that the child will understand. The way we discuss his condition with Jacob now that he is eight is very different from the way we talked to him even two years ago.

There is no one right way to share information with your child, but it is important to decide how to handle it when the time comes. Your child’s health could depend on it. ❤️



Jacob Eason slides down a gators mouth at the Mended Little Hearts of Jacksonville summer get together.

At some point every parent raising a child with a congenital heart defect or heart disease must face this question: What do I tell my child about his or her condition? Understandably, many parents fear that their child won’t understand or will be frightened if they find out that something is “wrong.”

However, there are important medical reasons for children to know and understand their conditions. For instance, Lori Means, Mended Little Hearts/Heart-to-Heart Coordinator in Iowa, is the mother of 3-year-old Derek, who was diagnosed in vitro with multiple conditions, including situs inversus totalis (his organs are reversed). Lori says, “I can envision Derek telling a doctor that he has a pain on his left side. This may not be much of an issue for most children, but in Derek’s case it could be his appendix, which is supposed to be on his right side.”



Amanda Eason (left) National MLH Committee Chairperson and Co-Coordinator of Jacksonville, Fla MLH is joined by Angela Livesay, MLH Jacksonville Co-Coordinator.