

A Parent's Guide to HLHS:

Confronting Prenatal Diagnosis

Learning during pregnancy that your baby has hypoplastic left heart syndrome (HLHS) or another single ventricle heart condition can be shocking and overwhelming. This bulletin was designed by parents of children with HLHS, in collaboration with mental health and healthcare professionals, to provide information and resources that may be helpful for your family as you prepare for your baby's HLHS journey.

Feelings

Parents often experience a wide range of thoughts and feelings after learning about their baby's heart condition. Many parents describe feeling like they are on an emotional rollercoaster. You are not alone in feeling:

- Worry
- Anticipation
- Guilt
- Protective
- Uncertainty
- Hope
- Conflict
- Helpless
- Excitement
- Fear
- Vulnerable

These feelings are normal, though they may become overwhelming. Many parents benefit from family and community support during this time.

Stress

Stress is a normal part of pregnancy and delivery. Having a baby with HLHS brings unique stressors including:

- Uncertainty about what the future holds for your baby, you, and your family
- Finding the best place for your baby's healthcare
- Managing finances, insurance challenges, and balancing your job(s) and your baby's health needs

While many of these stressors can't be avoided, knowing what to expect can often help you prepare.

Coping

There are many ways of coping with a new diagnosis of HLHS. Some parents want to know everything there is to know about their baby's heart, expected surgeries, and prognosis, while others may freeze and feel overwhelmed. It may be helpful to pace yourself on this journey as you learn new information.

Remember, there is no right way to cope. Every parent's experience is unique. Below are a few recommended coping strategies that can help during times of stress.

- Self-care
- Sleep/Rest
- Exercise/Yoga
- Counseling
- Laughter
- Journaling
- Learning about your baby's heart
- Faith/Spiritual connections
- Connecting with loved ones
- Talking with medical team
- Parent to Parent Support



Snuggletime with Mom and Dad

“The day I became a Heart Mom, my life forever changed. I thought we were just counting fingers and toes, how could I have prepared myself for half a heart? Disbelief mixed with overwhelming fear and loss consumed my thoughts. The following days and weeks were filled with more information than I could digest; I grieved for the loss of the joyful pregnancy and healthy baby.”

Nicole, Heart Mom

“In the beginning it is easy to become overwhelmed by the emotions of this new journey. While the future may appear dark, a brighter day awaits.”

Trent, Heart Dad



National Pediatric Cardiology
Quality Improvement Collaborative



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Support

There are many supports available for families dealing with HLHS.

Community Support

- Support is available online through Sisters by Heart/Linked by Heart, MLH CHD Chat, Postpartum Support International and others.
- Local and national groups (for example, Mended Little Hearts and Conquering CHD) may meet in your community to support and inform parents about congenital heart disease.
- Professional Mental Health Counseling for individuals, couples, and/or siblings. (Speak to your insurance company to find a provider.)
- Sibshop: offers support groups and resources for siblings.

Hospital Support

In the hospital and after discharge there are people who can help you with lodging, finances, feeding, reaching milestones, and wellness. Connect with a cardiac social worker for guidance about available supports.

Books/Apps

- Books for Adults: *HLHS Book of Hope*, *Single Ventricle Q&A Book*
- Talking about congenital heart disease with young children can be difficult. These children's books might help: *My Brother Needs an Operation*, *Hayden's Heart*, *Riley's Heart Machine*, *Zipline*, *Charlie the Courageous*, *Jeremiah the CHD Aware Bear*.
- There are numerous mindfulness apps (via the Android or Apple app stores) that can help with stress and anxiety. Several members of our community have found the "Calm" app to be helpful (available for free).



Heart siblings are the best!



Feeling great!

Although it can be shocking and overwhelming to find out that your baby has HLHS, there are many available supports to help your family. We encourage you to lean on these supports for healthy coping before and after your baby is born.

“One of the greatest assets on this journey are the supports provided by family, friends, and the practitioners at your care center. Find comfort in the support systems that are available and use them frequently.”

Walden, Heart Dad

“As the pregnancy progressed things began to normalize. We were able to understand the diagnosis and make decisions regarding treatment, I felt like I was slowly gaining some control and perspective in this unimaginable situation. Support from other heart moms flooded my inbox and I realized that this may not have been my chosen path, but it's the one I'm on and one that I don't have to walk alone. These babies are stronger than we can imagine and do more than survive, they thrive!”

Nicole, Heart Mom



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