

Understanding 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 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
- Conflicted
- Helpless
- Excited
- Fearful
- 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



Snuggle time 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



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Support

During this time of uncertainty it is important to seek out support from others, including your hospital care team, other heart parents, supports available in the community, and family and friends.

Hospital Support:

Our **Thrive Team** works together to ensure that patients and families have all of the support and resources they need while in the hospital and after discharge.

Our Thrive Team includes:

Child Life Specialist	Psychologist
Social Worker	Chaplain
Financial Counselor	Palliative Care Team
Music Therapist	

Thrive Team contact:

Email: thrive@cmh.edu

Phone: 816-302-8064



Other Helpful Hospital programs and locations:

- POPS (Parents Offering Parent Support)- connect with another parent who has a child with HLHS
- Ronald McDonald Family Room (2nd Floor near PICU) for meals/snacks and rest
- "Guided" Mindfulness Meditation- Chapel, every Tuesday & Friday from 12:30-12:50pm
- Heart Beads Program
- Kreamer Resource Center for Families (ground floor)
- Child Life Sibling Playgroups
- Lactation Services

Community Support/Resources:

- Congenital Heart Defects Families Association (local and regional) www.chdfamilies.org
- Sisters by Heart (national support specifically for HLHS) www.sistersbyheart.org
- Pediatric Congenital Heart Association (national) www.conqueringchd.org
- HopeKids KC: www.hopekids.org
- Imagination Library- Free Book Program!



Our Thrive Team often helps families connect to counseling resources in their community. Please let us know if you are interested in learning more about this option.

Books/Apps

- Books for Adults: HLHS Book of Hope, Single Ventricle Q&A Book
- Books for Kids: My Brother Needs an Operation, Hayden's Heart, Riley's Heart Machine, Zipline, Charlie the Courageous, Jeremiah the CHD Aware Bear
- Mindfulness Apps that can help with stress and anxiety: Calm, Headspace, Insight Timer, 10% Happier
- Apps for kids: Stop Breathe Think and Settle Your Glitter

*"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***



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