

A Parent's Guide to HLHS:

Understanding Postnatal Diagnosis

Learning soon after birth 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 who learn of their child's diagnosis of HLHS after birth have many feelings. You are not alone. Parents of children with HLHS have shared many of these feelings:

- Anger
- Sadness
- Fear
- Helplessness
- Nothing will be okay
- Everything is out of control

Stress

Stress is expected as you prepare for your baby's HLHS journey. Many families say the most stressful parts of finding out their baby has HLHS are:

- Seeing their baby sick and worrying about what is going to happen.
- How their baby looked after the first operation—the incision, medications and tubes can be frightening.
- Not being able to feed or take care of their baby.
- Worrying that their baby would not know them.
- Being away from other family members and children.

Coping

Parents cope in different ways. Many parents put themselves second to their baby at this time. It's important that you take care of yourself to be in the best shape to make decisions and to support your child. Some helpful hints include:

- Eating and taking care of your own health and hygiene needs.
- Getting a good amount of rest and sleep.
- Eating meals away from the hospital and exercising.
- Asking for help—leaning on friends and family members to help you.
- Talking with family, friends, ministers or people taking care of your baby.
- Asking for help with household tasks, child care, or other daily activities.

Finding Answers

Many parents find that asking a lot of questions helps them learn about their baby's condition.

- Write down questions as you think of them so that you have them when a nurse or doctor is available.
- Don't be afraid to ask care providers to go over things more than once.
- Ask nurses and doctors to use different words if they don't explain things in a way you understand.
- You know your child best. Partner with the medical team to understand all treatment options and participate in decision making.
- It is your right to know what is happening, and the more you know, the more you can help.



"We went from having a healthy baby at home to a critically ill one on life support and readied for emergency surgery in the space of a few hours. We didn't know what decisions were important and despite our educations, knew nothing about Lucy's disease or its treatment. The experience was traumatic, terrifying, and overwhelming."

Richard, Heart Dad



NATIONAL PEDIATRIC CARDIOLOGY
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Development

You can develop a connection with your baby and help promote your baby's development while in the intensive care unit. Some things you can do might seem small but can make a big difference:

- Ask for ways to hold, touch, and take care of your baby.
- Softly talk, sing, or read to your baby.
- Hold their hand, or put a hand around their head and feet.
- Leave a cloth in your baby's bed that you have worn so it smells like you.
- Bring in photos for around your baby's bed.
- Provide breastmilk for your baby.



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:

- 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 (ground floor near cafeteria), 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.sisterbyheart.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 or Settle Your Glitter



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